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Getting to Zero

Global Social Work
Responds to **HIV**

Getting to **Zero**

Global Social Work Responds to **HIV**

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Foreword

This is more than a compilation of scientific articles on the response to HIV by social workers. It is also a collection of stories told with candour about restoring hope, dignity and social capital to people and their families in order that they can withstand the shocks they encounter in life. It is about the experiences of people who are vulnerable to HIV and their caregivers, showing us that it is possible to live free from inequality and discrimination. And it is about enabling people living with HIV to live healthy and fulfilled lives.

Few can tell these stories better than social workers. Social workers are the conscience of the AIDS response. They are peer educators, researchers and decision-makers. They work at the centre and the margins of communities.

Taking a life-cycle approach, social workers accompany people through their life journey—connecting them to services and making services work for them. They make connections every day.

Social workers are helping a new generation of children to start free from HIV and remain AIDS-free. They are also helping to move the spotlight to an important group of vulnerable children—children whose parents are living with HIV but who were born free from HIV. Such children experience more health problems and deaths than children whose parents are not living with HIV. They require systematic follow-up and care, which social workers help to provide.

Social workers also help people to access antiretroviral therapy and support them to remain on treatment; they assist people to get condoms, opioid substitution therapy or sterile needles, food, housing and employment, and access transport support for clinic appointments; they protect the rights of vulnerable people and help to prevent and treat gender- and sexual-based violence—these are just a few of the connections that social workers make every day.

GETTING TO ZERO

Above all else, this book highlights the role that social workers play in the lives of vulnerable people and their families and in helping to bring about inclusive societies, dignity for all people, solidarity, social justice and hope.

UNAIDS is honoured to partner with the International Association of Schools of Social Work to share these stories.

Michel Sidibé

Executive Director, UNAIDS

Introduction

It is with the greatest pleasure that we present this collection of global social work responses to the global HIV epidemic. The book you are reading represents a collaboration between the International Association of Schools of Social Work (IASSW) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). IASSW is an association of institutions of social work education, organizations supporting social work education and social work educators around the world. The values and mission statements of the two organizations have synergies that encouraged cooperation between them in the realization of their shared aims.

Since a first joint meeting in March 2014, members of IASSW and UNAIDS discussed the feasibility of working together to achieve common goals of zero new HIV infections, zero discrimination and zero AIDS-related deaths. The joint work plan evolved through fruitful consultations between UNAIDS and IASSW led by Dr Mariangela Simao (Director, Rights, Gender, Prevention and Community Mobilization) and Mr David Chipanta (Senior Advisor, Social Protection, UNAIDS), along with Professor Vimla V. Nadkarni (then-President of IASSW), Professor Susan Lawrence (President of the European Association of Schools and Social Work and board member of IASSW), and Dr Klaus Kuhne, representing the International Federation of Social Workers (IFSW). On 21 October 2014, Professor Nadkarni and Luiz Loures (Deputy Executive Director of UNAIDS and Assistant Secretary General of the United Nations), signed a Memorandum of Understanding between IASSW and UNAIDS at UNAIDS headquarters in Geneva. It was the beginning of a formal joint plan of work between the two organizations.

As a first joint event, World Social Work Day was observed on 17 March 2015 with a seminar on the theme “Ending AIDS, Promoting Dignity and Respect for All” in the Kofi Annan conference room of the UNAIDS building in Geneva. There were 150 invited guests from the UN, IASSW, IFSW and

International Council on Social Welfare (ICSW), and their European regional associations. This seminar focused on the role of social work in working with people to prevent and mitigate the impact of HIV, and on how the social work profession could contribute to the goal of ending AIDS by 2030. Resource persons from the World Bank, International Labour Organization (ILO), the United Nations Development Programme India and the World Food Programme participated and shared their work on HIV, social protection and working with social workers. People living with, at risk for and most affected by HIV, government actors and civil society representatives also participated in the meeting. The participants affirmed the importance of social work organizations and professionals joining with UNAIDS to develop collaborative actions to end the AIDS epidemic. These actions include restoring and promoting dignity, guaranteeing access to social protection, scaling up access to HIV prevention, treatment, care and support for all, and accelerating actions for developing an HIV vaccine and a cure.

This publication represents the second joint collaboration between UNAIDS and IASSW. It focuses on the themes set out in UNAIDS' Getting to Zero Strategy (UNAIDS, 2010).

Social workers in all parts of the world have been responding to the unique challenges of HIV since the earliest days of the epidemic. HIV was, and remains, a social challenge as much as a biomedical challenge. Social work researchers and practitioners, laboratory scientists and medical practitioners, policy-makers and funders, together with people living with and affected by HIV, all must work in close partnership with each other to develop and deliver effective and compassionate prevention and care. Social work responses have evolved over the decades to meet the new challenges that have emerged as prevention and treatment opportunities have evolved. In this publication, international social workers, social work researchers and academics report on some of the innovative work they are doing so that these responses can be adapted in other places and communities around the world. When we first put out a call for contributions to this volume we received responses from 68 individuals or partnerships from every part of the world. The editorial challenge has been to identify the work that best represents social work responses to HIV, and that will be most useful to people and communities. The result is the 18 chapters in this publication.

Social work is perhaps uniquely positioned to address the multifarious challenges presented by HIV, given that social work is interdisciplinary, transdisciplinary and even intersectional. Social work is interdisciplinary because social workers frequently work or collaborate in research alongside professionals from other disciplines, such as nursing, medicine and public

health, and each discipline brings its own theories, perspectives, ways of working and research interests. It is transdisciplinary in that social workers are frequently expected or required to work across traditional professional disciplinary and knowledge boundaries with the well-being of the client, patient or service user as the highest goal. And social work is intersectional because it works not only at the individual level, but also uses individual and community-level experiences to advocate for individuals, families and communities at the policy-making level.

The Joint International Definition of Social Work defines social work in this way:

Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance well-being.

The above definition may be amplified at national and/or regional levels. (International Association of Schools of Social Work & International Federation of Social Work, 2014, para. 1).

One of the important aspects of this definition is that social work is underpinned by many different theories, and even different ways of knowing. Social work moves beyond positivist approaches to knowledge and seeks to understand a phenomenon more in depth, to understand the world in the way other individuals understand the world. It has long been recognized that the global HIV epidemic requires innovative approaches. Such approaches must promote the rights and dignity of people living with, at risk for and affected by HIV to access life-saving HIV prevention, treatment and care services. They must build on individual, social and cultural understandings of sex, relationships, substance use and misuse, sex work and other behaviours that may put people at risk for HIV, or that may be perceived as socially acceptable or unacceptable. This means that social workers and social work researchers utilize many different kinds of culturally aware research methodologies. The chapters that follow include many examples of interdisciplinary, transdisciplinary and intersectional thinking, different kinds of research methodologies and different ways of knowing. The hope is that this collection will add to the already rich international literature on

the global response to HIV, and also illustrate for all our non-social work colleagues what it is that social workers and social work researchers do.

There are, as always, limitations to this collection. We have not been able to include contributions from East or South-East Asia. We hope that this publication will inspire social workers in those regions to publicize their work to international audiences.

In this publication, in order to make each chapter accessible to the widest audience we have included abstracts in the five languages of IASSW (English, Chinese, Spanish, Japanese and French). Following the English abstract there may also be an abstract in the first language of the author, if it is not one of the other five languages. We hope that readers whose familiarity with English is limited will be able to access at least the key points of the chapters, and then perhaps make contact with the authors (using the email addresses found in the Author and Editor Notes section at the end of the book) for more details.

The chapters in this book have been organized into four general groups. Three of these groups follow the UNAIDS themes (zero new HIV infections, zero discrimination and zero AIDS-related deaths). The fourth group includes examples of transtinking that is so common among social workers, responses that are not limited to a particular zero-theme, or country or level of engagement. These groupings are more or less to make the work more accessible, as many of these chapters include a number of different perspectives on the vision of Getting to Zero. The process of developing this publication has helped us once again to become aware of the creativity and the broad scope of international social work responses to HIV. We salute our colleagues whose work is included in this volume, and those who continue to respond to one of the greatest social and health challenges of our time.

The Editors

March 2017

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The current state of the global HIV epidemic

Guided by a vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths, the world has achieved tremendous progress against HIV over the last 15 years, inspiring a global commitment to end the HIV epidemic by 2030. The United Nations General Assembly agreed in June 2016 that ending the HIV epidemic by 2030 requires a Fast-Track response to reach three milestones by 2020:

- Reduce AIDS-related deaths to fewer than 500 000 globally by 2020.
- Reduce new HIV infections to fewer than 500 000 globally by 2020.
- Eliminate HIV-related stigma and discrimination by 2020.

Remarkable scaling-up of the 90-90-90 treatment target—90% of people living with HIV know their HIV status, 90% of people who know their HIV-positive status are accessing treatment and 90% of people on treatment have suppressed viral loads—has put the world on track to reach the target on AIDS-related deaths. Intensive efforts to eliminate mother-to-child transmission of HIV have achieved steep declines in the annual number of new infections among children, from 290 000 in 2010 [250 000–350 000] to 150 000 in 2015 [110 000–190 000].

However, the decline in new HIV infections among adults has slowed, threatening progress towards ending the AIDS epidemic. Since 2010, the annual number of new HIV infections among adults (15 years and older) has remained static at an estimated 1.9 million [1.7 million–2.2 million]. Some countries have achieved declines of new HIV infections among adults of 50% or more over the last 10 years. Many have not made measurable progress, while others are experiencing worrying increases in new HIV infections.

Political commitment, continued financial investment by domestic and

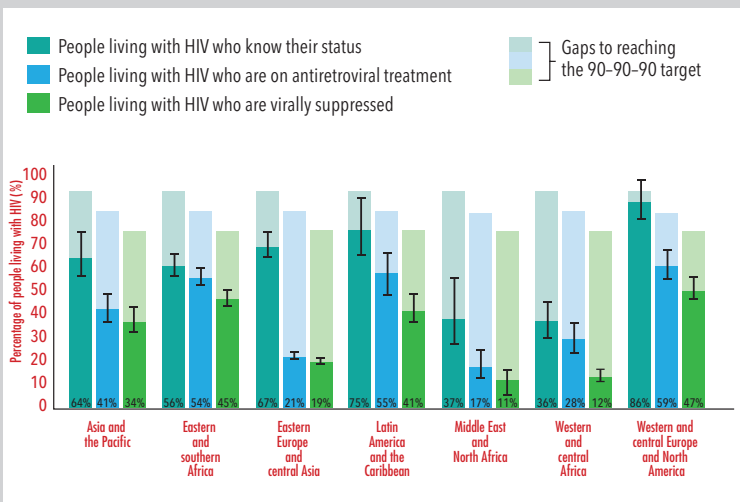
international partners and implementation of creative efforts to reduce the multidimensional barriers to accessing HIV services are required to increase the number of people living with HIV benefiting from the 90-90-90, to eliminate HIV-related stigma and discrimination, and to mount a major HIV-prevention push to end the AIDS epidemic by 2030. Box 1 and Figures 1, 2 and 3 summarise the current global state of the epidemic.

Box 1: Global statistics at the end of 2015

- 17 million people were accessing antiretroviral therapy.
- 36.7 million [34.0 million–39.8 million] people globally were living with HIV.
- 2.1 million [1.8 million–2.4 million] people became newly infected with HIV.
- 1.1 million [940 000–1.3 million] people died from AIDS-related illnesses.
- 78 million [69.5 million–87.6 million] people have become infected with HIV since the start of the epidemic.
- 35 million [29.6 million–40.8 million] people have died from AIDS-related illnesses since the start of the epidemic.

Source: UNAIDS 2016 estimates

Fig 1 Progress towards the 90-90-90 target, by region, 2015



Source: UNAIDS special analysis, 2016

Fig 2 New infections, globally, from 2000 to 2015

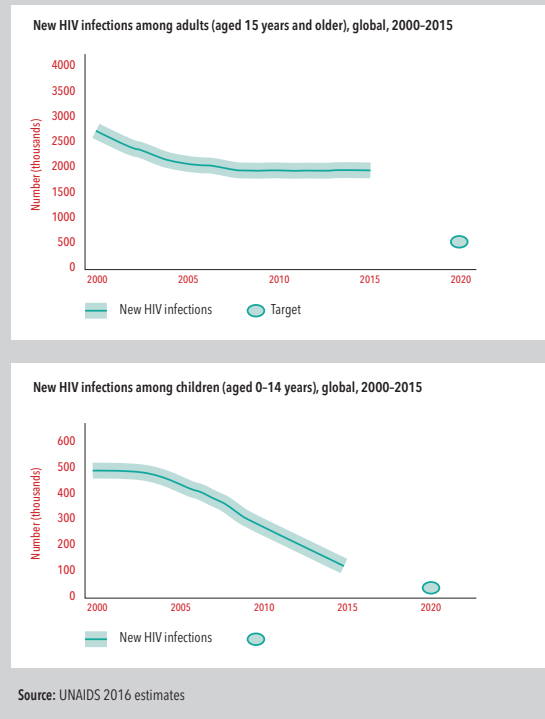
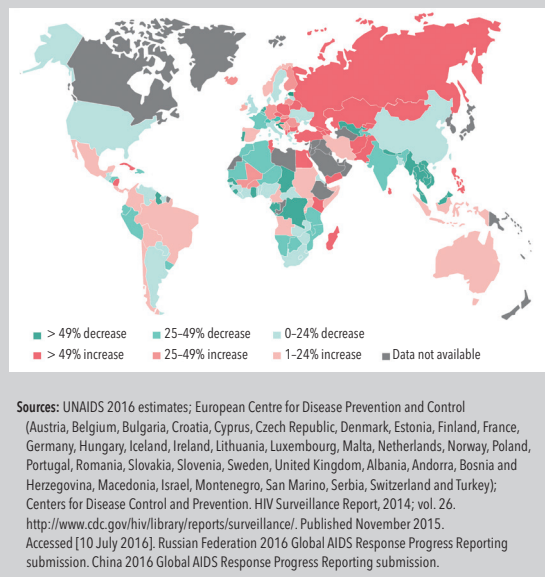


Fig 3 Percentage change in new HIV infections among adults (aged 15 years and older), from 2005 to 2015



Part 1: Zero new HIV infections

Best practices for evaluating care and support programmes for HIV-affected families: Lessons learned from South Africa

*Tonya R. Thurman, Brian G. Lockett, Tory M. Taylor,
Johanna K. Nice, Melissa R. Carnay and Alexandra Spyrelis*



ABSTRACTS

Community-based care and support programmes for orphaned and vulnerable children and their families are a critical component of HIV prevention and treatment efforts worldwide. The challenges of evaluating community-based programmes for HIV-affected families limit the evidence base for effective social work programming. Addressing these challenges can improve the validity of evaluations to provide better direction for the programme under study as well as promote best practices generally. This chapter describes lessons learned from five evaluations of care and support programmes for HIV-affected children and families in South Africa—home to the world’s largest HIV epidemic. Lessons learned include how to successfully collaborate with service providers, strategies to enhance the rigour, relevance and utility of evaluations, and to carefully consider the ethical issues of conducting research with this highly vulnerable population. These lessons may be applied internationally to strengthen the quality of evaluation research to more effectively guide social work practice.

评估关爱和扶持受艾滋病影响家庭项目的最佳做法：来自南非的经验教训

以社区为基础，为孤儿、弱势儿童及他们的家庭提供关爱和支持是全球范围内艾滋病病毒预防和治疗工作的一个重要组成部分。在评估以社区为基础的艾滋病病毒感染者家庭支持项目时所面临的挑战，限制了有效进行社会工作规划的证据基础。应对这些挑战，通常可以提高评估的有效性，为研究该项目提供更好的导向，并能进一步促进最佳实践。本章从南非受艾滋病病毒感染儿童和家庭关爱和扶持项目的五个方面进行了评估，介绍了世界上最大的艾滋病病毒流行区-南非的经验教训。这些经验教训包括：如何成功地与服务提供者协作；提升严谨性、相关性和效用评估的策略；并认真考虑对高度脆弱人群进行研究的伦理问题。这些经验教训在国际范围内均可适用，以提高评估研究的质量，并更有效地为社会工作提供指导。

Buenas prácticas para la evaluación de programas de apoyo y cuidado para familias afectadas por el VIH: Lecciones aprendidas en Suráfrica

Los programas de apoyo y cuidado comunitarios para niños huérfanos y vulnerables y sus familias son un componente crucial en los esfuerzos para la prevención y tratamiento del VIH en todo el mundo. Las dificultades de evaluar programas comunitarios para las familias afectadas de VIH limitan la base de pruebas para una programación efectiva del trabajo social. Hacer frente a estas dificultades puede mejorar la validez de las evaluaciones para proporcionar una mejor dirección al programa estudiado así como promocionar buenas prácticas en general. Este capítulo describe las lecciones aprendidas a través de cinco evaluaciones de programas de apoyo y cuidado para niños y familias afectadas por el VIH en Suráfrica, donde se alberga la mayor epidemia mundial de VIH. Las lecciones aprendidas incluyen cómo colaborar de manera exitosa con los proveedores de servicios, estrategias para mejorar el rigor, la relevancia y la utilidad de las evaluaciones, y considerar cuidadosamente los problemas éticos de llevar a cabo una investigación con una población altamente vulnerable. Estas lecciones pueden aplicarse internacionalmente para reforzar la calidad de la investigación de evaluación para guiar de manera más efectiva la práctica del trabajo social.

HIVの影響を受けた家族のケアと支援プログラムを評価するためのベストプラクティス：南アフリカから学んだ教訓

孤児や支援の必要な子供たちとその家族のための地域密着ケアと支援プログラムは、世界的なHIV予防と治療活動の重要な一部です。HIVの影響を受けた家族にむけた地域密着プログラムの評価を妨げる問題は、社会福祉プログラミングの効果を裏付ける証拠を制限しています。これらの課題について検討することは、一般的にベストプラクティスを促進するだけでなく、評価の有効性を向上することで、検討中のプログラムをより良い方向へ導くことができます。この章では、世界最大のHIV感染地である南アフリカで、HIV に感染した子供と家族のケア並びに支援プログラム5件の評価から学ぶことができる以下の様な教訓について述べます。学んだ教訓の中には、医療サービス提供者とうまく協力し合う方法、厳密さを強化する戦略、関連性や実用性の評価、そして、この非常に弱い立場の集団に対し、研究を行う上で倫理問題を慎重に考慮することなどがあります。これらの教訓は、評価研究の品質を強化し、社会福祉の実践をより効果的に導くために、国際的に適用できることでしょう。

Meilleures pratiques pour l'évaluation des programmes de soutien et de prise en charge des familles affectées par le VIH : Enseignements tirés d'Afrique du Sud

Les programmes communautaires de soutien et de prise en charge des orphelins et enfants vulnérables, ainsi que leurs familles sont une composante essentielle des initiatives de prévention et de traitement du VIH à travers le monde. Les défis liés à l'évaluation des programmes communautaires pour les familles affectées par le VIH limitent l'obtention de données probantes pour la planification du travail social. La résolution de ces défis peut améliorer la validité des évaluations afin de donner une meilleure orientation au programme à l'étude, et de promouvoir les meilleures pratiques de façon générale. Le présent chapitre décrit les enseignements tirés de cinq évaluations des programmes de soutien et de prise en charge pour les enfants et les familles affectés par le VIH en Afrique du Sud : foyer de la plus grande épidémie de VIH dans le monde. Les enseignements tirés consistent à déterminer la façon de collaborer efficacement avec les prestataires de services ; les stratégies visant à améliorer la rigueur, la pertinence et l'utilité des évaluations ; et la façon dont il convient de considérer minutieusement les questions éthiques relatives à la réalisation des recherches auprès de cette population très vulnérable. Ces enseignements peuvent être appliqués au niveau international afin de renforcer la qualité de la recherche en évaluation et de mieux guider le travail social dans la pratique.

INTRODUCTION & LITERATURE REVIEW

At least 13 million children around the world (UNAIDS, 2015a), and 4 million in South Africa alone, have lost one or both parents to AIDS (Proudlock, Dutschke, Jamieson, Monson, & Smith, 2008). Millions more reside with a parent who is living with HIV (Short & Goldberg, 2015). These orphans and other children made vulnerable by the epidemic are at elevated risk for HIV themselves due to perinatal transmission and a higher prevalence of risky sexual behaviours in adolescence and young adulthood (Gregson et al., 2005; Newell et al., 2004; Operario, Underhill, Chuong, & Cluver, 2011). Pooled analyses of data across 19 countries in sub-Saharan Africa found that orphans who had lost their mothers and adolescents residing with mothers living with HIV were twice as likely to test positive for HIV versus non-orphans and adolescents living with mothers who were HIV-negative (Kidman & Anglewicz, 2016). South Africa, home of the world's largest HIV epidemic (UNAIDS, 2016), faces a particularly high burden. Of the 2.6 million

children aged zero to 14 living with HIV in 2014 worldwide, 13% were from South Africa (United Nations Children's Fund, 2015).

The Getting to Zero Strategy calls for “smarter and more sustained multisectoral support for the community systems that shape people's lives and complement human resources for health” (UNAIDS, 2010, p. 19). Community-based care and support programmes for children and families affected by HIV are increasingly emphasized as a critical component of comprehensive responses. Home visiting is one of the most popular mechanisms for supporting HIV-affected households (Schenk, 2009; U.S. President's Emergency Plan for AIDS Relief [PEPFAR], 2012). It provides a platform for engaging the most vulnerable families through assessment of household needs, coordination of services and ongoing monitoring (DiPrete Brown, 2008). Research from South Africa has demonstrated higher uptake of HIV testing and social protection grants by orphans and vulnerable children enrolled in home visiting programmes (Thurman, Kidman, & Taylor, 2015; Thurman, Lockett, Taylor, & Carnay, 2016). These programmes are often complemented by structured group interventions offering information and support for HIV prevention, parenting and psychological well-being (Ncama, 2005; Kumakech, Cantor-Graae, Maling, & Bajunirwe, 2009). Group psychological interventions, such as interpersonal psychotherapy for groups and peer support groups, may be particularly helpful for reducing HIV risk by preventing or mitigating psychological distress among participants (Thurman, Kidman, Carton, & Chiroro, 2016). Parenting skills classes have also shown promise for improving parent-child interaction (Knerr, Gardner, & Cluver, 2013). In turn, this may decrease risky behaviour by adolescents (Wight & Fullerton, 2013).

In 2015, the Government of South Africa directed more than US \$2.1 billion towards HIV response, with US \$118 million of this to support services for orphans and HIV-affected families (PEPFAR, 2016). Home visiting and structured support services in South Africa are delivered by a diverse social welfare workforce comprising social workers, auxiliary social workers, accredited child and youth care workers and lay volunteers (United States Agency for International Development [USAID], 2010). Returns from these investments can be maximized through enabling stronger evidence about the most effective strategies (UNAIDS, 2014). Indeed, the vision of Getting to Zero—zero new HIV infections, zero discrimination and zero AIDS-related deaths—depends on continuing work to identify and expand high-quality, cost-effective programme approaches. Although social work has historically been viewed as a practice profession (Guerrero, 2014), attention has recently shifted to research to help define best practices (Royse, 2007).

Unfortunately, despite this shift, the scientific knowledge base underlying social services remains relatively limited (Brekke, 2012) and programming guidance for children affected by HIV has been largely based on anecdotal information, descriptive assessments or prior experiences (Bryant et al., 2012; King, De Silva, Stein, & Patel, 2009; Schenk, 2009).

In the past five years, the Tulane University Highly Vulnerable Children Research Center has conducted five major programme impact evaluations on home visiting, HIV prevention and psychological support programming for children and families affected by HIV in South Africa, including three randomized controlled trials (RCTs). This chapter draws upon these experiences to propose a number of best practices for planning and conducting evaluation research with this group. It also highlights key lessons related to the importance of: 1) thorough consideration of the ethical implications of conducting research with this highly vulnerable population; 2) cultivating close working relationships with local programme implementers for developing and conducting evaluations; and 3) careful attention to linguistic and cultural factors to help design and apply appropriate study methodologies.

METHODS

The lessons presented here are based on a structured review of the five programme impact evaluations conducted by the authors in South Africa between 2010 and 2016. Table 1 provides a brief overview of the interventions studied and the methods used for the evaluations included in this review. The table also includes the abbreviated title used in the text when referencing each evaluation.

The review was constructed via the compilation and analysis of the specific characteristics of each of the programme evaluations presented in Table 1, including: study design, control group assignments, sampling, response rates, data sources, analytical methods and gender subgroup analyses. Additional data sources included Institutional Review Board (IRB) applications and board feedback. The broader lessons learned by the authors were assembled by identifying and exploring commonalities between the challenges, successes and limitations associated with each evaluation.

Ethical approval for each evaluation was obtained in South Africa from the Human Sciences Research Council or a South African University IRB proximate to the study location (University of Limpopo Medusa; University of Free State; University of Pretoria). All evaluations also underwent review and

Table 1 Overview of evaluations

Abbreviated Study Title	Urban Home Visiting trial	Grief Groups trial
Intervention and Study Design	A randomized controlled trial (RCT) to evaluate the effectiveness of a community-based home visiting programme on the well-being of beneficiary orphans and vulnerable children (OVC), caregivers and households in Tshwane City, South Africa.	An RCT to evaluate the effectiveness of a school-based grief peer support group, Abangane, on the psychosocial well-being of bereaved female adolescents in the Free State, South Africa.
Sample	481 primary caregivers of participating households were surveyed at baseline and one year later (10.4% loss to follow-up).	423 adolescents and their primary caregivers were surveyed at baseline and three months post-intervention (about seven months post-baseline; 4% loss to follow-up).
Additional Methods	Surveys among caregivers enrolled in the programme for approximately 18 months were used in a propensity score matched analysis with RCT baseline respondents who had not received programme services. Service delivery records were used to test for intervention exposure effects.	Qualitative research (focus group discussions among adolescent participants and in-depth interviews among key programme staff). Cognitive interviewing of grief survey measures among youth. Complementary intervention exposure analyses using attendance registers.

Table continued page 22

Table 1 (continued) Overview of evaluations

Abbreviated Study Title	Adolescent Risk Reduction trial	Paraprofessional Home Visiting study	Let's Talk pilot study
Intervention and Study Design	A cluster RCT with a four-group factorial design to evaluate the effectiveness of two structured interventions, Interpersonal Psychotherapy for Groups (IPTG) and Vhutshilo, offered independently and in combination, on adolescent mental health and sexual risk behaviours among OVC in Eastern Cape, South Africa.	A longitudinal quasi-experimental study to evaluate community-based home visiting models comparing paraprofessional compensated workforce sites and volunteer-driven sites in KwaZulu Natal (KZN), South Africa.	A one group pretest/posttest study to assess the effectiveness of the pilot implementation of the cognitive-behavioural, group based Let's Talk programme on the psychosocial well-being of participating families in Gauteng and KZN, South Africa.
Sample	1014 adolescents and their primary caregivers were surveyed at baseline, immediately post-intervention (10 months post-baseline; 1% loss to follow-up) and one year later (22 months post-baseline; 5% loss to follow-up).	1856 children and their primary caregivers were surveyed at baseline and two years later (20% loss to follow-up).	234 adolescents and their primary caregivers were surveyed at baseline and three months post-intervention (about nine months post-baseline; 3% loss to follow-up).
Additional Methods	In-depth interviews and document reviews informed a case study of the IPTG intervention. Detailed analysis of intervention costs were linked to impact data to enable cost-effectiveness analysis. Complementary intervention exposure analyses using attendance registers. Qualitative research (focus groups with adolescent study participants).	Qualitative research (focus groups with a subset of caregivers and Child and Youth Care Workers from the paraprofessional model).	Qualitative research (facilitator focus groups). Session-specific fidelity checklists to refine curriculum and promote fidelity to model. Complementary intervention exposure analyses using attendance registers.

approval by the Tulane University IRB in the United States of America. Data collection activities commenced only after approval from both institutions.

LESSONS LEARNED

Lesson 1. Keep ethical considerations at the forefront

Apply creative solutions to balance methodological rigour with ethical concerns

Research planning may confront trade-offs between ethical conduct and scientifically rigorous methodology. Across disciplines, RCTs are considered the gold standard for measuring the impact of an intervention. Researchers are bound to the principles of beneficence, but the use of a true control group with no intervention may be unethical in certain settings, especially for studies involving highly vulnerable populations (Solomon, Cavanaugh, & Draine, 2009).

The RCTs discussed in this chapter have included provisions to guarantee some level of service delivery to all participants. In two studies, planned programme scale-up over time was leveraged to generate a control group waitlisted for future service receipt. In both the Urban Home Visiting and Grief Groups trials, the programme partners had established targets for the number of beneficiaries to serve over an extended period, but agreed to identify all of these prospective beneficiaries at the outset of the study, thus allowing for random assignment of some new enrollees to the waitlist. This approach requires higher initial investment by partners in terms of programme staff time but is offset by a lower future recruitment burden and subsequent expedited service delivery for the waitlist group. Careful explanation of the randomization process is important to manage beneficiaries' service expectations; a script was developed to ensure consistency in how this sensitive issue was addressed.

If the pool of new enrollees is not sufficiently large or future funding for a programme is uncertain, evaluators may not be able to use a waitlisted group as study controls. In these circumstances, comparison of the intervention against the best standard of care available is one option (Rubin & Babbie, 2016). In the Adolescent Risk Reduction trial, all participants continued to receive home visiting services and only the added benefits of structured HIV prevention and psychological health interventions were investigated. In the Paraprofessional Home Visiting quasi-experimental study, the differing resource levels of community-based organizations already serving vulnerable families were capitalized upon to designate a relatively low-level

local standard of care for comparison with the higher intensity care models under evaluation. Using designs like these, researchers are able to examine both shorter- and longer-term programme effects that may not be feasible with waitlisted groups.

Define special provisions for vulnerable children's participation

Both children and caregivers were included as study participants in four of the five evaluations included in this review. Adults have a unique perspective on children's behaviour, and can provide sensitive information about children by proxy (such as orphanhood or HIV status). Caregivers may also mediate the success of interventions aimed at children in a variety of ways. Engaging children in research directly is likewise crucial, but requires special attention to participants' developmental capacity and the imbalance of power between children and adults. Unfortunately, little guidance is available for social-behavioural researchers related to obtaining children's informed consent (Schenk, Murove, & Williamson, 2006). The development of consent protocols for parents/guardians and assent (or consent) protocols for children in the evaluations under review was, therefore, guided by stakeholder and community concerns, relevant research and IRB feedback.

Sensitivity in the wording of research tools and consent and assent scripts is necessary to avoid stigmatization or discrimination of participants throughout the research process (Schenk & Williamson, 2005). Consent documents must be written at the language level of participants, with youth-specific reassurances designed to ensure voluntary participation. Research in international settings also requires cultural and linguistic competence in order to develop appropriate consent and assent language and procedures. Provision for illiterate or subliterate respondents to have a witness present needs to be made. Evaluation research also demands sensitivity to service expectations, and researchers need to verify that participants understand the nature and intent of the study, that it will not affect service delivery and is strictly voluntary.

Research conducted with HIV-affected children often engages young participants who are not living with their biological parents. Even for orphaned children under the care of a family member, the lack of legal guardianship can be a constraint in obtaining consent. In some instances the child's parent may be alive and not reside in the home or may be a resident but too ill to provide consent. These situations were accommodated in the studies documented here by requesting consent from the child's caregiver: defined as the person who has daily responsibility for care of the child. Ethical requirements for obtaining consent from nonparents/informal guardians

can be context-specific and approval to use this procedure must be obtained before fieldwork begins.

Children who serve as the heads of their own households pose unique consent issues. Systematically excluding these children from research perpetuates a lack of evidence for how best to meet their needs, but their inclusion requires unusual consent procedures and, often, special advocacy with the ethical review board. As such, researchers need to be sufficiently familiar with their sample demographics to determine whether additional investment in such procedures is warranted versus excluding these (potentially few) participants. Where a decision is made to include child heads of household, children age 16 and above who do not have adult caregivers may be entrusted to provide consent for themselves and the children under their care. This recommendation is guided by prior research suggesting that adolescents exhibit significant cognitive capacity to offer informed consent, and adolescents with adverse life circumstances might even have *increased* capacity for decision-making (Kuther & Posada, 2004; Levine, 1995; Petersen & Leffert, 1995).

In South Africa, 12 year olds may legally consent to take part in research and medical treatment, including HIV testing (Children's Act, 2005), but that does not relieve researchers from addressing the ethical ramifications of consenting minors. Other studies conducted among child-headed households have accepted consent from a *de facto* guardian, such as a neighbour or extended family member (Cluver, Gardner, & Operario, 2009; Schenk, Ndhlovu, Tembo, Nsune, & Nkhata, 2006). However, exploitation of child-headed households by neighbours and extended family may be common in some contexts (Thurman et al., 2006) making it difficult to conclusively identify adults who will act in the child's best interest. Researchers should be cognizant of relevant local laws and norms in developing appropriate child consent and assent procedures, and do so in consultation with local IRBs.

Establish referral procedures that are sensitive to the research context

In the studies profiled here, social service referral sheets were typically generated in cooperation with programme partners for distribution to all potential study participants. This information is intended to enhance participants' knowledge about services available in their community. However, referral sheets are not a substitute for comprehensive active referral protocols. Interviewers must be provided with explicit guidelines for referring participants who are in overt distress or at risk of harm. Interviewers are generally not social workers and need to be trained to recognize and respond appropriately to situations where participants should be linked

with community-based counselling or other support services. Occasionally, the research procedures themselves may be used as part of referral-need determination. For example, in several of the studies documented here, the Center for Epidemiologic Studies Depression Scale (Radloff, 1977) was used to measure depression and also to identify participants with high scores for referral to counselling. Interviewers must be trained to anticipate and cope with participants' reactions to the emotionally sensitive issues often covered in surveys, such as bereavement, HIV status, food insecurity and abuse. At a minimum, evaluators should ensure that counselling is made available in a timely fashion to participants who may need or request it and that active referrals for medical or other care issues are in place.

Evaluators may also encounter situations covered under mandatory reporting laws. Referral protocols should be developed in close coordination with the programme implementing organization(s). Often, the implementer can simply follow its typical referral procedures with study participants in need, but the research team must ensure that these protocols are approved by the relevant ethical review boards. Context should inform referral procedures so that, for example, poverty can be meaningfully distinguished from neglect, and in order to avoid overwhelming local support services with unwarranted referrals. Limited availability of local support services may also influence referral protocols and decisions about which questions to include in evaluation surveys—a lack of round-the-clock crisis counselling may make asking questions about suicidal ideology inadvisable. A research team's legal responsibilities regarding actionable disclosures about physical or sexual abuse may also be country specific. For example, sexual activity between two minors in some jurisdictions, including South Africa, may constitute a reportable offence. Care should be taken to research these issues in advance to allow informed decision-making about survey content and how to respond to specific disclosures.

Lesson 2. Collaborate strategically with programme partners

Evaluators should promote best practices for partners implementing interventions

Lacking the substantial time and skills needed to assess the quality of evaluation findings, the majority of social workers do not appear to use research to inform their work (Gibbs & Gambrill, 2002; Mullen & Bacon, 2004). Thus, many of the recommendations produced from programme evaluations do not

find their way into practice. Evaluators can promote both local ownership and improved programme practice by facilitating workshops with implementing partners that are designed to help enumerate and expand the application of minimum standards for service delivery. Providing support for upgrading curricula or other programme materials can also help ensure the use of theory-informed approaches and programme alignment with current evidence.

In the Grief Groups study, group facilitators were engaged to help define appropriate activities for use in specific intervention sessions and to establish practice standards for conducting the sessions. Likewise in the Paraprofessional Home Visiting study programme, partners were invited to assist with identifying key services and expected outcomes across the four programme models to ensure that the research accurately captured each programme's efforts. These meetings also provided an opportunity for the research team to work with programme staff to review best practices and the aims of their work in an open but constructive appraisal process. For example, in the Paraprofessional Home Visiting study, marked discrepancies were found between care workers' and beneficiaries' reports of the frequency of visits, prompting programme implementers to enact spot-check procedures. During the evaluation of the Let's Talk programme, group facilitators participated in a self-assessment designed to identify implementation challenges. Later, related recommendations were incorporated into the programme implementation guide.

Support the development of systems to track intervention enrolment and participation

In preparing for the Paraprofessional Home Visiting study, one programme partner was assisted with formalizing paper-based data collection to create a comprehensive beneficiary registry. The newly standardized information was then used to develop an electronic list of beneficiaries that became the basis for the sampling frame. The new registry system was then transferred to programme staff after providing training in participant tracking and basic data visualization techniques.

Electronic database systems were also routinely developed to enable programme partners to record and track trends in programme attendance: an innovation that facilitates timely response to attrition or attendance problems. In the Adolescent Risk Reduction study, problems with intervention attendance were identified midway through the study, greatly affecting potential programme impact on the first wave of study participants. More immediate and ongoing attendance data reviews were therefore introduced in later studies to facilitate timely implementation modifications. For example, in the Grief Groups study, early detection of attendance

problems prompted the programme to partner with the Department of Education and deliver what had been conceived of as an after-school programme during school hours instead.

Evaluators must also work with programme partners to understand likely barriers to programme attendance and to try to mitigate these issues at the outset. A variety of incentives and practical supports were found to be important factors affecting participant engagement. Providing food or other incentives for attending structured interventions may be effective in increasing participation, but evaluators should also consider participants' travel expenses and childcare needs. Qualitative data for these evaluations highlighted that even the personal characteristics of programme facilitators, such as gender, age, and how reliable participants perceive them to be, can affect participant engagement. Early investment in counteracting potential barriers to programme participation will help ensure that the evaluation reflects the programme's true potential.

Communicate regularly with local stakeholders about evaluation processes and results

The priorities for the evaluations documented here were determined in consultation with programme partners, the funder (United States Agency for International Development Southern Africa) and the Research Working Group subcommittee of the South African National Action Committee for Children Affected by HIV and AIDS. Dialogue with implementing organizations and other local key stakeholders is critical to designing survey methods that are contextually appropriate and responsive to the needs of donors, programme partners and participants. Although it is important for researchers to operate independently from implementers, it is essential to have open communication about roles, the purpose of the evaluation and its protocols and potential benefits. At the outset of a study, evaluators should emphasize that the evaluation represents an opportunity to identify programme strengths and areas for potential improvement, satisfy reporting requirements, advocate for resources and promote success stories. Programme staff should be informed that while it is unlikely that all desired outcomes will be achieved, even null findings can be useful (for example, to make a case for additional funding to address unmet needs). In the authors' experience, when implementers and other stakeholders have a well-developed understanding of how learning about the programme supports quality improvement, they are often eager to support the research.

Continued engagement of local stakeholders was maintained throughout the research process to ensure local relevance and the broader utilization of

findings. Postevaluation workshops and other forums can help implementing partners understand and use study results. Disseminating baseline results prior to the start of an intervention, if possible, can help programme partners to identify needs and establish priorities for implementation. However, researchers should be careful to document any programme modifications implemented after the baseline, as this could affect study outcomes. Disseminating evaluation results to programme staff also provides opportunities to emphasize successes and is a way of maintaining positive relationships with implementers while reinforcing programme quality. These presentations can also build local capacity for data presentation and interpretation, which may in turn help programme staff members communicate more effectively with donors and other stakeholders. The dissemination activities for the evaluations discussed here incorporated the creation of programme action plans by the implementing partners to address unmet needs identified by the evaluation. This provides partners with a planning tool, instils a sense of both ownership and accountability and helps promote the use of research to enhance practice.

Communication in the evaluations profiled here was not limited to the partner organization's headquarters personnel, but also extended to include staff at the study sites. Local programme staff members are an important resource for developing complete and accurate sample frames, locating participants in the field and providing ongoing information about programme implementation. Evaluators should hold workshops or otherwise engage with site-based staff to ensure they understand the study process and the importance of adhering to related protocols. Evaluators must be forthcoming about how the research may burden the programme staff, and work to minimize that burden whenever possible. Involving site-based staff in the interpretation and application of study findings promotes the programme's growth and sustainability by increasing local capacity for data use.

Lesson 3. Adapt evaluation designs to local conditions

Preassessment work strengthens evaluations

Preliminary qualitative work and pilot studies are helpful, and often essential, to enhance an intervention prior to study and to identify and validate the key outcomes and mediators to be tested. Qualitative methods reflect a participatory approach that empowers people to be active agents of change by using their experiential knowledge to suggest programme

improvements. In the evaluations under review, qualitative case studies, in-depth interviews, focus groups and feedback forms were used to identify aspects of programmes and their environment that might influence success. For example, through preliminary qualitative inquiry the researchers discovered that grief groups for bereaved adolescents were likely to be received well by female participants but rejected by males, which allowed for relevant programming recommendations to be made. In the Let's Talk pilot study, intervention facilitators were asked to complete session feedback forms after each group meeting. Data reflecting the length of time required to complete specific exercises and how the exercises were received by the groups were used to adjust the programme to meet session length targets and limit activities to those that were acceptable to participants.

Qualitative research can also help identify likely programme outcomes and strengthen related measures. In addition to standard approaches to ensuring that survey instruments are ready for use (such as translating questionnaires into local languages, hiring bilingual interviewers and pretesting questions with age- and gender-appropriate groups) applied across each of the evaluations, cognitive interviewing was employed in the Grief Groups study as a cost-effective means to identify threats to validity and reliability (Taylor, Thurman & Nogela, 2016). From a social work perspective, cognitive interviewing also serves to ensure cultural competence in research practice. Qualitative question pretesting may be especially important for measures without histories of testing or use outside of Western settings (Sweetland, Belkin, & Verdelli, 2014).

Pilot studies also provide valuable insights for future evaluations. The Let's Talk pilot study, focused on an intervention under development, was conducted as a process evaluation to identify likely outcomes for a forthcoming, more rigorous and resource-intensive evaluation. A pretest/posttest study design without a comparison group was used to measure changes from baseline. Even though observed changes could not definitively be attributed to the intervention, the pilot study functioned as a low-cost way to garner insights about expected outcomes' reliability, sensitivity to change and cultural acceptability. For example, the Let's Talk pilot study found that the Depression Anxiety Stress Scale (Lovibond & Lovibond, 1996) had good reliability among both isiZulu- and Sesotho-speaking adolescents, but the Strengths and Difficulties Scale (Goodman, 1999) did not. Evaluators may also consider conducting posttest surveys with individuals who have prior programme exposure alongside the newly enrolled to gauge programme potential and refine survey measures.

Experience from these evaluations also highlights the value of waiting

to conduct a full evaluation and providing programme partners with preliminary/pilot data to allow them time to build skills for implementation, and to recognize and respond to potential obstacles to success. Facilitation, logistics and programme proficiency are likely to improve over time. Evaluations will better reflect the implementer's actual capacity and the programme's full potential when implemented after programme staff have some experience implementing the programme and an understanding of areas that require improvement. This, in turn, helps ensure that the costliest, most rigorous study designs are employed under circumstances that justify their investment.

Use strategies to maximize statistical power and precision

Evaluations of community-based social work interventions may lack the statistical power to detect programme effects. Community-based implementing partners often have a limited capacity to provide services, in turn limiting the potential sample size for an evaluation. Researchers must estimate the capacity of programme partners to serve clients and use this information to calculate the lowest detectable levels of change on key outcomes, then determine if these effects are realistic to expect from the programme. Study design decisions that affect power, such as the use of cluster versus individual randomization, should also be carefully considered. Special attention should be given to how participants' gender (or other characteristics) may be related to programme outcomes. Gender-specific analyses of programme impact require a stratified sampling approach to ensure sufficient power, and should be based on gender-specific potential effect sizes, when available. For example, girls and boys may become sexually active at different ages, requiring attention to age at enrolment in sample size estimates.

The study timeline also influences the choice of outcomes that can be effectively measured. The length of time between survey rounds and the time between the end of the intervention and follow-up surveys must be considered when deciding which outcome measures are most appropriate for use in an evaluation. The preventive effects of the programme may emerge only in the long term. Longer follow-up periods are necessary, for example, when the evaluation will examine sexual risk behaviours or other outcomes that emerge only after a number of years in adolescent or other populations. In the Adolescent Risk Reduction trial, for example, relatively small numbers of participants were sexually active even two years after the baseline survey, limiting the utility of those measures (Thurman, Kidman et al., 2016). Similarly, the short time between the two survey rounds in the Let's

Talk pilot study limited the measurable variation on key sexual behaviour outcomes. Measures that might be sensitive to rapid improvement were therefore added, including important precursors to sexual risk behaviour, such as HIV knowledge, self-efficacy for condom negotiation and attitudes about condom use.

Evaluators should plan to measure exposure to programme interventions alongside outcomes. Many participants in community-based structured social work programmes attend group sessions sporadically or not at all. It is therefore important to have and use study information about enrolment, session attendance and other factors underlying the response to intervention. In doing so, evaluators must consider that participants who choose to attend regularly may be different from participants who do not, in ways that directly influence the outcome being measured. Estimation of as-treated effects therefore requires advanced statistical modelling techniques and potentially the use of instrumental variables to address model endogeneity (Heckman, 1997). Close monitoring of attendance records maintained by the programme partners may be necessary to ensure the quality of attendance data—underscoring the value of support for the development of implementation data systems. Further, matched unique participant identifiers in both survey and attendance data are necessary to be able to link and use these data effectively.

Poorly maintained client lists from programme partners and loss to follow-up also pose threats to research quality. In the Adolescent Risk Reduction study, a large proportion of beneficiaries initially identified by programme partners as eligible were in fact found to be outside the study's age range or residing outside of the study's geographical area at boarding schools (Thurman, Kidman et al., 2016). Further, mobility among orphans is high (Ford & Hosegood, 2005). Sample sizes were typically established assuming an overall response rate of 80% at baseline with 20% loss to follow-up, although a 10% or less loss to follow-up has been achieved in four of the five studies examined here. This success in participant retention can be attributed to extra allowance in fieldwork timelines for repeat household visits and to the use of beneficiary tracking sheets that contain information collected from respondents at baseline about the best ways to reach them in the future.

Use technologies to minimize bias

Information technology can be used to minimize bias and promote efficient implementation of surveys. The use of paper survey forms was replaced with direct data entry into laptops or tablets linked to a cloud-based storage and processing system for the studies documented here. These systems lower

the risk of transcription errors, require fewer documents to be transported and guarded, strengthen confidentiality/data safety and make data available in real-time for immediate examination. Researchers should, however, be mindful of the minimum requirements for using these technologies, including a consistent source of electric power, multi plugs, internet connectivity and mechanisms to protect equipment from theft or damage. Additional time should be set aside during the survey planning phase for the preparation and testing of software applications. Computer-based data collection also requires that interviewers be computer literate (UNAIDS, 2015b).

Interviewer-administered survey methods were often combined with Audio Computer-Assisted Self-Interview (ACASI) technology in order to mitigate social desirability bias in measures of adolescent risk behaviour and abuse. Prior research has established the superiority of ACASI versus face-to-face interviewing for the collection of data on sensitive topics, including sexual behaviour (Waruru, Nduati, & Tylleskär, 2005). Face-to-face interviews have other advantages, such as the ability to offer neutral probing, explain questions and response options as needed, gain the confidence of subjects through interpersonal interaction and decrease the number of questions skipped inadvertently or by refusal. Thus, a mixed approach was often adopted in these evaluations wherein interviews began as face-to-face interactions with an interviewer, especially for items that used Likert scales as response options and when rapport could be especially necessary or valuable, with a transition to ACASI for sensitive questions on substance use, sexuality or similar subjects. Generally, adolescents responded well to an ACASI option, even preferring it to other methods, but it was not used with adults as they may be more likely to struggle with or reject the technology.

CONCLUSION

The Getting to Zero Strategy notes that “success depends on intensifying what we know works and focusing efforts where they are most needed” (UNAIDS, 2010, p. 22). Thoughtfully designed and implemented evaluations can help to discover, shape and expand best practices for mitigating HIV risk and strengthen care and social protection for vulnerable children and families. Lessons from these five evaluations in South Africa highlight the central roles of ethics and institutional collaboration in programme evaluations. Preliminary efforts to determine programme readiness and capacity, and to define achievable and appropriate outcome measures, strengthen evaluations

and promote the utility of research findings. Evaluations should be powered to enable gender-specific analyses and account adequately for nonresponse and varying levels of programme exposure. Researchers' collaboration with programme partners should be designed to build local capacity to plan, monitor and implement high-quality social work interventions.

Building a strong evidence base for social work interventions cannot come at the cost of withholding urgently needed services, but evaluations that balance rigour with ethical practice are possible. When RCT designs are not feasible, researchers should look for opportunities to employ alternative counterfactual approaches or other methods that offer strong evidence for programme impact. Rigorous programme evaluation is a uniquely valuable tool for developing the high-quality, cost-effective, inclusive and sustainable intervention approaches that are a hallmark of the Getting to Zero Strategy.

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Understanding the role of social workers in the promotion and uptake of prevention of mother-to-child transmission of HIV in Zimbabwe

Munyaradzi Muchacha and Abel Matsika



ABSTRACTS

This chapter discusses the role of social workers in the promotion of Prevention of Mother-to-Child Transmission of HIV (PMTCT) in Zimbabwe. Since the beginning of the HIV epidemic in Zimbabwe in the 1980s, social workers have been actively involved in crucial responses, such as voluntary counselling and testing, home-based and palliative care, community sensitizations and, recently, male circumcision. However, they have not been active in PMTCT promotion, which is cardinal in reducing the transmission of HIV to children. Equally important, it enhances the health and well-being of the mother. Access to PMTCT in Zimbabwe is limited by barriers such as lack of information, high user-fees, accessibility of health services, gender inequalities, limited male involvement and stigma and discrimination. To that end, we propose roles for social workers in addressing these barriers and enhancing PMTCT uptake.

了解津巴布韦社会工作者在推动和倡导预防艾滋病母婴传播中所发挥的角色

本章讨论了津巴布韦社会工作者在推动预防艾滋病母婴传播（PMTCT）工作中所发挥的作用。自20世纪80年代艾滋病病毒/艾滋病在津巴布韦开始流行以来，社会工作者一直积极参与重要的应对工作，如提供义务咨询和检测、家庭治疗和姑息治疗、社区敏化（宣传）、以及近期推行的男性包皮环切术等等。然而，他们并没能对艾滋病母婴传播的预防工作起到积极的推动作用。预防艾滋病母婴传播（PMTCT）是降低儿童感染艾滋病病毒数量的主要措施。同样重要的是，它也有助于改善母亲的身体和精神健康。在津巴布韦，参与预防艾滋病母婴传播（PMTCT）工作受到如下方面的限制：如信息缺乏、用户收费高、医疗服务的普及性、男女不平等、有限的男性参与、耻辱感和歧视等。为此，我们提出，社会工作者在解决这些限制问题和在倡导预防艾滋病母婴传播（PMTCT）工作方面应发挥积极作用。

Rol de los trabajadores sociales en Zimbabwe en la promoción y prevención de la transmisión materno-filial del VIH

En este capítulo se analiza el papel de los trabajadores sociales en Zimbabwe en la promoción de la prevención de transmisión materno-filial del VIH (PTMI). Desde el comienzo de la pandemia del VIH en Zimbabwe, en la década de los '80s, los trabajadores sociales han estado activamente involucrados en respuestas cruciales tales como asesoramiento y pruebas voluntarias, cuidados paliativos y a domicilio, concientización comunitaria, y recientemente, la circuncisión masculina. Sin embargo, no han estado activos en la promoción de la prevención de transmisión materno-filial. PTMI es fundamental en la reducción de la transmisión del VIH a los niños. Igualmente importante, mejora la salud y el bienestar de la madre. El acceso a la PTMI en Zimbabwe está limitado por barreras como la falta de información, las altas tarifas para los usuarios, la accesibilidad de los servicios de salud, las desigualdades de género, la participación limitada del hombre y el estigma y la discriminación. Por ello, se proponen funciones de los trabajadores sociales para hacer frente a estas barreras y mejorar la aceptación de la PTMI.

ジンバブエでのHIV母子感染予防推進と理解におけるソーシャル・ワーカーの役割を把握する

この章では、ジンバブエでのHIV母子感染防止プロモーション（PMTCT）における、ソーシャル・ワーカーの役割について述べます。1980年代にジンバブエでHIV/AIDSが流行し始めて以来、ソーシャル・ワーカーは重要な対応（例えば自発的なカウンセリングと検査、家庭における対症的治療、コミュニティ感作と最近では男性の割礼）に、積極的に関与してきました。しかし、彼らはHIV母子感染減小を基本とするPMTCTプロモーションでは活躍していませんでした。母親の健康と福祉を強化することは、同じくらい重要なことです。ジンバブエのPMTCTへのアクセスは、様々な障害により（例えば情報の不足、高い利用料金、公共医療のアクセスしにくさ、男女不平等、限られた男性の関与と汚名と差別など）制限されています。そのため、我々は、これらの障壁に対処して、PMTCTの取り込みを強化するために、ソーシャル・ワーカーの役割を提案します。

Comprendre le rôle des travailleurs sociaux dans la promotion et l'utilisation de la prévention de la transmission mère-enfant du VIH au Zimbabwe

Le présent chapitre analyse le rôle des travailleurs sociaux dans la promotion de la prévention de la transmission mère-enfant du VIH (PTME) au Zimbabwe. Depuis le début de la pandémie du VIH au Zimbabwe dans les années

1980, les travailleurs sociaux interviennent activement dans les ripostes essentielles, notamment dans l'offre de conseils et tests bénévoles, l'offre de soins palliatifs à domicile, la sensibilisation des communautés ; et, tout récemment, la circoncision. Cependant, ils n'interviennent pas activement dans la promotion de la prévention de la transmission mère-enfant. La PTME est capitale dans la réduction de la transmission du VIH aux enfants. Aussi, elle améliore la santé et le bien-être de la mère. L'accès à la PTME au Zimbabwe est limité par des barrières telles que l'absence d'informations, l'augmentation des frais dissuasifs, l'accès aux services de santé, les inégalités de genre, la participation limitée des hommes, la stigmatisation et la discrimination. Enfin, nous proposons que les travailleurs sociaux jouent des rôles dans la suppression de ces barrières et l'amélioration de l'utilisation de la PMTE.

INTRODUCTION

Equitable and universal access to HIV prevention, care, treatment and support is paramount if new infections and AIDS-related deaths are to be reduced. Significant progress has been made in enhancing universal access to these services across the globe. For instance, UNAIDS (2016a) notes that as of December 2015, 17 million people living with HIV were accessing antiretroviral therapy, compared with 15.8 million in June 2015 and 7.5 million in 2010. Progress has also been recorded in HIV-prevention programmes, such as male circumcision and voluntary counselling and testing. Despite this impressive progress there are still many gaps. For example, universal access to prevention and treatment, especially in the Global South, is hindered by factors such as stigma and discrimination, high user-fees and accessibility of services (Matsika, 2011). Furthermore, there are key populations who are disproportionately excluded from accessing services, such as adolescent girls and young women, sex workers, prisoners, children and women living with HIV, displaced persons, people who inject drugs, gay men and other men who have sex with men and transgender people, truck drivers and people living in underdeveloped rural areas (UNAIDS, 2015). To that end, it is important that further efforts are made to address structural barriers to universal access and facilitate the inclusion of people who are being left out.

There is no doubt that prevention of mother-to-child transmission of HIV (PMTCT) is vital. Such transmission occurs during pregnancy, labour and breastfeeding. PMTCT is thus a cascade of holistic and integrated services, such as HIV prevention, counselling and testing, adherence support,

antiretroviral therapy, safe childbirth, recommended infant-feeding practices and other postnatal services (Magaso, 2013; World Health Organization [WHO], 2010). A comprehensive approach to PMTCT is advocated by WHO (2010, p. 6) and includes the following four elements:

- Preventing new HIV infections among women of childbearing age.
- Preventing unintended pregnancies among women living with HIV.
- Preventing HIV transmission from a woman living with HIV to her baby.
- Providing appropriate treatment, care and support to mothers living with HIV and their children and families.

Substantial progress has been made in enhancing access to PMTCT services and reducing mother-to-child transmission. For example, UNAIDS (2016b) highlights that in the 21 highest-burdened countries in sub-Saharan Africa, new HIV infections have dropped from 270 000 [230 000–330 000] in 2009 to 110 000 [78 000–150 000] in 2015. Thus, 1.2 million new HIV infections among children have been prevented since 2009 (UNAIDS, 2016b). In 2015, across the globe, an estimated 77% [69–86%] of pregnant women living with HIV accessed antiretroviral medicines to prevent transmission of HIV to their children (UNAIDS, 2016a). However, further efforts are needed to achieve 100% access to PMTCT services and eliminate mother-to-child transmission.

Since the beginning of the epidemic, professional social workers have been actively engaged in the HIV response in Zimbabwe, especially through nongovernmental organizations [NGOs]; for example, social workers employed by community organizations such as Island Hospice and Mashambanzou implement community home-based care programmes. At Population Services International, an international NGO, social workers are involved in voluntary counselling and testing and, recently, male circumcision programmes. Africaid, a local NGO, has social workers who provide psychosocial support and access to treatment for children living with HIV. Social workers in the Department of Social Welfare provide support to children orphaned as a result of AIDS (Muchacha, 2015). These are a few examples that demonstrate the active engagement of social workers in the local HIV response. However, this chapter notes as a major concern that there is limited involvement of social workers in the promotion and uptake of PMTCT services. In view of this background, this chapter proposes roles for social workers to increase the uptake of PMTCT services. It argues that social workers have the relevant knowledge, skills and a long tradition of enabling access to services through addressing structural barriers and facilitating inclusion of the so-called hard-to-reach communities. Social work training in

Zimbabwe, and across the world, empowers social workers with various social intervention skills, such as advocacy, networking, effective communication, community organizing, social research, problem solving, social policy formulation and connecting service users to various services (Asquith, Clark, & Waterhouse, 2005). As such, this chapter proposes and discusses roles for social workers in promoting the uptake of PMTCT by facilitating the provision of psychosocial support, the conducting of community dialogues to address stigma, discrimination and gender inequalities, advocacy and economic empowerment and the addressing of faith-based objections to health care.

THE HIV SITUATION IN ZIMBABWE AND RESPONSES

The country of Zimbabwe is located in southern Africa and has a population of 13 million people. It is one of the countries most affected by HIV in sub-Saharan Africa. Zimbabwe's HIV prevalence rate is 14.7% [13.3%–16.0%], one of the highest in the sub-Saharan region (UNAIDS, 2016c). The prevalence of HIV is higher in urban areas than in rural areas. Furthermore, HIV prevalence is 1.5 times higher among women who are 15 to 24 years old than among males of the same age group (UNAIDS, 2015). An estimated 1 400 000 [1 300 000–1 500 000] people are living with HIV in this country (UNAIDS, 2016c). Many people living with HIV in Zimbabwe encounter various challenges that hamper positive living, a state whereby one pursues and lives a healthier life while also living with HIV (Matsika, 2011). These challenges include limited access to psychosocial support, health and nutritional services and social services, and the experiencing of many forms of stigma and discrimination (Matsika, 2011). Zimbabwe has significantly reduced its HIV prevalence rate and is enabling access to treatment, care and support. The UNAIDS World Day 2015 Report states, “The achievements of Zimbabwe's HIV response are among the most remarkable in southern Africa. From 2004 to 2014, the number of people accessing antiretroviral therapy increased from 11 800 to 788 000. Similarly, new HIV infections declined by 46% between 2002 and 2014, and HIV prevalence fell from 25.9% in 2002 to 16.7% in 2014” (UNAIDS, 2015, p. 17).

The above evidence indicates remarkable progress considering that the country has other major socioeconomic and structural challenges, such as high levels of unemployment and chronic poverty, limited access to social service provision, drought, and economic and political instability. This progress is credited to a robust multisectoral response comprising various

holistic services, such as condom promotion and distribution, PMTCT services, workplace policies, provider-initiated testing and counselling, voluntary counselling and testing and voluntary medical male circumcision (Ministry of Health and Child Care, 2014). The multisectoral response involves various and diverse actors, such as government, traditional and political leadership, local and international NGOs, the private sector, farmers' organizations and the informal sector. Undergirding the national HIV response is the five-year Zimbabwe National HIV and AIDS Strategic Plan II, which runs from 2011 to 2015. It is a successor to the Zimbabwe National HIV and AIDS Strategic Plan I that ran from 2006 to 2010 (Ministry of Health and Child Care, 2014).

BARRIERS TO ACCESS TO PREVENTION OF MOTHER-TO-CHILD TRANSMISSION INTERVENTIONS IN ZIMBABWE

Between 2009 and 2015, Zimbabwe witnessed a 65% reduction in new HIV infections among children. Furthermore, an estimated 8 out of 10 pregnant women living with HIV received antiretroviral medicine to prevent mother-to-child transmission. While this represents a remarkable success, there are still gaps. In 2015, there were 4900 new infections among children and there is currently a 7% rate of mother-to-child transmission (UNAIDS, 2016b). Hence, this section discusses the chief sociocultural and economic barriers to universal and equitable access to PMTCT in Zimbabwe (gender inequality, conservative religious beliefs, stigma and discrimination, and high user-fees), so as to inform possible social work interventions.

Stigma and discrimination

Stigmatization and discrimination of people living with HIV continue to present a major threat to access to treatment, care and support for these people (Matsika, 2011; UNAIDS, 2016b). UNAIDS (2016b) highlights that across the world, stigma and discrimination directed towards people with HIV are slowly decreasing, but progress has been slower for women. The Zimbabwe National Network for People Living with HIV [ZNNP+] People Living with HIV Stigma Index highlights that 65% of people living with HIV in Zimbabwe experience one or more forms of stigma and discrimination (ZNNP+, 2014). Similarly, Matsika (2011) observed that in Zimbabwe people living with HIV

are labelled with discriminatory terms, such as *shuramatongo*, a native Shona language term that refers to a person as having a dreadful disease. Another similar expression is *ari mubhazi*, which implies that the person is on a bus en route to death, due to living with HIV. Sambisa, Curtis, and Mishra (2010) noted that among their study respondents who were living positively, 55% of women and 40% of men experienced social rejection. It is evident that social rejection is significantly higher for women. This stigmatization and discrimination leads to limited uptake of voluntary counselling, testing and antiretroviral therapy, and to the fear of disclosure (Sambisa et al., 2010; Matsika, 2011).

PMTCT services, like other HIV programmes, are undermined by stigma and discrimination directed towards people living with HIV (Gulaid & Kiragu, 2012; UNAIDS, 2016b). As Turan and Nyblade (2013, p. 2529) point out, “The multiple steps required to successfully complete a full programme of PMTCT, and as the signs advance, to adhere to the increasingly more complex antiretroviral regimens for PMTCT, all increase the potential for unwanted disclosure of HIV status, heightening both anticipations of stigma, as well as the possibility of experiencing discrimination, at each step along the cascade.” Stigma and discrimination represent a major threat to various stages of the PMTCT process, resulting in treatment default and loss to follow-up (Gulaid & Kiragu, 2012; Matsika, 2011; UNAIDS, 2016b). The consequences of stigma and discrimination to PMTCT include limited uptake of HIV-testing services, lack of disclosure, non-utilization of antenatal care (ANC) services and recommended safe infant-feeding practices, home delivery and nonadherence to treatment for the mother and the child (Turan & Nyblade, 2013).

Gender inequality

Unbalanced power relationships between men and women in Zimbabwe and other patriarchal communities present a major structural barrier to equitable access to medical care for women (Ghanotakis, Peacock, & Wilcher, 2012). In Zimbabwe, most men have control over women and are the major decision-makers. They have control over various items and issues, including the woman’s body, the number of children she can have, the type of contraceptives she can use, and other decisions such as HIV testing and access to health-care services. Ghanotakis et al. (2012, p. 1) argues that “Gender inequality affects women and girls’ ability to protect themselves from HIV, control their fertility and access and adhere to HIV prevention, care and treatment services.” Ghanotakis et al. (2012) further state that men

exert considerable influence on women's uptake of HIV testing and that men's disapproval is associated with low counselling and testing rates and high loss to follow-up. Dube (2014, para 8) cites the District AIDS Coordinator of Bulilimangwe District,¹ who noted, "Some pregnant women do not turn up at clinics at all, unless they have the approval of their spouses, the problem is that women are not able to make the choices on their own." The District AIDS Coordinator goes on to say, "We encourage women to visit the clinic at the early stage of their pregnancy, some delay because of the resistance from their husbands, some are ordered not to come at all by their husbands" (Dube, 2014, para 9). Similarly, Muchacha and Mtetwa (2014), in their study on the barriers to exclusive breastfeeding uptake in rural Zimbabwe, identified that men had considerable influence and were major decision-makers on the infant-feeding practices that were adopted by women. This demonstrates the influence and impact that gender inequality has on access to health services by women.

Conservative religious beliefs

A number of conservative faith sects in Zimbabwe have religious beliefs that hinder access to health services for their members. Johane Marange (the largest conservative sect) prohibits any access to formal health care. Machingura (2014, p. 181) notes that "Apostles/Vapostori [apostolic sects] set themselves apart from their neighbours in many ways and have strict obligations to be followed." Due to strict faith values, members of the sect are a hard-to-reach population (Organisation for Public Health Interventions and Development [OPHID], 2014). OPHID (2014, p. 6) observes that "The conservative group believe that modern health-care services and therapeutics are deemed 'heathen', 'of the devil' and 'secular'. Members of the sect that do access formal medical services are perceived as being of 'weak faith', defiled and elevating the medical system above God and thus taking away God's glory." Matsika (2011) adds that this sect regards people who take antiretroviral medications as persons of limited faith in God. OPHID (2014) notes that as a result of these religious beliefs, PMTCT services, such as counselling and testing, antiretroviral therapy, safe delivery and infant-feeding practices, are not accessed by most of the members of the sects.

Johane Marange has an estimated three million-plus members. According to the Zimbabwe National Statistics Agency (ZIMSTAT, 2012),

1 Bulilimangwe is a district in Matebeleland South province in south-western Zimbabwe, close to the international border with Botswana.

approximately 38% of women in Zimbabwe belong to an apostolic sect and 74% of these are resident in rural areas. Considering that the total population in Zimbabwe is about 13 061 239 people, the Johane Marange sect has a significant impact on access to PMTCT and other health services. For example, OPHID (2014) highlights that most women of apostolic faith deliver their children at home and are assisted to deliver by designated apostolic women called home-birth attendants. Due to the high incidence of home deliveries, “Apostolic women and their new-born children are at higher risk of mortality and morbidity during pregnancy, delivery and postnatal periods” (OPHID, 2014, p. 1). A study by Tachiweyika et al. (2011) observed that infant mortality among the ultra-conservative apostolic sect in Marondera District was higher than the average for the whole district and province. Similarly, OPHID (2012) identified that among the 350 respondents who had home deliveries, 60% were members of conservative apostolic sects. Several other studies in Zimbabwe have observed limited access to PMTCT services, such as testing and counselling, antenatal, neonatal and postnatal care, and institutional delivery, among members of conservative apostolic sects (see, for example, Hove, Siziya, Katito, & Tshimanga, 1999; NEDICO, 2008; Perez, Aung, Ndoro, Engelsmann, & Dabis, 2008).

High user-fees

Affordability of a health service considerably influences access to health care (Magaso, 2013). Health services are a basic human right and should be universally accessible. Soon after independence, most health services in Zimbabwe were free at the point of service. However, charges have been added to most health services, which has an impact on access to the PMTCT holistic package. Some PMTCT services, such as voluntary counselling and testing and antiretroviral therapy, are free of charge; however, other equally important PMTCT services, such as institutional delivery and ANC, have a charge. The cost² attached to ANC and institutional delivery hinders pregnant women from booking (there is a booking fee for accessing ANC services) and delivering at a health-care centre, affecting their access to PMTCT and thereby losing the opportunity to get tested and receive necessary treatment. A study by Magaso (2013, p. 65) highlighted that 63% of respondents said that delivery and ANC costs were too high and beyond their reach. One of the respondents noted, “First we pay at the clinic US \$80 then later ... we are told to book with the hospital. Here, they don’t consider that we have paid before. We have to

2 The prices in Zimbabwe differ between urban and rural areas, public and private institutions, hospitals and clinics.

pay another US\$ 50 here to book [for] maternity and then US\$ 50 each time we come for ANC” (Magaso, 2013, p. 73). These costs are definitely considered high, considering that unemployment in Zimbabwe is currently over 80% and many people in the country have limited incomes and are living in poverty (Muchacha, Dziro, & Mtetwa, 2016).

The high costs of delivery are contributing to increased home deliveries. Magaso (2013, p. 73) cites a health provider who noted that “Pregnant women are failing to afford these services. We have seen a gradual decrease in the number of women attending ANC and even those delivering here. Because booking payments are no longer staggered and women have to pay the full amount at once, even more women are failing to come.” According to OPHID (2014), only 61% of women in Zimbabwe deliver their babies at institutional facilities; the rest deliver at home. This is a staggering statistic that presents a major barrier to PMTCT, as women who deliver at home may not access or complete a PMTCT programme. Furthermore, it is evident that uptake of postnatal care is poor among women who deliver at home. OPHID (2012) observed that the major cause of home deliveries was the high cost of institutional deliveries and other costs, such as transport and up-keep costs at the hospital. Fifty-two per cent of the respondents in OPHID’s 2012 study had home deliveries due to the high costs associated with institutional delivery. Most of these respondents had babies delivered by unskilled traditional birth attendants. Equally important, OPHID (2012) reports that most of its participants (35.7%) highlighted that if financial barriers were removed they would have an institutional delivery.

THE ROLE OF SOCIAL WORKERS IN THE PROMOTION AND UPTAKE OF PMTCT

The social work profession has a long tradition of facilitating and fostering human rights, equity, equality, social justice and social inclusion. Social workers in various settings deal with structural barriers that impede access to services. Their expertise is critical to enable equitable access to PMTCT services. To promote increased uptake and equitable and universal access to PMTCT services, social workers need to implement innovative interventions that address the structural barriers to access. There are many roles social workers can play within NGOs, the government health system or as part of their professional bodies, and to some extent as individual social change agents, to promote PMTCT. Below is a discussion of various roles social workers in Zimbabwe might undertake to facilitate increased uptake of PMTCT services.

Facilitating the provision of psychosocial support and strengthening community-based support structures to support people living with HIV

Many women living with HIV need ongoing social support to deal with the various challenges that affect their access to PMTCT, such as stigma and discrimination. Social support is also essential in facilitating adherence to treatment, preventing loss to follow-up and dealing with other issues such as gender-based violence (Shroufi, Mafara, Saint-Saveur, Taziwa, & Viñoles, 2013). Evidence shows that for women, support groups play an important role in providing psychosocial support to deal with stigma and discrimination, and enabling access to health services and recommended health practices such as exclusive breastfeeding. According to Muchedzi et al. (2010), women living with HIV who were in a support group were twice as likely to access HIV treatment than those who were not. Gillett and Parr (2010) observed in Kenya that support groups were very instrumental in enabling disclosure and dealing with resultant outcomes. Social workers in Zimbabwe and many other parts of the world are skilled at working with service users in groups, which is known as social work with groups or social group work; they also work with groups in various fields, such as substance abuse, parenting and juvenile justice. Social workers in Zimbabwe can play various roles in supporting the establishment and functioning of support groups, such as community mobilization, training, facilitation (especially in the early stages) and linking the group to various services that may be provided by community-based organizations, for example legal aid and nutrition services.

Social workers in Zimbabwe also need to explore other innovative approaches to facilitate the provision of social support to pregnant women living with HIV, such as mother mentors. For example, in South Africa the M2M project utilizes mothers who are living with HIV (mother mentors) to provide mentorship to other mothers who are living with HIV (UNAIDS, 2012). The mother mentors are trained in PMTCT and provide mentorship on issues such as treatment initiation, adherence, disclosure and infant testing and feeding. They also assist mothers to deal with psychosocial factors that affect access to PMTCT. A mother mentor programme similar to M2M has been implemented by Médecins Sans Frontières (MSF) in Bulawayo, the second-largest city in Zimbabwe. Evaluation of this small-scale programme highlighted that women who had a mother mentor were more likely to return for testing at 6–8 weeks of pregnancy than those who were not enrolled in the programme (99.2% vs 48.6%; Shroufi et al., 2013). In Kenya, as a result of a similar model, antiretroviral uptake was 97% among mothers who had interacted with mother mentors compared with 62% among women who

had no such interaction (UNAIDS, 2012). In Uganda, a similar peer and social support project utilizes people living with HIV as peer facilitators. This has resulted in high health-seeking behaviour among the mothers reached by this project (UNAIDS, 2012). In light of this background, social workers can play various roles, such as training, capacity-building, support and supervision and provision of social support, to support mother mentors.

It is important to note and acknowledge that there are limited numbers of social workers in Zimbabwe to provide direct support such as counselling to all women living with HIV (Muchacha et al., 2016). Hence, social workers need to support community-based health workers, such as village health workers and community behaviour change facilitators, to support people living with HIV to deal with challenges like stigma and discrimination. These cadres also play an important role in providing other health information, such as family planning, immunization and sexual reproductive health. Social workers in Zimbabwe have experience and expertise in utilizing community resources and structures, such as community volunteers, to enable access to services at grass-roots level and, to some extent, in hard-to-reach areas. For example, the National Case Management System in Zimbabwe, a national child protection programme led by social workers, utilizes community volunteers to support orphans and vulnerable children through assessments, referrals, follow-ups and provision of social support. Social workers are responsible for providing ongoing support and supervision, including clinical supervision, to these volunteers (Muchacha, 2015). As such, similar to the mother mentors initiative, the role of social workers is to provide training, supervision and psychosocial support to the community health workers.

Facilitating community dialogues, awareness and male involvement to address stigma, discrimination and gender inequalities

Social workers can play various roles in addressing stigma, discrimination and gender inequalities. Community dialogues are essential to enhance awareness, as they promote active participation and learning. They also allow participants to critically reflect on their attitudes and practices (Figueroa, Kincaid, Rani, & Lewis, 2002). Community dialogues enable exchanges of information between the people involved, with room for participants to critically reflect, ask questions and share ideas on how the community can collectively address this challenge. Community dialogues also have the potential to address power relationships associated with the dissemination of information, as they allow participants to lead and actively

take part in the learning process. They are also essential in addressing the social norms, attitudes and cultural practices that contribute to and sustain gender inequalities and violence in communities. The role of social workers in community dialogues includes facilitation, organizing, mobilizing the learning material and any other forms of logistical support. These dialogues should also target and involve other important stakeholders, such as health workers, police officers, teachers and political, traditional and religious leaders.

Other than community dialogues, social workers may also facilitate and raise awareness through other participatory mechanisms, such as drama and music. It is crucial that people living with HIV are provided with the opportunity and platform to actively participate in and lead awareness activities as champions of the social-change process, thereby dispelling prevailing myths. People living with HIV may need new skills to play this role; thus, social workers need to provide ongoing support and assist in capacity-building efforts. Support groups provide a platform for enhancing these skills. Furthermore, mother mentors and village health workers can also actively support women living with HIV to play an active role against stigma and discrimination (Gulaid & Kiragu, 2012).

Evidence indicates that people with influence, and even authority, such as politicians, celebrities, traditional and religious leaders, teachers and agricultural extension workers, have the potential and capacity to influence social and behaviour change in the community if they act as champions (UNAIDS, 2012). As such, social workers need to utilize people with influence in the community to act as champions of the zero discrimination message, gender equality, zero tolerance for gender-based violence and even the active involvement of men in family health services. This initiative is not new to Zimbabwe; it is currently being implemented in the promotion of programmes such as voluntary counselling and testing and, recently, male circumcision. However, it is important that social workers continue to implement this approach, particularly with regard to targeting communities that are considered hard-to-reach and are being left out.

There is currently limited involvement of men in PMTCT programming, despite the substantial influence that men have over women's access to health services in Zimbabwe. Involving men in PMTCT programmes also presents an opportunity to address gender-based violence and inequalities. Male involvement promotes shared decision-making, which is essential to the successful uptake of PMTCT (Morfaw et al., 2013). Furthermore, it enables men to play a role in reducing HIV transmission during pregnancy (Peltzer et al., 2011). Morfaw et al. (2013, para 4) highlight that "The lack of male

involvement in PMTCT consequently undermines the potential benefits of ANC HIV-preventive efforts, thus representing a missed opportunity to effectively prevent vertical HIV transmission.” Barriers to the involvement of men in PMTCT programmes include lack of information, health-system constraints and cultural attitudes, such as that ANC is for women, and a reluctance of men to know their HIV status (Morfaw et al., 2013). In light of this background, it is imperative that social workers facilitate and enable active male participation through activities such as community dialogue, social mobilization and advocacy for male-friendly maternal services.

Addressing faith-based objections to health care

Faith leaders have immense influence over their followers’ attitudes, health-seeking behaviour and patterns. Hence, social workers need to work closely with faith leaders to critically reflect on and identify faith-based objections to PMTCT and find a solution that enables access to PMTCT, and even to other health services. However, in the process of engaging sect leaders and members of various faith groups, social workers need to guard against prejudice and imposing their own values by being respectful of the various religious beliefs, practices and perspectives (United Nations Children’s Fund [UNICEF], 2015). This is crucial in building a nurturing and mutual relationship that promotes meaningful participation and enables both behaviour and social change. Addressing deep-rooted religious norms is a complex process in which achieving long-term results often takes a long time (Maguranyanga, 2011). It is, however, encouraging to note that in recent years there has been an increasing, albeit slow, acceptance of formal health services among the apostolic sect community, including its leadership.

The apostolic community in Zimbabwe has two major leadership and representative bodies—the Union for the Development of Apostolic Churches in Zimbabwe and the Apostolic Christian Council of Zimbabwe. These bodies have considerable influence over the country’s apostolic community and social workers need to engage these bodies for continued reform. Significant progress has indeed been made in engaging these bodies; for example, with the cooperation and participation of the apostolic leaders UNICEF Zimbabwe has developed a behaviour- and social-change model/framework titled *The apostolic maternal empowerment and newborn intervention (AMENI) model* to engage and to create dialogue and raise awareness of maternal health within the apostolic sect (UNICEF, 2015). Equally important, the Union for the Development of Apostolic Churches in Zimbabwe has recently developed a gender-equality policy. Social workers need to leverage off this progress and

cooperation, and support sect leaders in implementing these crucial policies and enhancing access to health.

Mother mentors and community health workers can also play an important role, especially in encouraging apostolic women to access health services such as voluntary testing, counselling and institutional delivery. Further, they can also provide individualized support to women who wish to access health services but fear being judged by other members or other consequences. The role of social workers is to provide technical support to these community structures to engage at grass-roots level with women from the apostolic community. Equally important, social workers may support mother mentors and community health workers to conduct dialogue and empower members of the apostolic sect to critically reflect on their practices and explore ways to access health services.

Advocacy and economic empowerment

Social work also has a strong tradition of advocacy that goes beyond representation of service users' needs, and includes empowering and mainstreaming the active participation of service users in the process of influencing social change (Dominelli, 2009; Schneider & Lester, 2001). The International Federation of Social Workers' (2012) manifesto on HIV urges social workers to advocate for health policies that are well informed by social determinants of health and which enable integrated and holistic care and well-being of people living with HIV and other people affected. At policy level, there are many platforms for political engagement and advocacy of which social workers in Zimbabwe, as part of NGOs or professional bodies or as individuals, can take advantage. These include the Parliamentary Portfolio Committee on Health, the Zimbabwe Human Rights Commission, the National Health Board and even the Constitutional Court. These are statutory structures intended to facilitate health-service delivery, advancement of human rights and political action. These bodies, and the Constitution mentioned above, provide crucial platforms from which to draw political will to address the challenges that hinder access to PMTCT services in Zimbabwe, including user-fees.

It is pertinent that social workers in Zimbabwe explore mechanisms for economically strengthening women to enable them to sustainably meet their needs, including health. Economic empowerment interventions have the potential to build up women's decision-making on choices of maternal and child health, which are ordinarily difficult to make if they are socially and economically dependent on a husband who may not be willing to take up those

responsibilities. For instance, cash transfers and microfinance initiatives such as savings groups, have considerable popularity in Zimbabwe. Social workers in Zimbabwe may promote these initiatives to support pregnant women and remove the social-economic barriers that impede women's access to PMTCT services. Muchacha et al. (2016) highlight that social workers in Zimbabwe are implementing savings groups to support caregivers to sustainably meet the needs of orphans and other vulnerable children.

Social workers are providing training in various economic skills (marketing, business management and basic accounting) and market linkages, and are also providing support and supervision. In relation to PMTCT, a possible innovation is to further utilize the support groups discussed earlier as savings groups, where social workers provide training on basic business management, and the processes of savings groups and facilitate access to various possible markets. Social workers may also link women to various organizations that provide different services, for example training on a specific income-generating activity such as poultry or mushroom production. It is imperative that social workers mainstream the active participation of pregnant women in the implementation of economic empowerment models to promote ownership and sustainability. Active participation should be mainstreamed from planning, resource mobilization, implementation and monitoring and evaluation. Furthermore, social workers need to ensure that the economic empowerment programmes are implemented close to or within local communities, so that distance will not pose a barrier to full participation.

CONCLUSION

PMTCT is crucial in the realization of an HIV-free generation. Significant progress has been made in enabling access to PMTCT across the world, including Zimbabwe. However, there are still many women who are excluded because of various structural barriers, such as the high costs of institutional birth deliveries, accessibility of health facilities, stigma and discrimination, conservative faiths, gender inequalities and, to some extent, lack of information. Lack of access to PMTCT affects the child, the mother and the whole of society. To address these and enhance access and uptake of PMTCT, this chapter has proposed and discussed various possible roles that social workers can perform to promote the uptake of PMTCT. The proposed roles are summarised below:

- Facilitating the provision of psychosocial support and strengthening community-based support structures to support people living with

HIV. Social work activities including facilitating the establishment of support groups and providing ongoing support, and supporting community cadres and structures, such as mother mentors, village health workers and behaviour-change facilitators.

- Facilitating community dialogue, awareness and male involvement to address stigma, discrimination and gender inequality.
- Addressing faith-based objections to health care through activities, such as dialogue with faith leaders and community mobilization of members of the faith groups.
- Advocacy and economic empowerment. This role seeks to advocate for the removal of cost-related barriers to PMTCT and to economically empower women living with HIV to sustainably meet their health needs through activities such as savings groups, cash transfers and livelihoods.

To effectively undertake these and other roles, social workers need to work closely with various stakeholders, such as other professionals, traditional, religious and political leaders, youth groups, civil society organizations, United Nations organizations and other international organizations and various government entities. Such collaboration is in line with the Zimbabwe National HIV and AIDS Strategic Plan II, which calls for a harmonized multisectoral response to HIV in Zimbabwe. Furthermore, the social work profession is a profession with values, and it is thus expected that social workers will continually reflect on their practices and respect social work values—such as social justice, participation, the importance of human relationships, the dignity and worth of the person, and competence. It is also essential that social workers be innovative in the development and implementation of their interventions so that they provide the best possible services. Ideas and insights for innovation can be derived from various sources, such as lessons emerging from practice—both promising local and international practices and best practices—input from active participant service users, and sharing of knowledge between social workers and other professionals across the world.

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**Exploring the
daily challenges of
female sex workers
to negotiate safe
sex in Mumbai,
India: What can
social workers do?**

Sharvari Karandikar and Lindsay Gezinski



ABSTRACTS

Sex workers are stigmatized in the context of HIV and blamed as being so-called vectors of the infection. In this chapter, we present the findings of a qualitative study of 48 female sex workers from the Kamathipura red-light area of Mumbai, India. Two themes are discussed: 1) health-related challenges of sex workers; and 2) challenges in HIV risk management, specifically safe-sex negotiation with clients and intimate partners. Sex workers described their poor health and poor living conditions, as well as safety concerns. They described acts of violence perpetrated against them in relation to their efforts to negotiate safe sex. HIV prevention was challenging, as sex workers had to confront stringent male attitudes against condom use. This chapter highlights the need for prevention efforts that counter stereotypes of sex workers, decrease stigmatization and increase gender equity. It is imperative that intimate partners, clients and pimps are included in these interventions for greater effectiveness.

在印度孟买女性性工作者每日为争取性安全而面临的挑战:社会工作者能做什么?

由于艾滋病毒传播的原因，性工作者常被污蔑并被指责为感染的“载体”。在这一章中，我们介绍了对印度孟买卡马提普拉（Kamathipura）红灯区48位女性性工作者的研究结果，并就如下两个主题进行了讨论：1）与性工作者健康有关的挑战，和2）在艾滋病毒风险管理方面，特别是与客户和亲密伴侣争取安全性交所面临的挑战。性工作者描述了她们较差的健康和生活状况以及安全问题，描述了她们在争取安全性交时所遇到的暴力行为。因为这些女性性工作者不得不与持强势态度的男性就使用安全套问题进行抗争，所以艾滋病预防非常具有挑战性。本章重点强调必须采取预防措施，打破对性工作者的陈腐观念、减少对他们的侮辱，提高性别平等。为了提高这些措施的有效性，把亲密性伙伴、客户和皮条客均包括在这些干预措施中是非常必要的。

Explorando los desafíos diarios de trabajadoras sexuales para negociar sexo seguro en Mumbai, India: ¿Qué pueden hacer las trabajadoras sociales?

Las trabajadoras sexuales son estigmatizadas en el contexto del VIH y culpadas como si fueran los “vectores” de la infección. En este capítulo se presentan los resultados de un estudio cualitativo de 48 trabajadoras sexuales de la zona del barrio rojo de Kamathipura de Mumbai, India. Se tratan dos temas: 1) los desafíos relacionados con la salud de las trabajadoras sexuales y 2) los retos en la gestión de riesgo del VIH, especialmente la negociación del sexo seguro con los clientes y socios íntimos. Las trabajadoras sexuales describen sus malas condiciones de vida y de salud, así como aspectos de seguridad, tales como los actos de violencia perpetrados contra ellas en relación con sus esfuerzos para negociar el sexo seguro. La prevención del VIH aparece como difícil ya que las profesionales del sexo tienen que enfrentarse a exigentes actitudes masculinas contra el uso del condón. En este capítulo se destaca la necesidad de esfuerzos de prevención que contrarresten los estereotipos de las trabajadoras sexuales, disminuyan la estigmatización y aumenten la equidad de género. Es imperativo que los compañeros sentimentales, clientes y proxenetas se incluyan en estas intervenciones para una mayor efectividad.

インドのムンバイで、女性売春労働者が安全なセックスを交渉するための日々の課題を調査：ソーシャル・ワーカーは、何ができるか。

売春労働者はHIVの背景で汚名をきせられ、感染の「媒介者」であると非難されています。この章では、インドのムンバイ、カマチプラ赤ランプ（売春）地域から、48人の女性売春労働者との定性的研究の調査結果を提示し、2つのテーマを議論します。1) 売春労働者の健康関連の課題 2) HIVリスク管理の課題（特に女性売春労働者とその親しいパートナーとの安全な性交渉）売春労働者は、安全に対する懸念だけでなく、健康不安と貧しい生活状況について述べました。そして、安全なセックスを交渉する努力に対して、彼女たちが被る暴力行為について話しました。コンドーム使用に対する男性の厳しい態度に直面しなければならなかったため、HIV防止は困難とのことでした。この章では、売春労働者に対する固定観念に対処し、汚名を着せられることを減少させ、異性間の平等を推進する予防活動の必要性を強調します。より効果を高めるため、親しいパートナー、顧客とヒモを、これらの介入へ関与させることは不可欠となります。

L'analyse des défis quotidiens rencontrés par les travailleuses du sexe dans la négociation des rapports sexuels protégés à Mumbai, Inde : Quelle action les travailleurs sociaux peuvent-ils mener?

Les travailleuses du sexe sont stigmatisées dans le contexte du VIH et blâmées comme des « vecteurs » de la transmission de l'infection. Dans le présent chapitre, nous présentons les résultats d'une étude qualitative menée auprès de 48 travailleuses du sexe dans le quartier chaud de Kamathipura de Mumbai en Inde. Deux thèmes sont soumis à l'étude : 1) les défis liés à la santé des travailleuses du sexe et 2) les défis rencontrés dans la gestion des risques liés au VIH, notamment dans la négociation des rapports sexuels protégés avec les clients et les partenaires intimes. Les travailleuses du sexe ont décrit leurs mauvaises conditions de santé et de vie, ainsi que les préoccupations liées à leur sécurité. Elles ont décrit les actes de violence qu'elles subissent dans leurs efforts de négociation des rapports sexuels protégés. La prévention du VIH posait un défi, car les travailleuses du sexe devaient faire face aux attitudes austères de refus du port du préservatif par les hommes. Le présent chapitre souligne la nécessité de mener des efforts de prévention qui contrecarrent les stéréotypes des travailleurs du sexe, réduisent la stigmatisation et améliorent l'égalité de genre. Il est impératif que les partenaires intimes, les clients et les proxénètes soient inclus dans ces interventions pour une plus grande efficacité.

INTRODUCTION AND BACKGROUND

Kamathipura, the red-light area of Mumbai, is located in the heart of the city and at one time was considered to be Asia's second-largest red-light area. Over the past five years, Kamathipura has undergone tremendous change due to increases in real-estate costs and building projects for both commercial and residential use in the neighbourhood. This has led to the disintegration of the traditional red-light area that Kamathipura used to be (Karandikar & Gezinski, 2013a). The sex workers that resided in Kamathipura have been displaced and are moving to other neighbourhoods; this has resulted in social workers finding it increasingly difficult to provide services to sex workers and their children due to their migration (Borges & Fernando, 2016). The current statistics around HIV in Kamathipura are unknown; however, sex workers continue to be vulnerable to the infection and have fewer health-care options due to their displacement to locations outside of the Kamathipura area. Further, an increased police presence in Kamathipura has made it difficult for sex workers to live in the neighbourhood (Karandikar

& Gezinski, 2013b). This chapter is based on empirical research conducted in 2008 with 48 sex workers in Kamathipura. In this chapter, we explore intimate partner violence (IPV) among female sex workers from their *admis* (regular clients/intimate partners) and in doing so we highlight sex workers' risks of HIV infection. While this chapter presents findings from India, it highlights important issues faced by sex workers all over the world. Violence against sex workers and a high prevalence of HIV infections are common occurrences among sex workers internationally. Therefore, the findings of this research are applicable to a larger international audience. Additionally, these research findings have direct implications for UNAIDS' *On the Fast-Track to End AIDS: 2016–2021 Strategy*, namely in the importance of revolutionizing HIV-prevention efforts, decreasing gender-based violence and advancing gender equity (UNAIDS, 2016).

In Kamathipura, an intimate partner is referred to as an *admi*. An *admi* has a strong influence on the lives of sex workers. In most cases, the *admi* is an ex-client of the sex worker. The relationship between a sex worker and her *admi* is similar to that of a married couple. Even though they may or may not be married to one another, sex workers prefer to have children with their *admis* rather than with their other clients. Falling in love with a client and making him an *admi* is a very important transition in the lives of sex workers. The change in relationship also means that sex between them is no longer exchanged for money. The *admi* may or may not allow female partners to continue sex work. In rare occasions, the *admi* takes the sex worker away from Kamathipura to live a different life. However, in the majority of cases, sex workers continue with their profession and *admis* either tolerate or support it. Prior research indicates that *admis* of sex workers often become pimps and exploit sex workers (Karandikar & Prospero, 2010). They control sex workers' movements and the number of clients, and also take a share of their income. The relationship transitions from client to intimate partner to pimp, and sex workers are exploited at every step. Throughout this chapter we will discuss the role of *admis* in sex workers' lives and how these relationships affect HIV transmission. Furthermore, we will examine challenges in HIV risk-prevention due to difficulties in negotiating safe sex with *admis*.

REVIEW OF LITERATURE

Most women involved in sex work in Kamathipura come from very poor backgrounds and are forced (bought and sold) into sex work (Karandikar & Prospero, 2010). The living conditions of both brothel-based and street-

based sex workers are deplorable. Even basic requirements of food, clothing, shelter, hygiene and health-care facilities are sparsely available. Apart from this, the day-to-day life of a sex worker is characterized by interpersonal struggles ranging from small arguments or fights to physical and sexual abuse causing injury and harm. These tussles are with coworkers, brothel keepers, intimate partners, pimps or clients and have an impact on their physical and mental health (Karandikar & Prospero, 2010).

Sex work poses significant personal risk to the women involved. Sex workers are often victims of physical and/or sexual assault, forced or coerced sex with intimate partners, clients, pimps and police officers, and rape and robbery (Dalla & Kennedy, 2003). In such situations, sex workers adopt strategies to cope with life—these are aimed at minimizing hurt and expense and maximizing safety and savings. Such strategies may include abusing drugs and alcohol, saving money on health care and personal needs, working longer hours, borrowing money for day-to-day needs, and offering sex without condoms for lower prices (Chattopadhyay & McKaig, 2004). Each of these strategies provides short-term gains but contributes to long-term ill health, including an increasing risk of acquiring and transmitting HIV infection. Factors such as housing instability (Reed, Gupta, Biradavolu, Devireddy, & Blankenship, 2011), economic insecurity (Reed, Gupta, Biradavolu, Devireddy, & Blankenship, 2010) and mobility (Ramesh, Ganju, Mahapatra, Mishra, & Saggurti, 2012) of sex workers have been found to contribute to risky sexual behaviours. A history of sex trafficking was found to be a risk factor for both violence and HIV infection (George & Sabarwal, 2013; Gupta, Raj, Decker, Reed, & Silverman, 2009; Gupta, Reed, Kershaw, & Blankenship, 2011; Sarkar et al., 2008; Silverman et al., 2011). However, sex workers who experienced sexual violence reported more inconsistent condom use and STI symptoms than those who experienced physical violence (Swain, Saggurti, Battala, Verma, & Jain, 2011).

Community collectivization (Halli, Ramesh, O'Neil, Moses, & Blanchard, 2006; Vejella, Patel, Saggurti, & Prabhakar, 2016) and community mobilization (Blanchard et al., 2013; Erausquin, Biradavolu, Reed, Burroway, & Blankenship, 2012) interventions have been found to be effective in increasing condom use among sex workers in India. A randomized controlled trial replicated the Sonagachi Project in two communities in West Bengal and found that overall condom use and consistent condom use increased significantly for the intervention group (Basu et al., 2004). This intervention combined peer outreach, empowerment activities and advocacy, and was heavily reliant on the sex-worker community for sustainability. The Aastha programme, which established crisis response services, found an

increase in sex workers' check-ups at STI clinics (Ranebennur, Gaikwad, Ramesh, & Bhende, 2014). However, these interventions tended to target sex workers for HIV-prevention efforts only, neglecting the influence of IPV and gender-based violence on HIV transmission, as well as the role that male intimate partners and clients play in unsafe sex. Moreover, gentrification of Kamathipura makes it increasingly difficult to reach sex workers with HIV-prevention activities (Kongelf, Bandewar, Bharat, & Collumbien, 2015).

Prior research indicates a strong relationship between physical and sexual violence against sex workers and risk of HIV infection (Wojcicki & Malala, 2001; El-Bassel, Witte, Wada, Gilbert, & Wallace, 2001; Karandikar & Gezinski, 2013b; Panchanadeswaran et al., 2008; Prakash et al., 2016). Moreover, the two variables violence committed by a nonpartner and police arrest were independently associated with increased STI and HIV transmission among female sex workers (Beattie et al., 2015). In each of these studies, researchers discussed sex workers' vulnerabilities to HIV infection. Violence from male intimate partners, pimps and clients contributed to sex workers' inability to negotiate safe sex and increased risk of HIV infection. Recent research from India, however, highlights the importance of studying IPV among sex workers. A study among sex workers in Kamathipura by Karandikar and Prospero (2010) reported severe forms of violence from male intimate partners and pimps. The researchers also highlighted the need for studying IPV in connection to HIV risk among sex workers in Mumbai. Another study conducted in south India also confirmed that IPV was just as important as client violence in increasing HIV risk among sex workers (Panchanadeswaran et al., 2008).

Several interventions have been found to decrease violence for sex workers over time. Female sex workers who had a peer group were significantly less likely to have experienced violence in the past six months than those without a peer group (Bhattacharjee et al., 2013). Creating a safe space for sex workers and working with lodge owners were also found to decrease violence by clients (Reza-Paul et al., 2012). Again, these violence interventions focused on sex workers only, rather than the perpetrators of violence. Violence prevention is necessary to decrease HIV transmission. As well, the mobilization of sex workers to own interventions is necessary to create effective and sustainable programmes.

It has been estimated that 2.8% of sex workers in India have HIV (World Health Organization, UNAIDS & United Nations Children's Fund, 2011). While high levels of violence and HIV infection are reported in Kamathipura, most of the social work interventions in the area focus on HIV prevention among sex workers alone. These interventions fail to address the issue of IPV in the area, which is a significant contributing factor to increased HIV risk.

METHODS

Procedures and participants

Sex workers from Kamathipura were the population of interest for the study. An in-depth interviewing method was used to gather data. The study was carried out in collaboration with a social work nongovernmental organization that works on improving the health of women and children in Kamathipura, Mumbai. One co-author of this paper, along with four social worker research assistants, conducted interviews with 48 women for this study. The researchers conducted field visits to recruit respondents over a period of five months during July to November 2008. During these field visits the researchers introduced the topic to potential participants in Kamathipura. Female sex worker volunteers accompanied the researchers for the recruitment process. The volunteers along with the researchers identified potential respondents in brothels and on the streets of Kamathipura. Any woman above the age of 18 and currently soliciting sex in Kamathipura was considered eligible for this research study. The researchers also provided their contact information (name, address in Kamathipura and phone numbers) and women were asked to contact the researchers if they were interested in participating in the study. Only those who came to the interview site and volunteered to participate were interviewed.

Due to the high rate of illiteracy among respondents and to cultural norms, it was not appropriate nor a standard of practice to require respondents to sign consent forms. Consent was established through verbal communication and subsequent participation in the study. This informed consent technique revealed that respondents had a clear understanding of the study and an appreciation of the invasiveness of the questions, and were willing to proceed despite the minimal risks involved with discussing sensitive information about themselves. Recruitment continued until saturation was reached. Incentives to participate in this study were in the form of health kits, which included soap, hand towels, sanitary napkins, toothpaste, a toothbrush and a comb.

The average interview lasted about an hour-and-a-half, with some interviews lasting approximately two hours. The interviews were conducted in two of the local languages: Hindi and/or Marathi. Interviews were not recorded. Interviewers quickly wrote notes throughout the duration of the interview. For cultural reasons, the researchers all agreed that tape-recording respondents would make them feel extremely uncomfortable as this practice is against cultural norms and therefore was inappropriate for this type of research. The study was conducted from 1 July 2008 to 30 November 2008. In this five-month period, 48 interviews were conducted.

Data collection tool

An interview guide (in English) was developed for this research study and subsequently was translated into Hindi and Marathi. The interview guide contained several questions on demographics (such as age, marital status, number of children, education, place of origin), entry into sex work and reasons for entry, as well as specific questions about experiences living as sex workers in Kamathipura. The interviews were semi-structured and the respondents could choose to speak on any area of particular relevance to them.

Data analysis

For the purpose of analysis, we transcribed and rewrote each interview in the form of a narrative. Each narrative had quotes from the interviews and captured the voice and language of sex workers directly from the field. While writing the narratives, we also made notes of personal impressions and interpretations of the interviews and recorded them separately from the actual narrative. This helped to maintain credibility and ensured that the voice of the researcher could be separated from the voice of the respondent. Although several themes emerged from the interviews, for the purpose of this chapter we will discuss two themes: 1) health-related challenges experienced by sex workers; and 2) challenges in HIV prevention, specifically safe-sex negotiation with *admis*. Each theme is supported by quotes from the narratives and is followed by personal and theoretical interpretations of the theme. All respondents were given pseudonyms for this chapter.

The results of this study are presented below. Even though the findings are presented in the form of actual quotes from our research participants in Kamathipura, we urge our readers to relate to the findings from their personalized contexts. Sex work is illegal in most parts of the world and sex workers live in similar criminalized circumstances, facing violence and health risks on a day-to-day basis. We therefore encourage our readers to associate the findings with their own specific setting and draw inferences.

RESULTS

The ages of the participants ranged from 20 years to 60 years, with a mean age of 35.07 years. Most of the women were street-based sex workers, and the majority of the respondents indicated that they were trafficked for sex. The mean age at entry into sex work was 18.12 years with a mode of 13 years.

The time spent in sex work ranged from four months to 42 years with a mean of 16.36 years. Of those who spoke about education, 87.5% were illiterate/had no education and the others had very little education. The majority of the women in this sample (81.3%) self-reported that they were HIV-positive and all the women were living with their *admis* in the Kamathipura area.

Health-related challenges experienced by sex workers

Sex workers in Kamathipura indicated that they suffered from several health problems. Many women were able to name their health problems, which included HIV, tuberculosis (TB), sexually transmitted infections (STIs), malaria, asthma, high blood pressure, skin infections and diabetes. Other women discussed health symptoms such as stomach pain, chest pain, cough and fever. Women discussed difficulty in acquiring treatment and medication for various illnesses, as well as their experiences of stigma and discrimination in health-related settings. Respondents spoke about their ill-health in the context of their relationships with *admis* in Kamathipura. They talked about being beaten up by *admis* or clients and even policemen from time to time. This added to their ill health and overall feeling of helplessness.

Below are synopses of the experiences of some of the sex workers that participated in the study.

One of the participants, Pooja, indicated that she is HIV-positive and has health problems, such as chest pain and stomach pain. She indicated that she seeks treatment at a hospital in Mumbai every month. She said,

Sometimes it is difficult to get medicine because doctor prescribes medicine and asks me to get it from outside. I don't have money to buy those medicines on my own. I have to wait for money. When I earn money, I buy those medicines. My admi does not help one bit. He does not have any money of his own. I have to even pay for his medicines. If I give him the money he wastes it on alcohol. He suspects that I have an affair with someone and beats me if he gets angry. It's impossible to stay with him without fighting.

Rina discussed a similar predicament—getting beaten up by her *admi* and falling sick but having limited finances to devote to medical care. She stated,

I was beaten up so badly by him [admi] one day that I had a cut on my head. After that I had so many headaches and I fainted and fell in the gutter. I could not work. I had to borrow money from the

madam and I don't know how I will pay it back.

Another sex worker, Laxmi, talked about her *admi* who forces her to take clients even when she is sick. She said,

My admi does not have any money and in fact he wants me to work all the time. He brings clients when he wants and I have to go with them even when I am sick. I was pregnant and feeling so sick, still I worked until seven months and sometimes I just cried all night because of the pain.

In addition to violence and lack of financial resources, stigma and discrimination were mentioned as barriers to accessing medical care. At the time of interview, Khatun was suffering from fever and a wounded leg. There was a swollen gland on her neck that she suspected was a sign of TB. She also stated that she was suffering from white discharge and was HIV-positive. Khatun stated,

The problems I face in getting medicines are long queue, discrimination in the hospital and money I have to spend to buy my medicines. I have started coming to Roshni [nongovernmental organization] from last three months and it has helped me in getting medicines.

Rekha reflected a similar sentiment. She stated, “Going to municipal hospitals means going from one department to another, wasting time, and people look at prostitutes with different attitude.” Rekha went on to describe the stigma and discrimination associated with this “different attitude”.

Finally, participants indicated that sex workers are “thrown on the road when they are sick”. Rasika discussed the importance of health awareness to all the people of Kamathipura, not just the sex workers. She stated,

Women are suffering HIV, TB and various STIs but they don't have enough food and can't maintain hygiene as they are staying on road. More awareness should be given to men of Kamathipura to prevent the spread of HIV. They don't want to use condoms and give HIV to women. Also women should be taught about how to use female condoms. But they are very expensive and no woman would be able to afford it.

Rita echoed the importance of raising awareness. She has suffered from STIs and skin infections, and is affected by malaria in the rainy season. Rita shared that she gets tested for HIV approximately every three months. She said,

Organization working in the community does an awareness programme on HIV and STIs. To prevent HIV infection it is essential to use condoms, have correct information about HIV. I get free condoms from SAI [NGO]. There is a need to create awareness about HIV, provide condoms for men and women in the community for free, and help women negotiate with admis and clients.

The above theme highlights some of the health-related challenges, such as limited financial resources and stigma and discrimination, faced by sex workers and how they try to overcome these challenges on a day-to-day basis. These challenges are presented in the context of their violent relationships with their *admis*, thus making it imperative to address both issues simultaneously. Both violence and the poor health conditions of sex workers are reported in research all over the world (Wojcicki & Malala, 2001; El-Bassel et al., 2001; Panchanadeswaran et al., 2008). Therefore, with regard to understanding the overall health conditions of sex workers and the violent environments in which they live, the above results from Kamathipura are applicable to an international setting. The next theme that is analysed for this chapter is the specific challenges pertaining to HIV prevention among sex workers in Kamathipura.

Challenges in HIV prevention among sex workers

While women in Kamathipura suffered several health problems, HIV infection was one of the most critical issues mentioned by all the respondents of this study. As the researchers explored details regarding HIV, two subthemes around how sex workers were infected by HIV evolved. Two particular challenges are discussed here: lack of awareness of HIV and inability to negotiate safe sex.

Sex workers recalled their entry into sex work and how they were unaware of HIV infection during that time. The majority of the women (79.2%) were trafficked into Kamathipura as minors aged under 18 years, and during their early days in the brothels were forced to have sex without condoms. Many of them did not know about condoms and simply followed orders from their pimps, brothel keepers or clients.

Rani stated,

I was 14 years old when I came to Kamathipura. The first few months were so hard. I was locked up in the brothel and not allowed to even talk to anyone. I did not know anything about HIV or condoms. I just did whatever he [pimp] told me. My madam [brothel keeper] would beat me if I cried. I could not say anything.

Geeta said,

After 15 years in Kamathipura, I came to know I am HIV-positive. Now I don't even know how it happened and when. When I came to Kamathipura I did not even speak Hindi. I had never heard of condoms or even HIV. During that time no one even talked about HIV and condoms in the brothel.

Some of the sex workers talked about being aware of HIV but afraid of asking their clients to use condoms. Sex workers reported violence from pimps and clients, as well as partners, that prevented them from negotiating safe sex: whenever they tried to talk about condoms, they either lost business or got beaten up. Rasika stated,

When I get a client, I ask him to use condom. Sometimes he says yes, but when we go to the room, he says no and starts pushing and forcing, and then I don't know what to do. I get so scared. Some nights are so bad, I need the money so I have to agree to take clients without condoms.

In this quote Rasika talks about facing resistance from clients to use condoms. Zeenath, on the other hand, spoke of a regular client and how she got beaten up for asking him to use a condom.

She said, "He beats me up so much for asking to use condom. He says he is clean and I should not suspect him. He comes to me regularly so after some time, even I agreed. Now we don't use condoms."

Bharthi discusses the role of her pimp in bringing clients and how she does not have a say in condom use:

My pimp brings all the clients, I don't get to choose ... If they agree for no condoms then I have to agree. If I don't, I will get beating and no dhandha [business]. The pimp beats me with his belt, sometimes with his shoes.

Sex workers also noted that if the client visited them regularly, they were more likely to accept the client without condoms. The relationship between a casual client and a regular client is different and is clarified by Mona:

He is my regular client. I like him. He comes to me only so I think he likes me too. He is not one of them who come only once. He comes three or four times in the week. He talks to me and spends the night ... how can I ask him to use a condom?

In many situations the sex workers have regular clients who eventually become *admis* and promise to either get married or live together. In these relationships condom negotiations are extremely difficult.

Parvati gives an example of this:

I tell my admis to use condoms but he refuses. He says that he is not my client he is in love with me. He wants to get married and have children. When I tell him to use condoms he gets angry and says he will find another girl.

Sumita says,

My admis is so suspicious of me. When I told him to use a condom, he beat me up. He said he is not my client and I should give him what he wants. No man likes condom. That is the main problem ...

Another reason for lack of negotiation revolved around financial instability. For example, Reshma stated,

When there were no clients for the whole night and no other source of income, I had to accept clients without condoms for money. All the men want sex without condoms, in that situation how can a woman negotiate safe sex? It's impossible! Men who come as clients also understood my desperation for money and started taking advantage of me. They would agree to use condoms during negotiations and later refused to use them. They troubled me to have anal sex and remove all my clothes without giving any extra money.

Again, Reshma discusses how condom negotiation is ineffectual, as men are able to elicit condom-free intercourse with other sex workers. Therefore, condom negotiation has financial implications given that sex without

condoms creates better profits than sex with condoms.

The overall summary of these themes indicates lack of negotiating power among sex workers when it comes to condom use. Sex workers discuss the risks associated with HIV infection in the context of their relationship with client, pimps and *admis*. They speak about making the men aware of HIV and condom use, thus placing responsibility on the men to prevent HIV and not just on the female sex workers.

DISCUSSION

The overall results of this research indicated that sex workers face a variety of health-based challenges, as well as specific challenges related to violence and HIV risk behaviours. Sex workers reported being physically and sexually abused and many of them expressed anxiety about their safety and security in the red-light area. Sex workers felt exploited by their *admis* who became pimps and controlled their sexual decisions as well as their income. Male *admis* turned pimps used physical, sexual and emotional violence against female sex workers. They were reluctant to use condoms and any attempt by female sex workers to negotiate condom use was strongly resisted. Female sex workers found it extremely difficult to negotiate safe sex in the hostile environment of Kamathipura.

This research also highlights some of the strategies used by female sex workers to resist violence. Although the majority identified themselves as victims of both violence and HIV, they occasionally sought refuge at social work organizations in the area to avoid violence. Some of them threatened to kill themselves or their partners, while others used their own children as means to avoid sex and violence. For example, participants reported sleeping beside their children, knowing that their abusive partner would not disturb the slumber. In their day-to-day lives, the sex workers faced a number of challenges, some of which were related to their survival and others which were related to protecting themselves from male violence. In such a patriarchal environment, condom negotiation and HIV prevention was considered secondary. This in turn increased their risk of HIV infection.

CONCLUSION

This research makes two important observations: 1) there is a strong relationship between IPV and HIV risks among female sex workers in

Kamathipura; and 2) males are not being effectively reached by the HIV-prevention efforts in the area. In order to prevent HIV, it is thus important to work on violence prevention in the area, as well as HIV prevention with both sex workers and the males they interact with.

Getting to zero infections among sex workers will not be achieved until interventions are focused on male clients, pimps and partners, and male bias regarding condom use is addressed. Since all the decisions about using condoms are made by male partners and pimps, it is imperative to work with them along with female sex workers on HIV prevention. Female sex workers are trained to negotiate safe sex in order to prevent HIV. However, this training does not translate into action, as seen in this research. Even though female sex workers negotiate safe sex with clients from time to time, they are unable to do so with their *admis*. This research highlights the importance of the inclusion of males in HIV-prevention efforts in the area. This finding is in line with prior suggestions by researchers such as Marten (2005) and Panchandeswaran et al. (2008).

With the current structural and physical changes occurring in Kamathipura, the relationships between sex workers and their *admis* and clients in relation to HIV prevention have become more complex. It is harder to locate sex workers, as they are driven out of the Kamathipura area to solicit sex in more unsafe locations across Mumbai. As such, identifying male clients, pimps and partners is also becoming more difficult. Spreading awareness of HIV among this population is now facing additional challenges (Kamathipura Committed Communities Development Trust staff, personal communication, 13 August 2015). With increased construction in and around Kamathipura and the lack of alternative living arrangements made for sex workers in the area, sex work has been swept further under the rug. The government policy of driving sex workers away has not stopped sex work; it has made it more dangerous and unsafe (Karandikar & Gezinski, 2013a).

The findings of this chapter therefore have very significant implications as the issue of HIV infection among sex workers in Kamathipura has become more complex to resolve. As we move forward, strategies for HIV prevention will no longer be targeted to a certain red-light area but to a much larger geographical location where sex workers may solicit sex. The social services available to sex workers to combat violence and HIV also need to be spread out beyond the boundaries of Kamathipura (Kamathipura Prerana staff, personal communication, 15 May 2013). Thus a more integrated effort to provide security and safety from violence for sex workers, as well as provision of HIV care and support services to all sex workers, is essential. The State AIDS Control Organizations need to be cognizant of this change and engage

in outreach efforts for sex workers in all districts in Mumbai, not just those that were traditionally known to be red-light districts. Attempts to target male clients, pimps and partners for gender-sensitization, violence- and HIV-prevention and condom use should also be undertaken all over Mumbai through active outreach efforts. Targeting sex workers alone does not prove effective in HIV prevention, and equal resources need to focus on altering male bias on condom use—thus shifting the bias and blame to males instead of females in the context of sex work and HIV infection.

Even though this chapter is based on research done in India, we feel that these findings are contextualized in the hostile environment in which sex workers live. This hostile environment is similar for sex workers all over the world. Through this chapter we aim to provide critical information to an international audience on combating violence against sex workers, and the integration of male clients, pimps and partners in the process of HIV prevention.

LESSONS LEARNED

It has been reported that 84.5% of sex workers have been reached with HIV-prevention efforts (National AIDS Control Organization, 2014); however, more work needs to be done. As sex workers are displaced by globalization and gentrification, their safety is put at increased risk and there is also increased risk of HIV transmission. This research has led to many lessons learned, including the importance of:

- Locating displaced sex workers and channelling HIV resources to them, requiring broadening of the service area.
- Addressing stigma and discrimination in health-care settings, and increasing access to costly antiretroviral medications for sex workers.
- Recognizing the intimate connection between gender-based violence and HIV transmission and targeting both in HIV-prevention efforts.
- Targeting men, especially intimate partners of sex workers, for HIV education, violence prevention and gender-sensitization programming.
- Increasing access to condoms and female condoms and targeting HIV education to newly entered sex workers in brothels, as well as teaching women condom negotiation skills.

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**Social workers at
the frontiers of
technology:
Online-based HIV
prevention and care
for men who have
sex with men**

Rusty Souleymanov



ABSTRACTS

Globally, men who have sex with men are 24 times more likely to live with HIV than the general population. As sex and dating websites and apps have become more popular among men who have sex with men, these online platforms have also created new opportunities for social workers and other health- and social-care professionals to carry out advocacy initiatives, sex education, and HIV prevention and care. However, access to online-based services is complicated by profound barriers, such as criminalization and violence against sexual minorities, gender-based violence, stigma, punitive laws around HIV transmission, socioeconomic disparities between industrialized and developing nations, and the fact that existing online HIV-prevention initiatives tend to adopt values from English-speaking, western cultures. This chapter provides recommendations on how researchers, practitioners, funders and the private sector could help promote the worldwide development of culturally sensitive, online-based initiatives, programmes and services for sexual education, advocacy and HIV prevention for men who have sex with men.

身处技术前沿的社会工作者：在线进行艾滋病预防，关爱男男性接触者

在全球范围内，男男性接触者群体罹患艾滋病的机率是一般人群的24倍。随着性爱和交友网站以及APP（应用软件）在男男性接触者人群中变得越来越流行，这些网络在线平台也为社会工作者和其他健康与保健专业人员创造了新的机会，如开展宣传活动、进行性健康教育、进行艾滋病预防和为其提供关怀。然而，由于受到某些因素的阻碍和影响，访问在线服务变得极为复杂。这些阻碍包括对性少数群体的暴力犯罪、基于性别的暴力、社会歧视、针对HIV传播而设置的惩罚性法律、工业化国家和发展中国家之间的经济差距，以及现有在线艾滋病预防措施均以以讲英语的西方人的文化价值观为基础。本章为研究人员、从业人员、投资者和私人部门提出了一些建议，这些建议可以帮助他们在性教育、项目和服务。。

Trabajadores sociales a la vanguardia de la tecnología: Prevención y cuidado online del VIH para hombres que tienen sexo con hombres

A nivel global, los hombres que tienen sexo con hombres tienen 24 veces más probabilidades de vivir con VIH que la población en general. A medida de que las webs y las aplicaciones de móvil de citas y de sexo se han vuelto más populares entre los HSH, estas plataformas online también han creado nuevas oportunidades para los trabajadores sociales y otros profesionales de la asistencia sanitaria y social para llevar a cabo iniciativas de promoción, educación sexual y prevención y cuidado del VIH. Sin embargo, el acceso a los servicios online se complica debido a grandes obstáculos, como la criminalización y la violencia contra las minorías sexuales, la violencia de género, el estigma, las leyes punitivas en torno a la transmisión del VIH, las disparidades socioeconómicas entre los países industrializados y en desarrollo, y el hecho de que las iniciativas de prevención del VIH online que existen tienden a adoptar los valores de las culturas de habla inglesa, u occidentales. En este capítulo se proporcionan recomendaciones sobre cómo los investigadores, profesionales, entes patrocinadores, y el sector privado podrían ayudar a promover el desarrollo de programas, iniciativas online de conciencia cultural, y servicios para la educación sexual, la promoción y la prevención del VIH para los hombres que tienen sexo con hombres en todo el mundo.

テクノロジー最先端でのソーシャル・ワーカー：オンライン・ベースのHIV予防と男性とセックスする男性のためのケア

世界的に見て、男性とセックスする男性は、一般集団より24倍HIVに感染する可能性が高いです。セックスやデートのウェブサイトとアプリが男性の間で人気が高まるとともに、これらのオンライン・プラットフォームにより、ソーシャル・ワーカーと他の医療・社会福祉専門家が政策提言イニシアティブ、性教育とHIV予防とケアを実施する新しい機会ができました。しかし、オンライン・ベースのサービスの利用は、いくらかの深刻な障壁により複雑になっています。例えば、性的なマイノリティに対する犯罪者扱いや暴力行為、ジェンダーに基づく暴力、汚名、HIVの感染に関わる懲罰的な法律、先進工業国と発展途上国間の社会経済的格差、既存のオンラインHIV予防イニシアティブが英語圏の価値観、つまり欧米文化を採用する傾向があるという事実などです。この章では、世界中の男性とセックスする男性のために、どのように研究者、開業医、資金提供者と民間部門が、文化的配慮がなされている、オンライン・ベースのイニシアティブ、プログラムと性教育サービス、政策提言とHIV防止を促進する援助ができるかについて推奨事項を提案します。

Travailleurs sociaux aux frontières de la technologie : Une intervention en ligne axée sur le VIH et la prise en charge des hommes ayant des rapports sexuels avec des hommes

Globalement, les hommes ayant des rapports sexuels avec des hommes (HSH) ont 24 fois plus de chance de vivre avec le VIH que l'ensemble de la population. Étant donné que les sites et les applications de rencontre sont devenus plus populaires chez les HSH, ces plateformes en ligne ont également créé de nouvelles opportunités pour que les travailleurs sociaux et d'autres professionnels de santé et de soins sociaux puissent promouvoir les initiatives de plaidoyer, l'éducation sexuelle, ainsi que la prévention et le traitement du VIH. Cependant, l'accès aux services en ligne est compliqué par des barrières profondes, telles que la criminalisation et la violence faites aux minorités sexuelles, la violence basée sur le genre, la stigmatisation, les lois punitives sur la transmission du VIH, les disparités socioéconomiques entre les pays industrialisés et les pays en développement, sans oublier le fait que les initiatives en ligne actuelles de prévention du VIH tendent à adopter les valeurs des cultures anglophones et occidentales. Le présent chapitre formule des recommandations sur la manière dont les chercheurs, les praticiens, les bailleurs de fonds et le secteur privé peuvent aider à promouvoir le développement des initiatives culturellement sensibles et axées sur Internet, les programmes et les services pour l'éducation sexuelle, le plaidoyer et la prévention du VIH en faveur des hommes ayant des rapports sexuels avec des hommes dans le monde.

BACKGROUND

Globally, gay, bisexual and other men who have sex with men (MSM) carry a heavy burden of HIV. A systematic review (conducted in 2007) on published reports of HIV prevalence among MSM in low- and middle-income countries in Asia, Africa, the Americas and Eastern Europe found that MSM had a 19.3 times greater chance of being infected with HIV than the general population (Baral, Sifakis, Cleghorn, & Beyrer, 2007). However, current evidence now indicates that HIV incidence among MSM is rising worldwide (UNAIDS, 2016b). Recent studies suggest that MSM are 24 times more likely to acquire HIV than adults in the general population, which represents approximately 8% of new infections (UNAIDS, 2016b). HIV prevalence among MSM is highest in western and central Africa (15%) and eastern and southern Africa (14%). New infections are further increasing in several countries across the Middle East and North Africa, Asia and the Pacific (UNAIDS, 2015). The situation with HIV prevalence

among MSM in high-income nation states of the Global North (particularly the United States, Canada and the United Kingdom of Great Britain and Northern Ireland) is just as alarming, if not more so (Beyrer et al., 2013). When examined by incidence density, HIV rates are particularly high among MSM in Thailand, Kenya, China, the United States of America and the United Kingdom, with disparities observed in marginalized communities of MSM and among young MSM (Beyrer et al., 2016).

Online information and communication technologies, which comprise smartphone applications (apps), short message services (SMS), Internet-based websites, chat rooms, and social media platforms, are currently utilized globally across the HIV continuum of prevention, treatment and care (Muessig, Nekkanti, Bauermeister, Bull, & Hightow-Weidman, 2015). Online technologies bring several efficiencies to health-service delivery. First, online HIV prevention and care are cost-effective, high-impact innovations (Schnall, Travers, Rojas, & Carballo-Diéguez, 2014). Second, online technologies can help to keep track of clients to see if they have been tested or are on antiretroviral treatments, as well as prompting reminders for follow-ups or improving referral processes (Global Forum on MSM & HIV, 2015).

A plethora of geo-social networking apps and websites that display potential contacts based on their physical proximity have gained popularity among MSM (Beymer et al., 2014; Bien et al., 2015). Some examples include Grindr, Blued, PlanetRomeo, Scruff, 9Monsters, Hornet, BoyAhoy and many others (Karlan, Feder, & Rial, 2015). These technologies have significantly changed the way many MSM network with one another to find sexual partners or access health information (Groves, Breslow, Newcomb, Rosenberger, & Bauermeister, 2014; Krakower et al., 2012).

Advances in online technologies offer an opportunity to influence how HIV prevention and care initiatives are delivered to, and accessed by, MSM; especially how marginalized, hard-to-reach populations of MSM can be reached and engaged in a variety of HIV and other health- and social-care services and programmes. A systematic review of online HIV-prevention interventions for MSM found that online HIV outreach can be an effective way to increase testing and decrease risk behaviours that may lead to HIV transmission (Schnall et al., 2014).

The communication between MSM, social workers and organizations for the purposes of HIV testing and treatment or with regard to other issues can be facilitated through the use of online technologies. Social workers are increasingly turning to online technologies to carry out HIV outreach with MSM (Brennan et al., 2015). However, while social workers consider the Internet a good venue for HIV education and prevention, they also recognize

the challenges in providing effective online outreach services to marginalized MSM. Barriers like socioeconomic and political disparities between high-income and middle- or low-income countries, the criminalization of homosexuality or HIV-positive status, and stigma significantly complicate access to, and engagement with, online HIV-related programmes and services.

Importantly, as smartphone use rates continue to rise and more people are seeking information on mobile devices rather than desktop computers (UNAIDS, 2016a), there has also been a decline in the number of public locations where MSM meet one another, particularly in areas of the world where same-sex relationships are criminalized or punishable by death (United Nations Population Fund et al., 2015). Thus, providing information and delivering services through online technologies presents a critical opportunity to reach marginalized groups of MSM, particularly those who cannot easily be reached due to geographical isolation or other socioeconomic and cultural factors (Global Forum on MSM & HIV, 2015).

This chapter argues that the social work profession, rooted in anti-oppressive traditions, is well positioned to advance the liberation of sexual-minority populations and promote the health and well-being of marginalized MSM globally.

ON THE FAST-TRACK TO END AIDS WITH UNAIDS LEADERSHIP

The time has come to acknowledge the growing role of online technologies in the lives of MSM, and their significance in transforming HIV services and programmes. As part of its Fast-Track to End AIDS Strategy, UNAIDS has called on governments and communities to ensure that 90% of key populations, including MSM, have access to HIV combination prevention services by 2020 and that 90% of people at risk of and affected by HIV report no discrimination, especially in health, education and workplace settings. UNAIDS has called for scaling up action to address specific barriers faced by key populations in protecting themselves from HIV and accessing HIV-related services (UNAIDS, 2015).

Online technologies present the means to achieve these targets. However, the 2020 targets to end AIDS as a public health threat by 2030 are complicated by profound structural barriers, such as criminalization and violence against sexual minorities, gender-based violence, stigma and punitive laws around HIV transmission, among many other issues. The coverage of and access

to HIV programmes is already insufficient, and in countries where official HIV programmes do exist they are often underresourced and insufficiently tailored to the needs of MSM (UNAIDS, 2016a). This creates additional barriers for HIV-related responses in multiple regions of the world.

In 2009, UNAIDS urged governments to remove punitive laws, policies and practices that block effective responses to HIV-prevention and care, as well as to enact laws that ensure that sexual health education and HIV services are available to all MSM living with or at risk of acquiring HIV (UNAIDS, 2009).

In 2015, UNAIDS created a venue for various stakeholders, including social workers, to meet and discuss the potential role that online technologies can play in advancing the sexual health of MSM, as well as the uptake of these technologies among MSM (UNAIDS, 2016a). UNAIDS urged the private and public sectors, as well as communities, to work together on the potential use of online technologies for HIV programmes with MSM (UNAIDS, 2016a). The meeting report, published by UNAIDS, identified that online technologies (in particular apps and websites) bring multiple strengths to health-service delivery for MSM (UNAIDS, 2016a). Common strengths of online technologies include: 1) the ability to reach a large number of MSM using geo-targeting strategies; 2) the incorporation of sexual health resources and information within online venues where MSM seek sex; 3) the engagement of marginalized and hard-to-reach populations of MSM, such as people who are not connected to or do not identify with queer communities due to stigma or fear of persecution, as well as MSM who may not otherwise seek information about health, HIV or safe sex (UNAIDS, 2016a).

The global HIV response for MSM may need to incorporate innovative solutions, capitalizing on emerging technologies. As UNAIDS begins to engage the private and public sectors alongside communities in the use of online technologies for HIV programmes with MSM, human rights abuses and structural barriers complicate access to and engagement with online-based HIV-prevention and care initiatives. Emerging online technologies present the means to achieve goals and objectives outlined in the Getting to Zero Strategy with regard to reducing HIV infections and creating a strategic platform to catalyse structural, rights-based initiatives.

ONLINE TECHNOLOGIES AND SOCIAL WORK

Recently, social work scholarship has highlighted the importance of using innovative technologies within social work practice (Barman-Adhikari & Rice, 2011; Mishna, Bogo, Root, Sawyer, & Khoury-Kassabri, 2012; Parrott &

Madoc-Jones, 2008; Perron, Taylor, Glass, & Margerum-Leys, 2010; Ramsey & Montgomery, 2014). Rapid development in technology has also greatly transformed social work education (Mishna et al., 2012; Perron et al., 2010).

In a study that explored the perspectives of social workers on the impact of online technologies on social work practice, findings indicated that online communication has dramatically revolutionized the nature of professional relationships and communications between social workers and their clients (Mishna et al., 2012). Core elements of social work have been affected, including boundaries between clients and social workers, disclosure of information with regard to both practitioners and clients, therapeutic relationships, ethical and legal dilemmas, and policies and procedures (Mishna et al., 2012).

Traditionally, social workers committed to HIV outreach are trained to engage with their clients face-to-face. However, given the popularity of online technologies among MSM, these technologies could offer the means for social workers to reach and connect with diverse groups of these men in different parts of the world. Importantly, online technologies could emerge as venues through which social work services are delivered to marginalized communities of MSM in low-income, industrializing nations.

Social workers are starting to document the potential of incorporating the Internet and smartphones into direct practice, research and advocacy with marginalized sexual minority communities globally (Souleymanov & Huang, 2016). In order for social workers to help advance the lives of marginalized MSM through greater access to education, knowledge and resources, it is necessary that social workers are competent in the use of these technologies and the context surrounding them (Parrott & Madoc-Jones, 2008). Social work research suggests that online technologies can address isolation by allowing individuals to interact and share experiences on an ongoing basis (Parrott & Madoc-Jones, 2008). The inherent ability in online technologies to transcend geographical and social spaces can lead to significant practical empowerment of MSM who may live at a distance from organizations that serve MSM and people living with HIV, or who may otherwise be constrained—in time or space, and for socio-political or economic reasons. As a matter of fact, online technologies allow social workers not only to impart information but also to get involved in social justice activism and advocacy (Parrott & Madoc-Jones, 2008).

There are multiple examples of social work services using online technologies (Barman-Adhikari & Rice, 2011; Craig & Calleja Lorenzo, 2014; Ramsey & Montgomery, 2014). However, despite an emerging body of literature that examines the impact of technologies on the social work profession, limited research has examined how these new technologies

influence social work practice, research and education in the realm of HIV prevention, treatment and care.

Social workers in Canada and the United States of America are currently at the forefront of this innovative work. In the United States of America, Holloway and colleagues examined the acceptability of smartphone application-based HIV prevention among young MSM, as well as how technology use affects the sexual risk behaviours of young MSM (Holloway et al., 2014). In their US-based study 70% of young MSM ($n = 195$) expressed a willingness to participate in a smartphone app-based HIV-prevention programme (Holloway et al., 2014). This work points out that the development and testing of smartphone apps has significant potential for HIV prevention (Holloway et al., 2014).

In Canada, Brennan and colleagues (2015) have been advancing knowledge on the use of online technologies, aimed at promoting the sexual health of MSM, reducing the impacts of HIV and STIs and developing national guidelines for online HIV outreach with MSM in Canada. Their work with MSM in Canada ($n = 1830$) suggests that online outreach is a promising health-promotion strategy that can engage diverse groups of men in sexual health education (Brennan et al., 2015). Brennan has also consulted with UNAIDS on the use of information and communication technologies in HIV education with MSM (UNAIDS, 2016a).

Therefore, it would be fair to assert that the social work profession has been proactive in responding to the potential of online technologies for HIV prevention and care for MSM. The social work profession has also deepened our understanding of the role of emerging online technologies in the field of HIV by generating knowledge that informs both practice and policies.

GLOBAL REVIEW OF ONLINE-BASED HIV INITIATIVES FOR MSM

This section reports on how online technologies are utilized across the continuum of HIV prevention, treatment and care with MSM in the United States of America, the United Kingdom of Great Britain and Northern Ireland, Uganda, Thailand, China and Australia, as well as countries in central America and the Middle East. Online technologies are used by a variety of agencies and organizations globally to reach MSM in order to disseminate information on sexual health and HIV, as well as for advocacy, community mobilization or fundraising (Adams, Klindera, Walsh, & Wolf, 2014). For instance, a campaign that centres on linking online outreach to in-person HIV services for MSM has been reported in Thailand (Anand, Nitpolprasert,

Ananworanich, Pakam, & Nonenoy, 2015). In the United Kingdom of Great Britain and Northern Ireland, the Terrence Higgins Trust places paid advertising on Grindr for free HIV-testing kits that can be delivered by post (Terrence Higgins Trust, n.d.). In Belize, Guatemala, El Salvador, Honduras, Nicaragua, Costa Rica and Panama, outreach workers use social media to conduct online HIV outreach and education, and make referrals for HIV counselling and testing to MSM communities (Rivas, Wheeler, Rodas, & Lundo, 2014). In Uganda, Spectrum Uganda uses websites and apps to post messages advising where MSM can drop in and receive free condoms and lubricants from trained HIV outreach workers (Spectrum Uganda Initiatives Incorporated, n.d.). Similarly, successful programmes and services using smartphone text messages, focusing on HIV testing and condom use, were reported in Australia (Bourne et al., 2011) and the United States of America (Juzang, Fortune, Black, Wright, & Bull, 2011), respectively. Also in the United States of America, Muessig, Baltierra, Pike, LeGrand, and Hightow-Weidman (2014) report on an innovative online smartphone initiative for Black MSM, which uses a series of games and role-playing scenarios with the goal of reducing high-HIV-risk sexual behaviours.

In addition to programmes and services, there are multiple research initiatives. For instance, research on MSM ($n = 86$) conducted in various countries in the Middle East (Bahrain, Iran, Iraq, Jordan, Kuwait, Lebanon, Oman, Palestine, Saudi Arabia, Syria, United Arab Emirates, Yemen and Egypt) suggests that adopting Internet-based HIV education and prevention programmes could instrumentally enhance efforts to reduce the likelihood of new HIV transmissions in MSM and their sexual partners (Matarelli, 2013). A US-based study of MSM ($n = 105$) documented the success of using apps such as Grindr to enroll MSM in a large rectal microbicide trial (Burrell et al., 2012). Finally, research with MSM ($n = 399$) conducted in China suggested that scaling up online outreach efforts using apps increases the uptake of HIV testing and is an essential step towards reducing HIV transmission (Zou et al., 2013). Therefore, as can be observed, the potential for using online technologies in HIV prevention, care and research initiatives for MSM is enormous.

ACCESS BARRIERS TO ONLINE-BASED HIV INITIATIVES

Criminalization, violence and stigma

Criminalization, violence and punitive laws that affect MSM create

profound access barriers to HIV services delivered online. Homosexuality is criminalized in 73 countries (International Lesbian, Gay, Bisexual, Trans and Intersex Association, Carroll & Itaborahy, 2015), which encourages human rights abuses, violence, discrimination and stigma, and has deleterious effects on the health and well-being of MSM (Arreola et al., 2015; Santos, Makofane, Arreola, Do, & Ayala, 2016; Kelly et al., 2002). In many cases, HIV and other STIs may not be the primary concern for MSM, because more pressing issues, such as violence and persecution, may arise (Eurasian Coalition on Male Health, 2015). In addition, as data related to MSM may not be collected or reported in many countries, when it comes to estimates, new infections, sexual risk practices or access to HIV programmes, the data are lacking or largely insufficient to grasp the reality of the HIV epidemic among MSM.

Importantly, media from around the world are starting to document how issues related to the security and confidentiality of data on apps and websites can pose significant threats to MSM. In 2014, a serial killer in Pakistan confessed to using a gay dating app to meet men at their homes, where he drugged and strangled them (Gillani & Walsh, 2014). Similarly, after India's Supreme Court recriminalized same-sex relationships in 2013, MSM were subjected to an increase in robberies, extortion, bashings, blackmailing and physical attacks by criminals who met MSM using dating apps (Parussini, 2015). Cases of robberies and targeting of MSM were also reported in the United Kingdom of Great Britain and Northern Ireland (Cowburn, 2015).

Furthermore, stigma attached to living with HIV, gender nonconformity or homosexuality hampers effective online outreach initiatives for MSM. For instance, when developing online campaigns to engage MSM, stigma may constrain the use of sexually explicit images. Research studies conducted in South Africa, Uganda and China point out that sexual stigma is linked with adverse HIV-related outcomes among MSM, including reduced rates of HIV testing and increased sexual risk practices (Hladik et al., 2012; Hu et al., 2014; Knox, Sandfort, Yi, Reddy, & Maimane, 2011). Stigma within health-care systems can also limit the provision and uptake of sexual-health programmes, as well as opportunities for access to HIV-prevention services (Ayala et al., 2013; Baral et al., 2013; Beyrer et al., 2016; Pachankis et al., 2015; Stahlman et al., 2016).

Disparities between nations

While a variety of apps and websites are emerging in different parts of the world, the socioeconomic disparities between high-income, industrialized

nations and developing low-income nations make social workers question the accessibility of HIV services delivered online (Souleymanov & Huang, 2016). Given that low-income, industrializing nations might not be technologically wired, it is primarily higher- or middle-class MSM that have access to the Internet, computers or smartphones in those countries. For instance, it is often mandatory for MSM to pay fees in order to be able to register and use apps or websites. Thus, online-based HIV care may remain unattainable for poor or socially excluded MSM. In addition, there are access issues for marginalized populations of MSM, particularly younger MSM and MSM who do not identify with, and therefore don't have access to, queer cultures.

Additionally, there may be differences between MSM who live in high-income countries and those that live in low-income countries in terms of: demographics, sexual-risk practices, structural drivers of HIV transmission (e.g. homophobia, violence), online devices and platforms where sex is being sought, the degree of privacy of online technologies being used by MSM, and the access, availability and cost of these online technologies.

Moreover, in some regions of the world MSM are often excluded from political dialogues and planning processes, and when included in HIV policy-making the extent of their influence is extremely low (Eurasian Coalition on Male Health, 2015). Even in North America, MSM who have unstable housing, as well as those with low incomes and a slower Internet connection, report less access to condoms, lubricants, prevention programmes and HIV testing (Global Forum on MSM & HIV, 2015).

Importantly, while in some countries efforts to make online HIV services a key component of national HIV programmes have been weak or nonexistent, in many low-income nations it is not even clear what capacity (if any) community-based organizations or public health systems have in terms of carrying out strategic communication with MSM via online technologies.

Cultural context and diversity

Online technologies may have their own unique ways of displaying and conveying information, and MSM in different parts of the world will consume the content of HIV messaging in different ways. However, most research on how MSM find and interact with sexual partners online has been conducted in English-speaking nations in the Global North, primarily the United States of America, Canada, the United Kingdom of Great Britain and Northern Ireland and Australia (Souleymanov & Huang, 2016). Given that access to culturally relevant information is bound by language, as long as English remains the dominant language of the Internet, this will create barriers for MSM who live

in places where English is not an official language (Huang et al., 2014).

Furthermore, existing research on technology use among MSM ignores the structural drivers of HIV for marginalized MSM in the Global South, and tends to adopt the values of western, European cultures, with little awareness of the transnational dynamics of sexual minorities (Souleymanov & Huang, 2016). Even more problematically, colonial legacies manifest themselves through the importing of sexuality labels from western scholarship, by naming and describing sexuality and sexual practices of MSM through the language of western scholarship (Souleymanov & Huang, 2016). Ethnic communities and nation states deal differently with queer people, and it is possible that people who fall under the western category of MSM may understand and structure their sexuality in ways that are very different from people in nonwestern contexts (Souleymanov & Huang, 2016). In addition, the cultural identities of MSM are fluid and are further complicated by technological advances (Mowlabocus, 2016), as well as globalization and migration (Atay, 2015), which present challenges for HIV control and prevention. Given that the universalization of western sexualities across the globe is problematic, even the term MSM erases differences between queer people and homogenizes sexual minorities. This universalization effect has pragmatic implications for online-based HIV initiatives because critical, context-dependent content could be missing or some content may be misleading or wrong if all populations of MSM are treated as a homogeneous risk group.

SPECIAL CONSIDERATIONS FOR CULTURALLY RESPONSIVE PROGRAMMES

Given that communities of MSM are heterogeneous, when it comes to engaging, online messaging and content related to HIV and STIs, the socioeconomic, cultural, linguistic and political contexts of online-based HIV services and programmes have to be considered. Investments in culturally sensitive, online-based programmes and services for sexual education, advocacy and HIV prevention for MSM are needed. Culturally insensitive initiatives may result in MSM avoiding HIV-prevention services or HIV treatment and may hamper the engagement of hard-to-reach populations of MSM (Stahlman et al., 2016).

Special consideration must be given to understanding the make-up and meaning of MSM communities in different parts of the world in order to deliver culturally relevant content. Getting MSM from diverse contexts to use mobile apps and websites for more than just meeting people, such as

using them to seek health services, is already a challenge (UNAIDS, 2016a). This challenge can be exacerbated in situations where the content on apps or websites is unable to create compelling, engaging, culturally relevant messages for MSM in order to engage them in prevention and treatment efforts.

Research suggests that in order to deliver culturally appropriate messages through the Internet and mobile phones to motivate MSM to get tested for HIV, programmes and services should avoid stigmatizing messages regarding sexuality, include motivational messages that reduce the fear of getting tested, disclose the venue where the testing will be conducted, and disclose the professionals who will perform the tests and the type of tests available (Blas, Menacho, Alva, Cabello, & Orellana, 2013). Therefore, the development of websites or apps for HIV programming for MSM should always be undertaken with attention to the current political climate and be embedded in the social and economic contexts that surround the lives of MSM.

User-centric, culturally sensitive approaches are critical, as are finding ways to plug into existing online platforms that are already in use by MSM in different regions of the world (UNAIDS, 2016a). The engagement of MSM in the design and implementation of online-based HIV services is essential when trying to create culturally responsive initiatives, in particular the engagement of MSM who are opinion leaders.

CONCLUSION AND LESSONS LEARNED

This chapter outlines how emerging online technologies can be used with MSM across the HIV continuum of prevention, treatment and care. Online technologies can be an important tool in creating an enabling environment for HIV prevention and can help MSM communicate information about their needs and rights, or collect and aggregate data about incidents of violence, abuse and discrimination experienced by MSM and other sexual minorities.

Online outreach to MSM in general, and specifically to MSM in low-income, industrializing nations who are not linked to HIV-prevention or care, may be facilitated through the use of smartphone apps, Internet websites and other platforms. Smartphone apps and Internet websites present opportunities for discreet, targeted outreach to marginalized MSM. The potential for anonymity and confidentiality offered by these online technologies is of particular importance to MSM who fear violence and persecution in different parts of the world. Online HIV services have the potential to increase HIV

testing and linkage to appropriate HIV care and services by enabling MSM in various regions of the world to find nearby HIV testing centres, public health units or other HIV community-based organizations.

As UNAIDS engages various stakeholders in the use of online technologies for HIV programmes with MSM, social workers have positioned themselves as leaders in this arena. The social work profession is well positioned to catalyse transformative social movements using emerging technologies, implement protective legal environments, advance antioppressive agendas, advocate for HIV-related services and advance the promotion of health and well-being of MSM and sexual minorities globally. In order to facilitate online outreach, HIV testing and linkage to appropriate HIV services through emerging technologies, social work researchers and practitioners must be prepared to partner with key stakeholders in MSM communities, including MSM themselves, organizations that focus on HIV prevention and care, and website and app developers who target MSM.

RECOMMENDATIONS

Online-based HIV outreach should always consider the socioeconomic, cultural, linguistic and political contexts that surround the lives of MSM. Investment in culturally sensitive online programmes and services for sexual education, advocacy and HIV prevention for MSM worldwide is crucial. These online services may engage hard-to-reach, marginalized MSM who are not otherwise accessible because they do not identify with western sexuality labels (e.g. gay or bisexual), or those who do not attend social venues frequented by MSM but nevertheless engage in a variety of high-risk sexual practices. In an effort to provide culturally responsive online HIV services to MSM, social workers and other health- and social-care practitioners, researchers and policy-makers are encouraged to attend to the unique experiences, practices, cultures and identities of these men in different parts of the world. Online content that is driven by MSM and reflects the value systems, language (colloquialisms) and ways of expressing sexuality is likely to have the greatest appeal for men in different parts of the world.

Importantly, online services for MSM must be accompanied by investment in structural initiatives that deal with criminalization laws, violence and the multiple forms of oppression directed towards sexual minorities throughout the world. This can include creating and developing websites and SMS-based systems for reporting and aggregating incidents of discrimination against marginalized, oppressed groups. As suggested by

UNAIDS (2016a), other structural interventions can include the strengthening of the technological capacities and funding of civil society, public sector and community-based nongovernmental organizations in terms of infrastructure, staffing needs and other types of assistance. Similarly, the briefing of national governments and funders on the potential of incorporating structural interventions within existing online-based HIV initiatives, programmes and services for MSM is strongly recommended (UNAIDS, 2016a).

Sensitivity around safety, security and privacy is required in all online-based HIV programming with MSM. Some MSM may adopt multiple online identities for use with different websites and apps, and use different phone numbers to protect their identities. While it is crucial to link online outreach programmes to physical, venue-based services, the safety, security and privacy of MSM must always be a key component of any online service or programme. Given that geo-targeting of MSM can be used in harmful ways (e.g. blackmailing, robberies, extortion, bashings and physical attacks, or even tracking by the police), app and website providers should consider how to increase the security of their information. Similarly, any organization using online technologies to engage with MSM has a responsibility to protect the safety, security and privacy of these individuals as well as programme staff. HIV programme staff should always identify themselves (names, organizations, purpose of their work) immediately to MSM when initiating conversations with them.

Finally, UNAIDS should consider forming working groups to engage MSM, social workers, the private sector and other interested parties: 1) to generate research data using online technologies to produce better MSM population-size estimates, and improve the tracking of HIV risk practices for marginalized, hard-to-reach men; 2) to improve online-based HIV service uptake; 3) to measure the effectiveness and impact of online advocacy initiatives; 4) to identify the level of priority for skills, capacities, infrastructure and budgets needed by organizations to allocate for online-based HIV initiatives with MSM in low-income, industrializing nations. Generating this type of knowledge is an imperative as we prepare the younger generation of HIV researchers and policy-makers to enter the social-work field and move the profession forward in a global context.

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**Social work and
support of people
who use drugs
in Germany**

Heino Stöver, Daniel Deimel and Susann Höbelbarth



ABSTRACTS

Germany was hit by the HIV epidemic in the early 1980s. Social work became active on two levels. On one level, vulnerable communities and individuals have been supported by targeted interventions (e.g. needle and syringe programmes); on another level, social work became active on a structural level by contributing to the abolition of social and health-access inequalities, stigmatization and discrimination (e.g. by improving availability and accessibility of treatment). In this respect vulnerable groups were empowered. Social work related to HIV has mainly focused on the support of two vulnerable groups disproportionately affected by HIV: gay men and other men who have sex with men, and people who use drugs. This article shows how social work structures of HIV prevention, testing, treatment and support are able to strengthen target-group communities, especially people who use drugs.

Soziale Arbeit und Unterstützung von Drogenkonsumenten in Deutschland

Die AIDS-Pandemie erreichte Deutschland in den frühen 1980er Jahren. Die Aktivitäten der Sozialen Arbeit im Feld der HIV-Arbeit beinhaltet zwei Stränge: einerseits sollen durch direkte Maßnahmen vulnerable Personengruppen durch gezielte Präventions- und Hilfsmaßnahmen unterstützt werden. Andererseits soll Soziale Arbeit auch strukturell und politisch wirksam sein, indem sie an der Beseitigung der gesellschaftlichen Ursachen für soziale Ungleichheit, Stigmatisierungen und Diskriminierungen arbeitet und zu einer Selbstermächtigung im Sinne des Empowerments der betroffenen Gruppen beiträgt. In der deutschen HIV-Arbeit wird dies insbesondere in den Aktivitäten mit homosexuellen Männern und i.v.-Drogenkonsumenten deutlich. Beide Gruppen stellen gesellschaftliche Randgruppen dar, welche durch Stigmatisierungen, Marginalisierungen sowie einer fehlenden

gesellschaftlichen Lobby gekennzeichnet sind. Wir zeigen in unserem Beitrag auf, durch welche strukturellen und konzeptionellen Maßnahmen Soziale Arbeit in der HIV-Arbeit in den Bereichen Prävention, Testberatung, Behandlung und Unterstützung der Zielgruppen entwickeln und diese wirkungsvoll implementieren konnte.

德国对吸毒者的社会工作和援助

80年代初，德国受到艾滋病毒/艾滋病流行的冲击。社会工作在两个层面上变得积极主动。一方面，弱势群体和个人受到有针对性的干预（例如，针头和注射器交换项目）援助。另一方面，社会工作通过消除社会和保健方面的不平等、侮辱和歧视（例如，通过提高药物供应和治疗的普及性）而在社会结构层面上变得活跃起来。在这方面，弱势群体获得了某些权利。与艾滋病毒/艾滋病等相关的社会工作主要是为受到艾滋病毒/艾滋病严重影响两个弱势群体-男男性接触者和吸毒者提供援助。本文指出，艾滋病预防、检测、治疗和援助的社会工作结构是如何加强特定群体社区，特别是吸毒者群体的。

Trabajo social y apoyo para personas que consumen drogas en Alemania

Alemania se vio afectada por la epidemia de VIH en la década de los '80s. El trabajo social tomó parte en dos niveles. Por un lado, las poblaciones y personas vulnerables han recibido el apoyo de intervenciones específicas (por ejemplo, programas de intercambio de agujas y jeringas). Por otra parte el trabajo social tomó un papel activo a nivel estructural, contribuyendo a la eliminación de las desigualdades sociales y de salud, la estigmatización y la discriminación (por ejemplo, mediante la mejora de la accesibilidad y la disponibilidad del tratamiento). A este respecto, se fortaleció a los grupos vulnerables. El trabajo social relacionado con el VIH se ha centrado principalmente en el apoyo de dos grupos vulnerables desproporcionadamente afectados por el VIH: hombres que tienen sexo con hombres y personas que consumen drogas. El artículo muestra cómo el trabajo social ha estado desarrollando estructuras de prevención del VIH, pruebas, tratamiento y apoyo para fortalecer los grupos a los que va destinado, especialmente las personas que consumen drogas.

ドイツでドラッグを使う人への支援と社会福祉

ドイツは、1980年代初期にHIVの流行によって打撃を受けました。そして、社会福祉は、2つのレベルで活発になりました。一つは、影響を受けやすいコミュニティと個人を、目標を絞った介入（例えば、針と注射器の交換プログラム）で支援しました。一方では、社会福祉が、社会および医療の不平等、標徴形成と差別の廃止（例えば、治療の利用やアクセスのしやすさを改善）に関与

することによって、構造的なレベルで活発になりました。この点においては、社会的弱者は力を与えられました。HIVに関連した社会福祉は、主にHIVの影響を過度に受けている2つの被害を受けやすいグループの支援に、重点を置きました。同性愛の男性や男性とセックスする男性 とドラッグを使う人です。この記事では、HIV予防、検査、治療と支援などの社会福祉構造が、いかに対象集団、特にドラッグを使う人を強化することが出来るかを提示します。

Travail social et prise en charge des consommateurs de drogues injectables en Allemagne

L'Allemagne a été frappée par l'épidémie de VIH au début des années 1980. Le travail social s'est alors accentué sur deux niveaux. D'une part, les populations et les individus vulnérables ont été pris en charge à travers d'interventions ciblées (notamment à travers des programmes d'échange des aiguilles et des seringues). D'autre part, le travail social a été renforcé à un niveau structurel en contribuant à l'abolition des inégalités sociales et sanitaires, de la stigmatisation et de la discrimination (notamment par l'amélioration de la disponibilité et l'accès au traitement). Dans cette perspective, les capacités d'intervention des groupes vulnérables ont été renforcées. L'assistance sociale liée au VIH est restée principalement axée sur la prise en charge de deux groupes vulnérables disproportionnellement affectés par le VIH, notamment les hommes ayant des rapports sexuels avec des hommes et les consommateurs de drogues injectables. Le présent article montre comment le travail social développe des structures de prévention, de test, de traitement et de prise en charge de VIH afin de renforcer les capacités d'intervention des groupes cibles, notamment les consommateurs de drogues injectables.

INTRODUCTION

Social workers have been responding to the HIV epidemic in Germany over the past 30 years. Their main objective was to build on traditional social-work methods and techniques to assist and support poor, marginalized and stigmatized communities. Social work relating to HIV has mainly focused on the support of two vulnerable groups disproportionately affected by HIV: gay men and other men who have sex with men, and people who use drugs. The aim of this paper is to present available evidence and experiences of how social work contributed to the response to the threat of HIV/AIDS in the target groups of people who use drugs and men who have sex with men.

On one level, vulnerable populations and individuals have been supported

by targeted interventions (e.g. needle and syringe programmes). On another level, social work became active on a structural level by contributing to the abolition of social and health inequalities, stigmatization and discrimination (e.g. by improving availability and accessibility of treatment, improving access to work and occupation, strengthening patients' rights and supporting and initiating self-help and self-organization activities for the people concerned). In this respect, vulnerable groups were empowered.

In Germany and northern Europe, social work is both a profession (direct support and help) and a scientific discipline. In Germany, state-approved bachelor's and master's courses at universities of applied sciences are where social work is taught and professionals are trained. DBSH, the German professional association for social work (www.dbsh.de), represents the interests of practising social workers. Scientists from the field of social work are organized into the German Association of Social Work (www.dgsainfo.de/en/dgsa/). The profession of social work and its concept of itself are based on the global definition adopted by the International Federation of Social Workers (IFSW) and the International Association of Schools of Social Work (IASSW) (2014).

In the area of supporting people who use drugs, when new drugs came on the scene in the 1970s (for example cannabis, LSD and heroin), social workers played an important role in setting up help for people who use drugs that responded to their particular needs. These interventions ran parallel to the professionalization of social work, in the context of training becoming established at colleges (Knoll, 2010). Today, an estimated 15 000 social workers work in the field of drug-dependence treatment for people who use legal and illegal drugs (Klein, 2012) and therefore represent the largest occupational group in this field. The advice, support and prevention work that is provided by social work is normally based on the clients' entitlement under social law and is financed by public bodies (Lenski, 2016). In addition to advice and treatment options, care for people dependent on drugs in Germany also encompasses low-threshold harm-reduction services. This includes provision of options for overnight accommodation, food and health care, distribution of equipment for safer use and safer sex and operation of drug-consumption facilities.

In particular, social work courses teach skills in the fields of psychosocial diagnostics, psychosocial counselling, crisis intervention, intervention planning and case management, as well as discussion (particularly motivational interviewing; Miller & Rollnick, 2012), social group work and street work (Galuske, 2013; Pauls, 2013). Work with mentally ill people and addicts (Bischkopf, Deimel, Walther, & Zimmermann, 2017), as well as

prevention and advice in the field of HIV (Hülshoff, 2011), are among the main areas of responsibility of social workers.

Since the mid-1970s, social workers have been able to work in the psychotherapeutic and sociotherapeutic treatment of addicts, after completing recognized further training to become an addiction therapist (Knoll, 2010). Furthermore, specific master's degrees in the spheres of clinical social work and addiction therapy have been developed in the past 10 years, which has furthered the process of professionalization.

Clinical social work is aimed at so-called hard-to-reach clients who are difficult or impossible to reach with classic medical or psychotherapeutic support systems (Walther & Deimel, 2016). The theoretical starting point is a biopsychosocial understanding of health and illness (Engel, 1977, 1980), as well as of how the individual interacts with their social environment (person-in-environment perspective); these are jointly responsible for the emergence and continuance of illnesses (Richmond, 1922). Social work acts on different levels: in addition to direct practice in the context of casework, it supports affected people and their social milieu. Social work also tries to initiate helpful processes in communities. On a political and structural level, social work helps to address inequalities among groups of people, which influences the health of individuals (Mielck, 2005).

For both target groups, people who use drugs and gay men and other men who have sex with men, social work has contributed massively to the containment of the HIV epidemic. Social work has built up a structure of harm-reduction services to empower people who use drugs to protect themselves from acquiring the virus. In this paper we focus on five interventions:

- In more than 120 cities, approximately 170 needle and syringe dispensing machines have been installed to guarantee unrestricted access to clean needles, syringes and equipment.
- 25 drug-consumption rooms in 18 cities have been opened in the past 20 years. These are run by social workers and nurses to assist people who use drugs with safer drug use.
- Psychosocial support for people who use drugs, especially for those in medication-assisted treatment of opioid dependency.
- Promoting a change in the opiate consumption pattern, from injecting to inhaling.
- Campaigns and support for, and with, gay men and other men who have sex with men.

Most of these interventions began with a participatory approach: people who use drugs and men who have sex with men have been consulted or even

integrated into the teams. Social work is also a profession that organizes local-level discussions on the adequate provision of health care and social services for men who have sex with men and people who use drugs and who are living with HIV (for example, access to and support of adherence to antiretroviral therapy, housing projects, qualification and occupational opportunities). These accomplishments could only be achieved by working collaboratively with other disciplines, professions and politicians.

The guiding theoretical framework of this paper is the World Health Organization's (WHO) health-promotion approach, which is understood as the process of enabling people to increase control over, and to improve, their health: "Health promotion action aims at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential" (WHO, 1986, para 6). HIV is a threat to people and society, especially vulnerable key populations (people who use drugs, men who have sex with men, and others), who are at particular risk of acquiring the virus. Vulnerable key populations need comprehensive support, because laws, social norms and limited access to and coverage of adequate services are massive barriers to coping with the disease. Harm reduction and target-group-specific prevention, in particular, are key strategies for offering effective health care and social support.

The underlying methodological approach is analysis of the health and social needs of the target groups, their involvement in designing and operating support services and enabling them to organize themselves. We have examined relevant documents and research reports in order to formulate the processes of development of the interventions, and the lessons learned and not learned.

KEY ISSUES AND RESPONSES

Exclusion of people living with HIV: historical review

When HIV emerged in the early 1980s, the health system in Germany was not prepared at all to include people who were affected by its disorders and diseases. The health system was dichotomously divided into doctors on the one hand and patients on the other hand. The latter had been excluded from planning, decision-making and operational processes and had no say at all. The health system was far from having a participatory approach or good access to the target groups. On the contrary, the health system was built on the exclusion of patients in operational areas and on policy and planning.

Even when the Ottawa Charter was released in 1986 (WHO, 1986), the

health promotion and prevention approach did not immediately affect Germany's health system. It took years until the first projects relating to health promotion and a participatory approach came into force (e.g. WHO's healthy settings approach: healthy cities, healthy hospitals and healthy schools; Baggott, 2011). However, HIV changed the system substantially. HIV was a health threat to the whole of society, characterized by the fact that no one had a convincing strategy to respond to the disease, including the doctors who traditionally were supposed to have an answer. This led to the fact that people living with HIV, their friends and their families came onto the scene, requested medicines (being tested in other countries) and fought for their rights to be informed and involved. Several AIDS Coalition to Unleash Power groups, mainly from the gay movement, demanded more research, counselling and treatment efforts, and robustly denounced stigma and discrimination. For the first time, mainly young men were affected by HIV, and an early publication expressed that the HIV epidemic could be overcome more quickly once the right interventions were installed (mainly free access to syringes, needles and condoms), and stigma, discrimination and criminalization of the affected people would be reduced (Rosenbrock, 1987).

However, the main dispute around coping with the HIV threat in Germany was centred on opposing strategies. On the one hand, in a special Bavarian manual of operations, politicians demanded forced testing for so-called risk groups, such as people who inject drugs, men who have sex with men and sex workers (Stroh, 2012). The core goal was a search and control strategy. On the other hand, supported by the politics of the other *Länder* (states), was the strategy of education and information. The learning strategy finally succeeded (Wicht, 2012), and focused on inclusion, participation and support of the target groups. It became clear that instead of panicking, a resource-oriented approach would be more successful at reaching and approaching the target groups and maintaining contact with them, instead of pushing them into clandestine behaviour. Once the target groups feared forced testing and stigma, they would drift into the subculture and would not be accessible for information and later treatment efforts.

This (partly ongoing) discourse around exclusion and inclusion was key for further support strategies and built a basis for target-group-specific services for people who use drugs, men who have sex with men, and sex workers. It became evident that an adequate and successful response to the threat of HIV could only be achieved by integrating the power and expertise of the target groups: "Nothing about us without us!" The contribution of social workers was to create supportive environments for improved access

to testing services, effective prevention, treatment and care. Often social workers offered the framework in which communities could access the services and express their demands (for example, supporting court cases, confronting politicians and media with gaps in services or adequate health-care delivery).

Installing needle and syringe dispensing machines for people who inject drugs: unrestricted access

Over the past 30 years, needle and syringe programmes (NSP) have become an indispensable tool and a primary component of the integral and pragmatic public health response to the risk of HIV and hepatitis transmission among people who inject drugs and, ultimately, the general public (WHO, United Nations Office on Drugs & Crime, & UNAIDS, 2007). Extensive studies on the effectiveness of these programmes have been carried out, providing scientific evidence that the provision of sterile injection equipment is an appropriate and important preventive health measure. NSPs have been implemented in 82 countries. Regional and national coverage has varied substantially (Mathers et al., 2010).

In order to improve access to prevention materials and sterile injection equipment, publicly accessible needle and syringe dispensing machines were installed. By 2013, 120 German cities with approximately 170 machines had provided an estimated 400 000 packages (Die Drogenbeauftragte der Bundesregierung, 2013). These packages contain syringes and needles in different sizes, condoms, sterile water, ascorbic acid, plasters and other items; the variety of the assortment reflects the local needs of people who use drugs (Schuller & Stöver, 1989).

The initiative began in 1987, five years after the virus was first identified in Germany. Most of the pharmacies and drug counselling agencies were not able to provide sterile injection equipment to people who inject drugs due to moral and legal constraints. Activists and social workers therefore started early with the provision of clean injection equipment and condoms to guarantee easy, unrestricted access to prevention material for approximately US\$ 1. Cigarette vending machines, which are widespread in Germany (330 000), were converted to contain boxes of clean injection equipment, safer-use information and package inserts in order to communicate with people who use drugs. The work of filling the packages is mainly done by people who use drugs themselves, who use this opportunity to pay community fines or earn money. The dispensing machines are run and maintained by social workers and activists in drug- or HIV-counselling agencies.

A significant proportion of the users of the dispensing machines acquire their needles and syringes solely via this way because of anonymity—they would never access a drug counselling agency or drop-in centre (Kaplan, Stöver, Leicht, & Schäffer, 2014).

Installation of these dispensing machines is never easy. Most people from the neighbourhood oppose it, and sometimes even damage this prevention tool. However, discussions with neighbours have been organized by social workers in order to obtain support and acceptance for these interventions. This is useful for pointing out the needs of people who inject drugs in the community and local areas, and for making this offer more explicit and understandable for the neighbours.

Prison-based needle exchange projects: still controversial after all these years

No prison system has yet succeeded in remaining drug-free. For instance, 30–40% of inmates in German prisons use drugs, and a substantial proportion continue to inject drugs during their incarceration (Stöver, 2012). Although injecting in prisons may be less frequent, in most situations prisoners had to use and share unsterile injecting equipment (Stöver, 2016). Therefore, imprisonment is associated with risk factors and forms of risk behaviour, primarily related to injecting drug use and to unsafe needle-use practices including injecting, tattooing and piercing, but also to unprotected sexual contact.

In most countries, the spread of HIV and hepatitis C virus (HCV) in prisons is clearly driven by injecting drug use, with many prisoners unaware of their HIV status. In many prisons worldwide, HIV testing is offered to prisoners immediately after admission. Pre- and post-test counselling is not being offered everywhere. Diagnosis and uptake of antiretroviral therapy (ART) for HIV-positive people is mostly carried out at specialist centres outside the medical units of the prisons. Uptake or continuation of ART is carried out in most prisons worldwide. However, the modalities of treatment and support of adherence vary considerably. After release, a substantial number of ex-prisoners do not continue ART for various reasons (for example, no support by health insurance, no financial resources, homelessness and relapse).

Despite many studies confirming the facts about risk behaviour and the prison setting as a risk environment for maintaining or taking up risk behaviour, little progress has been made around effective and efficient infectious prophylaxis by means of prison-based needle and syringe programmes and associated education (Stöver & Hariga, 2016). The question

remains as to why effective and efficient prevention models applied in the community are very rarely implemented in prison settings.

Worldwide, only approximately 60 out of more than 10 000 prisons provide needle exchange. Thus, HIV and HCV prevention is almost exclusively limited to verbal advice, leaflets and other measures directed at cognitive behavioural change (Arain, Robaeys, & Stöver, 2014). Raising awareness, and information, education and communication (IEC) programmes about HIV, sexually transmitted infections (STIs), viral hepatitis and tuberculosis, are needed in all closed settings. However, IEC strategies are only one out of 15 interventions within a comprehensive package suggested by the United Nations Office on Drugs & Crime (UNODC), International Labour Organization, United Nations Development Programme (UNDP), WHO and UNAIDS (2013) to combat HIV and other infectious diseases. As stand-alone measures of IEC activities would not be sufficient, they should be complemented by other interventions.

A UNODC handbook on the implementation of prison-based needle exchange has been elaborated upon to better inform and guide officials in the Ministries of Justice and Health and those in charge of health care in prisons. It integrates the views and experiences of many experts throughout the world (UNODC, 2016).

Prison needle-exchange programmes have been successfully implemented in both men's and women's prisons in Germany. They have been implemented in institutions of varying sizes; in both civilian and military systems; in institutions that house prisoners in individual cells and those that house prisoners in barracks; in institutions with different security ratings; and in different forms of custody (remand and sentenced, open and closed). Needle exchanges were typically implemented initially on a pilot basis, and later expanded based on the information learned during the pilot phase. Several different methods of syringe distribution are employed, based on the specific needs and the environment of the given institution. These methods include automatic dispensing machines, hand-to-hand distribution by prison physicians/health-care staff or by external community-health workers, and programmes using prisoners trained as peer outreach workers (Lines et al., 2006).

In a meta-analysis of 11 prisons that were scientifically evaluated to assess feasibility and efficacy, the results did not support fears that commonly arise about the implementation of prison-based needle and syringe programmes (PNSP; Stöver & Nelles, 2003). Syringe distribution was not followed by an increase in drug use or injecting drug use. Syringes were not misused, and disposal of used syringes was uncomplicated. Sharing of syringes

among people who inject drugs was reduced. Based on these experiences, the authors concluded that in these settings, harm-reduction measures, including syringe exchange, were not only feasible but also efficient (Stöver & Nelles, 2003). One important lesson to be learned from this meta-analysis is that PNSPs are part of a broader health approach and should therefore be embedded in a global, comprehensive, prison-based drug and health-promotion strategy. Looking at PNSPs in an integrated way was part of the success of PNSPs in penal institutions.

Evidence from countries where prison needle-exchange programmes exist clearly demonstrates that:

- PNSPs are feasible and affordable in a wide range of prison settings.
- PNSPs have been effective in decreasing syringe sharing among people injecting drugs in prison, thereby reducing the risk of disease transmission (HIV, HCV) among both prisoners and prison staff.
- PNSPs encourage prisoners to readily accept and use sterile syringes provided through PNSPs, as has been found in previous studies.
- PNSPs have not been associated with increased attacks on prison staff or other prisoners.
- PNSPs have not led to an increased initiation of drug consumption or injection.
- PNSPs contribute to workplace safety. When prisoners are not forced to conceal injection equipment and a prisoner is permitted to have a sterile syringe for personal use, guards conducting searches of prisoners or cells are less likely to be pricked by a contaminated needle.
- PNSPs can lead to reduced overdose risks and a decrease in abscesses, and facilitate referral to and utilization of drug dependence treatment programmes (where available).
- PNSPs can employ any of several different methods of needle distribution successfully in response to staff and inmate needs.
- PNSPs can successfully coexist with other drug prevention and treatment programmes (Lines et al., 2006).

For PNSPs to be successful in prisons, prisoners need to have easy, confidential access to syringes and equipment, and both prisoners and staff should be involved in the design and implementation of the programme. Successful PNSPs also feature a rigorous mechanism for safe disposal of syringes and good monitoring, evaluation and quality control.

A key problem, apart from political problems in implementing and

legitimizing PNSPs, is still the lack of guaranteed confidentiality for prisoners. This hinders prisoners from participating in the programmes. A second problem is that HIV and opioid consumption are no longer the key drivers of the debate around drugs and infectious diseases in prisons; instead, new psychoactive substances (NPS) and steroids have become the priority. In many countries, the HIV rate among prisoners who use drugs is lower than the rate 20 years ago (for example, in western Europe). While hepatitis C is by far the most prevalent infectious disease, it has been neglected by policy-makers. It has been difficult to develop momentum to legitimize concerted action to prevent the spread of infectious diseases (Arain et al., 2014). However, in Germany, a nationwide manual to tackle the threats of HCV in closed settings has been put together by social workers, along with user groups, medical doctors and lawyers, funded by the Federal Ministry of Health (Aktionsbündnis Hepatitis und Drogengebrauch, 2013).

In Germany, numerous concentrated attempts and efforts by activists and social workers, working inside and outside prisons, have been made to introduce prison-based needle and syringe exchange programmes. However, due to political reasons, six out of seven prisons closed down their needle and syringe programmes and only one out of more than 180 custodial institutions in Germany provides needles and syringes via dispensing machines to female prisoners (at the women's prison in Berlin Lichtenberg). This programme has been running for approximately 20 years without any problems (Stöver & Knorr, 2014). However, the discrepancy around the success of PNSPs in prisons on the one hand, and their low acceptance and adoption on the other hand, is striking.

Activists and social workers are completely dependent on the decisions and goodwill of the 16 different state Ministries of Justice in Germany (prisons are entirely the responsibility of the *Länder*). Apart from throwing needles and syringes over the prison wall as a public action, they are not in a practical position to start a PNSP, as was successfully done in the community.

Drug consumption rooms

Drug consumption rooms (DCRs) facilitate a hygienic intake of drugs with additional assistance in health and social matters (Deutsche AIDS-Hilfe & Akzept, 2011). Approximately 90 facilities have been set up worldwide (see Table 1).

DCRs are typically part of a broader and interlinked network of services. Today, DCRs are mostly based in drug service centres alongside a range of other services, such as counselling and testing for blood-borne viruses, drop-

in centres (DIC) with needle and syringe programmes (NSPs), psychosocial care, care for people who are homeless, medical services (e.g. wound care), and access to employment programmes. The DCR is usually provided in a dedicated area of the centre and access is normally controlled by staff. This allows staff to limit the number of people who use drugs using the DCR at any one time and also to manage entry restrictions, most commonly to enforce a minimum age limit of 18 years, and also to prevent those in opiate substitution treatment from accessing the service (this is a restriction in Germany). However, there are also specialized and mobile models of DCRs, which are dedicated solely to drug consumption without the broader social and health-work approach (Schäffer, Stöver, & Weichert, 2014).

DCRs have mostly been implemented by social workers, together with medical doctors and nurses, in order to get into contact with people who use drugs and to provide low-threshold social and health services. Historically these facilities developed in a juridical grey area, without official permission,

**Table 1 Drug consumption rooms set up worldwide
(as of 2014)**

Country	Number of drug consumption rooms
Switzerland	13
Netherlands	30
Germany	24
Spain	13
Luxembourg	1
Norway	1
Denmark	5
Greece	1
Australia	1
Canada	1
Total	90

Source: Schäffer, D., Stöver, H., & Weichert, L. (2014). *Drug consumption rooms in Europe models, best practice and challenges*. Amsterdam, The Netherlands: European Harm Reduction Network. Retrieved from http://www.eurohrn.eu/images/stories/pdf/publications/dcr_europe.pdf.

from the late 1980s on (Stöver, 1991). However, as a result of ongoing pressure from social workers and activists, the national opium law was changed in Germany in 2000, allowing implementation of DCRs under certain conditions (Stöver, 2002). These have to be ratified by each of the 16 *Länder*, which has led to a very heterogeneous picture as only six out of 16 *Länder* have allowed the implementation of DCRs; the other *Länder* have refused or do not see a necessity or benefit.

However, DCRs have contributed substantially to a reduction in drug-related mortality in the cities where they have been installed. Looking at the four DCRs in Frankfurt, a quarter of a million consumption events are monitored there every year, and it is likely that this hygienic situation for intravenous and inhaled drug use contributes substantially to a reduction in the transmission risks for infectious diseases (Hedrich, Kerr, & Dubois-Arber, 2010).

Psychosocial support for people who use drugs, especially those on opioid substitution treatment

Over a time span of almost 30 years, social workers and activists have fought for the introduction of a client-based opioid substitution treatment (OST). In some parts of Germany there is still controversy and debate about the benefits of OST, which was first introduced in Germany in 1987. The number of patients on OST has increased considerably to some 77 000 patients in 2015, representing approximately 40–50% of the total population of people in Germany who inject drugs (Bundesinstitut für Arzneimittel und Medizinprodukte, 2016). The results of research studies and practical experiences clearly indicate that patients benefit substantially from OST, with improvements in physical and psychological health (Michels, Stöver, & Gerlach, 2007). Methadone Maintenance Therapy (MMT) has proved to be successful in attaining high retention rates and plays a major role in accessing and maintaining ongoing medical treatment for HIV and hepatitis (Zippel-Schultz et al., 2016).

The regulations for substitution treatment in Germany demand the mandatory participation of patients in psychosocial care, although there is no empirical evidence of a general necessity for psychosocial support for all patients at every point in their life (Haasen et al., 2006). However, these regulations do not provide any instructions on the frequency, mode and scope of psychosocial care provisions and, to date, there are no nationwide standards on how to organize and structure accompanying support. Psychosocial care is a collective name for a number of different services. These may include, for example, legal advice, managing financial problems (e.g.

debts, rent), recreational activities, crisis intervention, (psychotherapeutic) group sessions, assistance with finding accommodation and jobs, and with qualifying for college and vocational training. Psychosocial care is not funded by health insurance. There are great variations in psychosocial care provision between different states and communities, and variations in quality and funding. Special cognitive behaviour interventions might reduce additional consumption of psychoactive substances (Deimel & Stöver, 2015b, 2015c; Gerlach & Stöver, 2007). An alternative strategy is contingency management, in which patients are given positive reinforcement (e.g. vouchers or a take-home dose) for each drug-free urine sample.

Psychosocial counselling can support patients with restructuring their life based on changed values, because the pressure to find drugs is reduced substantially. However, massive problems are often revealed that might lead to a state of crisis, as confrontation with injuries, illnesses and other negative experiences from the past can be very painful. The loss of daily structures (and generally all-consuming) activities focused on financing and consuming drugs, the loss of the euphoric effects of substances like heroin and the consequences of massive illness (dual diagnosis, viral infections) and limited future prospects may lead to depression (Deimel, 2013). Some patients become apathetic and unable to structure their lives; for example, they hang around all day long watching TV. Former social networks no longer have the same function they once had. Keeping away from the so-called drug scene and establishing a new life is not easy when meeting old acquaintances at the substitution doctor's office every day. The additional use of alcohol and benzodiazepines might function as a kind of self-medication for dealing with depression, but often has the opposite effect (Elsner, 2006). Improving family life is not easy without professional support, as family integration plays an ambivalent role. Early childhood family experiences are often part of the problem. Family involvement is crucial for successful treatment, while its dynamics might only be understood and confronted with expert psychological support.

Promoting a change in opiate consumption pattern: from injecting to inhaling

Social workers and activists have been very busy promoting a change in opiate consumption pattern, from injecting to inhaling, in order to avoid the risk of transmitting HIV and other infectious diseases. Injecting drug use has predominantly been practised since illegal heroin use became known in Germany in the early 1970s. Available data suggests that the risk of accidental

overdose when smoking heroin is substantially reduced compared with injecting a substance of unknown purity and quality. Moreover, the risk of transmitting HIV or hepatitis B or C via blood contact is considerably reduced when smoking heroin compared with injecting it. In spite of the significant strain on the lungs and respiratory tract caused by smoking, it can be concluded that inhaled use—measured by the indicators overdose and viral infections—is considerably less dangerous than injected use. Inhaled drug use is done with foils: heroin is heated on an appropriate foil and the rising vapours are inhaled using a small tube. The project Smoke IT! was initiated, accompanied by an evaluation study (Stöver & Schäffer, 2014). The aim of the project was to investigate the influence of supplying smoking foils and tubes, together with accompanying information about inhalation (flyers, posters, cards), on a change of consumption patterns from standard intravenous drug use to inhalative methods. The participants of the study were contacted by social workers in DCRs in five different German cities. Data were collected through written questionnaires at three different times (immediately after recruitment, after using the foil and at least 30 days later).

The study indicated that the vast majority (82.5%) of the 165 respondents favoured using the thick aluminium foils provided. Two-thirds of the sample used these foils for inhaling, instead of injecting. Almost six out of ten respondents said that smoking was healthier than injecting, and 35% of participants named the reduced risk of a hepatitis or HIV infection as a particularly important factor. One-third of the respondents used the smoking foils to avoid the danger of an overdose.

Targeted media and personal interventions, in association with the dispensing of attractive drug-use equipment, can motivate people who use opiates to change their method of drug use. The main reason for inhalative use is that it is significantly less dangerous, measured by the indicators overdose and viral infections. Smoking foils appear to be an important addition to risk-reduction strategies in drop-in centres.

The above-mentioned survey results demonstrate that patterns of heroin use can be influenced by providing a mixture of new, high-quality prevention tools (foils that are pre-cut, uncoated, thicker and thus more resistant to tearing) and a target-group-specific approach. Similar to the present survey, previous studies have also shown that despite their current drug use, people who use drugs are highly interested in preserving their health and are willing to accept measures and/or information and advice provided by social workers with risk-reducing content and objectives.

It became clear that professionalism is required to address safer-use issues during the daily routine of a DCR and other drug services at the right time,

or at all. Some users received information from social workers about the new foils while they were waiting to enter the consumption room. A new medium enables social and health workers to address use patterns and risks (infection, overdose) in an entirely new way; for example, as a new medium the new and thicker foils aroused interest and provided new ways of approaching people who used opiates. The new foils provided an opportunity to once again address old issues, such as giving veins a break, with a new, convincing service. Ultimately, new drug-use equipment not only makes it possible to renew prevention messages or convey them for the first time, but also provides the opportunity for social workers to approach people who have so far not been approached, as well as those with whom contact has been lost.

Campaigns and support for and with gay men and other men who have sex with men

Men who have sex with men have been a vulnerable group since the beginning of the global AIDS epidemic (Sander, 2010) and have the highest share of new HIV infections in Germany. Of the estimated 83 400 people living with HIV, approximately 53 800 belong to the group of men who have sex with men (Robert Koch Institut, 2015). According to the syndemic approach (Singer, 1996, 2009; Stall, Friedmann, & Catania, 2007), men who have sex with men suffer from discrimination and exclusion due to their sexual orientation, and report significantly higher psychological burdens, experiences of violence, drug use and HIV infections than the general population (Drewes & Kruspe, 2016).

Both in the past and today, men who have sex with men are strongly exposed to stigma and discrimination. Sex between men was a punishable offence in Germany between 1935 and 1994 (Steinke, 2005). Of those convicted during this period, compensation for men convicted of having sex with men is now under discussion.

At the beginning of the AIDS epidemic in Germany in 1983, men who have sex with men were synonymous with the disease, with the media reporting on the “gay disease” (“Aids: Eine Epidemie die erst beginnt”, 1983). During the same period of time, local groups of AIDS self-help groups were founded by gay activists, who later organized themselves under the national umbrella organization Deutschen AIDS-Hilfe (Pieper & Vael, 1993). Besides direct support for people suffering from AIDS, antidiscrimination work was, and still is, the focus of all the policies and practices of the 130 local AIDS self-help groups as well as the national organization. The national self-help group is financed by and closely cooperates with the Federal Centre for Health

Education and the Federal Ministry of Health. This health provision structure is unique in Europe: an organization developed within self-help groups is being financially supported and is closely cooperating in their concepts and prevention strategies with governmental bodies.

Social workers play a key role in the local AIDS assistance centres:

- Social workers are educators on the subjects of HIV and other STIs. They support people with regard to HIV testing and highly active antiretroviral therapy and conduct crisis interventions. Moreover, social workers in offices for the unemployment benefit and social welfare and foundations support people who apply for benefits and assistance.
- Along with direct, face-to-face counselling, low threshold and anonymous counselling practices via telephone and online are being implemented.
- Social workers accompany self-help groups for people living with HIV, through which networking and activation (empowerment) is supported.
- Social workers collaborate with men who have sex with men on HIV-prevention topics and strategies within the men who have sex with men scene. This is done through street work in clubs, bars and saunas within the men who have sex with men scene.
- Social workers conduct events dealing with prevention topics in schools, specifically the topics of sexuality, relationships and STIs.
- By means of public relations and lobbying, social workers promote a supportive attitude towards men who have sex with men in the wider society.
- Social workers assist young men who have sex with men and other people who are lesbian, gay, bisexual, transgender and/or intersex (LGBTI) with regard to coming out (for example, in Cologne there is a youth centre for LGBTI).
- Social workers counsel people living with HIV with regard to legal issues, social assistance and employment law (e.g. discrimination at the workplace).
- Social workers support and counsel elderly people living with HIV.
- Social workers support and accompany male sex workers. Psychosocial counselling, provision of condoms and low-threshold support is offered in specific drop-in centres.
- Social workers closely collaborate with other professions (e.g. physicians, psychologists, nurses) on the development of specific concepts for prevention and interventions.

With these specific efforts, a nationwide support and networking structure for people living with HIV has been established over the past 30 years.

The current challenges lie in reaching specific client groups, such as men who have sex with men and who also use drugs. In cities with large communities of men who have sex with men (such as Berlin, Cologne and Hamburg), increased drug use can be observed in parts of these communities. Drug consumption in the context of sex sessions (so-called chemsex) is of increasing importance (Deimel & Stöver, 2015a). This corresponds with observations in other European countries such as the UK or Sweden (Bourne, Reid, Hickson, Torres-Rueda, & Weatherburn, 2015; Bourne et al., 2015; Petersson, Tikkanen, & Schmidt, 2016). Such drug consumption is associated with increased sexual risk behaviour (Deimel, Gebhardt, & Stöver, 2016). As these men who have sex with men do not identify themselves as drug-dependent, they would never appear in drug-services institutions. In 2015, Deutsche AIDS-Hilfe therefore initiated better connection of local counselling agencies working in AIDS and addiction services through a project called QUADROS.

Besides a transfer of knowledge between different support and counselling institutions, counsellors have been trained in motivational interviewing and living-environment-oriented counselling (Dichtl, Graf, & Sander, 2016).

GETTING TO ZERO

The current UNAIDS ambition is known as 90-90-90: by 2020, 90% of people living with HIV will know their HIV status; 90% of people who know their HIV-positive status will be accessing treatment; and 90% of people on treatment will have suppressed viral loads. There is a Fast-Track Strategy to end the AIDS epidemic by 2030 (UNAIDS, 2014). The goal is ending the HIV epidemic as a public health threat among people who use drugs and people in prisons by 2030, through promoting public health, human rights, justice and equality of access to HIV services within the framework of UNAIDS. The overall goal of UNODC and UNAIDS is to support countries to achieve major reductions in new HIV infections and HIV-related deaths among people who use drugs and are at risk of HIV, and people in prison, while working to eliminate discrimination. However, by 2013 only a fraction of the people who inject drugs—10% coverage globally—had accessed priority interventions such as NSPs, while only 14% of people living with HIV who inject drugs had accessed ART, and only 8% had accessed opioid substitution treatment (UNODC, 2015). Despite widespread knowledge of which interventions work

and high-level publications of comprehensive packages of interventions (UNODC, UNDP, ILO, WHO, UNAIDS, 2013), the coverage of key interventions (e.g. NSP in prisons and OST and DCRs in the community) as described for Germany in this chapter, remains insufficient. Fast-tracking to zero calls for a 75% reduction in new HIV infections among key populations, including people who use drugs and people in prisons, by 2020 (UNODC, 2015). In order to achieve this goal, enormous efforts must be made to increase coverage of and access to harm-reduction services. The barriers to supporting men who have sex with men and people who use drugs globally, and in Germany, are:

- Punitive laws, policies (often not aligned) and practices, a high degree of criminalization of people who use drugs (Statistisches Bundesamt, 2016).
- Widespread stigma, discrimination, violence and poor prison conditions.
- A lack of community engagement.
- Inadequate gender- and age-responsive services.
- Lack of sustainable and predictable funding.
- Limited strategic information.

Social workers can play a substantial role in overcoming these barriers.

LESSONS LEARNED

The five interventions described in this paper demonstrate that social work plays a substantial role in contributing to an adequate response in preventing HIV. Social work is able to respond particularly well to the health needs of the target groups described, because of the skills, reflections and methods (resource-orientated and in touch with the realities of people's lives) of social workers. Social work in this area acts on three levels: as direct practice with specific, vulnerable target groups, as part of individual casework and as part of social group work. In addition, it also initiates support and help processes in social networks and communities. Furthermore, social work acts as an advocate for its clients on a political level in supporting marginalized and discriminated groups, such as people who use drugs and men who have sex with men.

However, further progress is needed in order to achieve the ambitious goal of zero new infections by 2030. The five examples described in this paper showed that substantial efforts are still needed both on an individual level and on a structural and political level. On an individual level, people who use

drugs and men who have sex with men need to be informed and educated about the prevention of HIV-transmission risks and in the application of harm-reduction measures. On a structural and political level, coverage and access to services needs to be increased substantially. The examples of NSP, OST and DCRs illustrate that coverage and access to harm-reduction services are still insufficient; in some regions and settings (such as prisons) they are poor and patchy, or even nonexistent. The reasons for this are not limited resources, but rather lack of political will, ideological barriers and nonallocation of funds to vulnerable populations. Evidence-informed research and monitoring will become more important in future in order to deliver a solid basis for political decisions.

But even when there is evidence for interventions that work, the lack of political will can lead to a reality where effective and efficient services will either not be implemented at all, or will be implemented after a huge time gap (e.g. the introduction of heroin-assisted treatment for opioid-dependent people, or needle exchange programmes in prisons). Social work can put pressure on politicians at the community or national level in a participatory process by involving the vulnerable target groups, their partners and families. One example is the lack of access to OST in Bavarian prisons. A Bavarian prisoner complained to the European Court of Human Rights, supported by a social worker from Deutsche AIDS-Hilfe. The judgement, delivered on 1 September 2016, was against Germany and confirmed the lack of support for the prisoner, which was a breach of human rights (Wenner v. Germany, 2016). The future motto should be, “Nothing about us without us!”

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Part 2: Zero discrimination

**Getting to Zero:
A conversation on
the label OVC and the
welfare of children in
sub-Saharan Africa**

Margaret Lombe, Harriet Mabikke and Ngozi Enelamah



ABSTRACTS

The impact of HIV and AIDS has received substantial attention worldwide. This chapter focuses specifically on sub-Saharan Africa, a region devastated by the global epidemic. We draw attention to the staggering numbers of children affected by HIV and AIDS, estimated at 11 million in this region alone. Highlighting the label Orphan and Vulnerable Children (OVC), which has been used to classify affected children, we examine its impact on the welfare of affected children. Challenges embedded in formal and informal systems of OVC care are underscored. Drawing upon labelling literature, OVC policies and programming as well as the Convention on the Rights of the Child (CRC) and the African Charter on the Rights and Welfare of the Child (ACRWC), attention is devoted to Getting to Zero in relation to the care of labelled children and their communities. The chapter concludes with lessons learned and their implications for practice, policy and scholarship.

向零艾滋病迈进：关于“孤儿与弱势儿童（OVC）”的对话和撒哈拉以南非洲的儿童福利问题

艾滋病/艾滋病的影响在世界范围内受到了人们的广泛关注。本章重点介绍了撒哈拉沙漠以南的非洲地区，艾滋病给这个地区造成了毁灭性的影响。我们特别要指出，这个地区受艾滋病/ 艾滋病影响的儿童数量惊人，估计仅在这一地区就有1100万人。通过强调这个一直用来识别受影响儿童的“孤儿和弱势儿童（OVC）”名称，我们研究了它对儿童福利的影响，我们也特别研究了“孤儿和弱势儿童（OVC）”群体援助的正式和非正式体系中潜在的挑战。“。根据“孤儿和弱势儿童（OVC）”的文献、“OVC的政策、项目，以及儿童权利公约(CRC)和非洲儿童权利和福利宪章（ACRWC），援助冠以OVC这个名称的儿童，使他们社区“向零艾滋迈进”的目标受到了关注。本章总结了所获得的经验，也指出了它们对实践、政策制定和学术等方面的启发意义。

Llegar a cero: Una conversación sobre la etiqueta 'NHV' y el bienestar de los niños en el África subsahariana

El impacto del VIH y SIDA ha recibido una gran atención en todo el mundo. Este capítulo se centra específicamente en el África subsahariana, una región devastada por la pandemia. Ponemos atención sobre las cifras escandalosas números de escalonamiento de niños afectados por el VIH/SIDA, que se estiman en 11 millones sólo en esta región. Se destaca la etiqueta 'niños huérfanos y vulnerables' (NHV), que se ha utilizado para clasificar a los niños afectados, para analizar su impacto en el bienestar de dichos niños, con atención a los desafíos implícitos en los sistemas de cuidado formales e informales. . . Basándose en la literatura, las políticas y programas de los NHV, así como la Convención sobre los Derechos del Niño (CDC) y la Carta Africana sobre los Derechos y el Bienestar del Niño (CADBN), se dedica atención a “Llegar a cero” en relación al cuidado de los niños etiquetados y sus comunidades. El capítulo concluye con las lecciones aprendidas y sus implicaciones en la práctica, la política y las becas.

ゼロにすること：ラベル『OVC』に関する会話とアフリカのサブサハラの子供たちの福祉

HIVとエイズによる影響は、世界全体から相当な関心を集めました。この章では、特にアフリカのサブサハラに焦点をあてます。感染の広がりや荒廃した地域です。HIVとエイズによって影響を受けた子供の驚くべき数に、注目を向けます。この地域だけで1100万人と推定されています。『孤児および立場の弱い子供たち』（OVC）というラベル（それは影響を受けた子供たちを分類するのに用いられました）に着目し、感染した子供の社会福祉に対するその影響を調べます。そして、OVCケアの公式および非公式制度に横たわる課題を強調します。OVC政策とプログラミングだけではなく、子供の権利条約（CRC）および子供の権利と福祉に関するアフリカ憲章（ACRWC）を標識文献とし依拠して、レッテルをはられた子供たちと彼らのコミュニティのケアに関して『ゼロとする』ことに注意を集中します。この章は、学んだ教訓および実践、政策と奨学金への意義で結びます。

L'atteinte de l'objectif zéro : Une conversation sur l'étiquette « OEV » et le bien-être des enfants en Afrique subsaharienne

L'impact du VIH et du Sida a reçu une attention considérable à travers le monde. Le présent chapitre met un accent particulier sur l'Afrique subsaharienne, une région dévastée par la pandémie. Nous attirons l'attention sur le nombre alarmant d'enfants affectés par le VIH/Sida, estimé à 11 millions

dans cette région uniquement. En mettant en avant l'étiquette « Orphelin et enfants vulnérables (OEV) » utilisée dans le classement des enfants affectés, nous examinons son impact sur le bien-être des enfants affectés. Les défis inhérents aux systèmes formels et informels de prise en charge des OEV sont mis en évidence. En nous inspirant de la littérature sur l'étiquetage, les politiques et programmes relatifs aux OEV, ainsi que de la Convention sur les Droits de l'enfance (CIDE) et la Charte africaine des Droits et du Bien-être de l'enfant (ACRWC), nous portons l'attention sur l'atteinte de l'objectif « zéro » concernant la prise en charge des enfants étiquetés et leurs communautés. Le présent chapitre conclut en présentant les enseignements tirés et leurs implications pour la pratique, la politique et les bourses d'études.

INTRODUCTION: OVERVIEW OF THE ISSUE

Worldwide, the issue of HIV and AIDS has received considerable attention since the first case of AIDS was reported in the early 1980s. Over the past two decades, progress has been made on the scientific front; the focus has been mainly on preventing and controlling opportunistic diseases. Indeed, interventions targeting prevention and treatment have been implemented, resulting in reduced HIV incidence and prevalence rates. Further, new HIV infections globally have declined by about 58% since 2000 (UNAIDS, 2015). In addition, the number of people living with HIV who are able to access and receive life-enhancing treatment in resource-constrained environments has increased (UNAIDS, 2015). Progress has also been reported with respect to preventing mother-to-child transmission of HIV and keeping mothers alive (UNAIDS, 2016b). In addition, the number of AIDS-related deaths has gone down considerably—a decline of about 42% since 2004, when it was at its highest (UNAIDS, 2016a). Attention has also been devoted to strengthening systems of care (Regien et al., 2009).

Despite this, the consequence of the epidemic, especially in countries where mechanisms for prevention, treatment and care are limited, continue to be felt. Data in place indicates that sub-Saharan Africa, one of the regions hardest hit by the epidemic, has experienced disproportional loss of individuals in their most productive years. This raises concerns over the welfare of surviving members of affected families, especially children (Averting HIV and AIDS [AVERT], 2015a, 2015b; Stover, Fidzani, Molomo, Moeti, & Musuka, 2008). According to AVERT (2015a, 2015b), sub-Saharan Africa alone accounts for about 85% of the global figure of children orphaned by AIDS. In response, individuals, communities and external actors—from

a grandmother in a remote village to the policy-maker in the city—have been mobilized to address the challenge. However, mainly because of the unprecedented numbers of adult deaths, reduced capacity of the extended family to cope and high levels of poverty, gaps in care are evident. To help capture the growing challenges of vulnerability experienced by affected children, the label OVC (orphans and vulnerable children) has been coined. This label has facilitated the implementation of programmes focused on mitigating the social malaise faced by children so classified. Children, however, continue to experience high levels of vulnerability, provoking further dialogue.

Through the years it has become apparent that the HIV and AIDS epidemic does not only affect the health of individuals, it also disrupts the welfare of households/families, communities and the development of nations (Collier, Manning, & Sterck, 2015; Mondal & Shitan, 2013; UNAIDS, 2010). Getting to Zero, in the areas of discrimination, prevention and care, will therefore require mending and even reweaving the social fabric that holds communities together. History, through the fight against polio and other major diseases, has taught us that humanity is at its best when we work together. Indeed, daunting tasks can be, and have been, accomplished with well-coordinated, targeted approaches that engage multiple stakeholders. Too many lives have been lost, potential squandered and possibilities unattained; social work can no longer afford to stand on the sideline. Social work has the mandate, political will and moral authority for accelerating efforts to get to zero.

Directing attention on sub-Saharan Africa, the objective of this chapter is to contribute to the conversation on the utility of community-informed interventions in Getting to Zero. Specifically, the chapter focuses narrowly on children affected by HIV and AIDS and uses the label OVC to highlight their plight. The discussion addresses the utility of the label and examines its impact on the welfare of affected children. Using social work lenses, the chapter draws upon the Convention on the Rights of the Child (CRC) and the African Charter on the Rights and Welfare of the Child (ACRWC; also known as the Charter) as well as policies and programming put in place to enhance the welfare of children classified as OVC. Attention is also placed on formal and informal systems of care. The chapter builds upon lessons learned and concludes with implications to guide social work practice, policy and scholarship. The premise advanced is that Getting to Zero is not merely a medical undertaking—it demands an integrated, strengths-based approach that takes into consideration the psychosocial aspect of the African context while maximizing effort from individuals, households and communities.

THE LABEL OVC AND GETTING TO ZERO

The origins of the label OVC are not well-known. Evidence exists to suggest that use of the label gained traction in the early 1990s, when the United Nations Children's Fund (UNICEF) hosted its first meeting focusing on the welfare of children affected by AIDS. The label was initially used to identify a child whose parent/s had died due to AIDS or related causes. This categorization, at that time, provided a platform for facilitating the development of holistic programming, targeting the needs of children who were affected by HIV and AIDS, ensuring that crucial needs were met and that resources and services reached those most in need (Handa, Devereux, & Webb, 2010).

Use of the acronym evolved to include children in dire situations (Ferguson & Heidemann, 2009; Kirkpatrick, Rojjanasrirat, South, Sindt, & Williams, 2012). The label is said to have broad appeal because it brings together efforts addressing factors associated with the optimal development of the child (World Bank, 2005) and takes into consideration the welfare of the child in relation to the rights guaranteed under the CRC, which are also articulated in the Charter (World Bank, 2005). Areas of concern that have been embraced include health, food, shelter, education, leisure and protection from abuse.

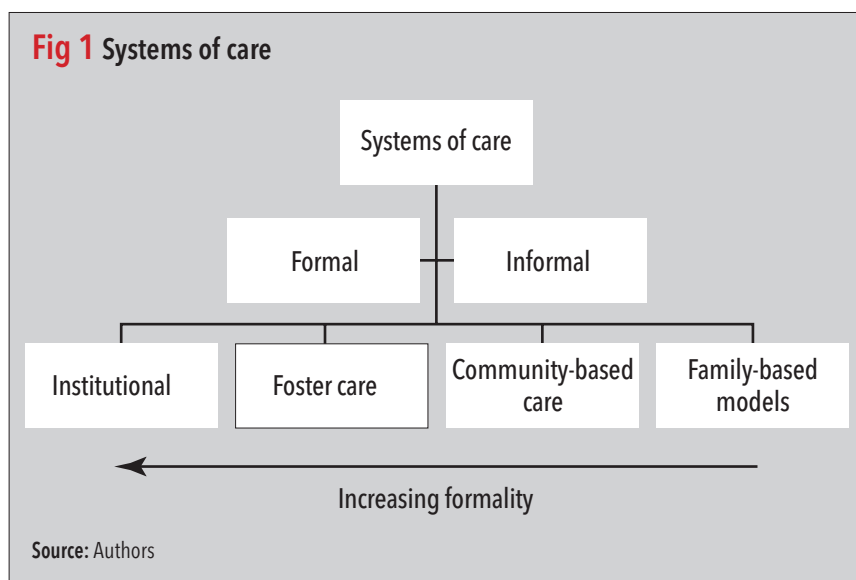
As debate over AIDS-related funding and programming intensified, the label OVC became a tool employed to call attention to the gravity of problems experienced by children affected by the epidemic, and their communities. It served as an instrument to mount pressure on governments so they could intervene in the plight of children so classified. The label also helped reveal the lack of capacity of the primary duty-bearers to respond adequately to the rights and needs of affected children.

Despite its promise to positively influence efforts to enhance the welfare of children classified as vulnerable, the label OVC may have unintended negative effects—compromising the life chances of affected children and the capacity to get to zero. For example, it may negatively influence the way labelled children interact with the world and vice versa. Indeed, children so classified may engage with the world from a position of diffidence, and the world may respond accordingly. In addition, the label may perpetuate the notion that children classified as vulnerable are inherently different from other children, heightening incidences of discrimination/otherization. Moreover, by drawing attention to the vulnerable status of children classified as OVC, the label may stall prevention efforts; labelled children may be perceived as alone—lacking adult support and protection—and may be exploited. Further, for many children given this label, vulnerability has become a state of being that they have not been able to move from.

In the light of the challenges alluded to in the foregoing discussion, Getting to Zero may require reconceptualization of perceptions of vulnerability, along with effort undertaken to address challenges experienced by labelled children and their communities. Utilization of characterization with forward-looking terms informed by communities may be a useful approach.

GETTING TO ZERO AND THE CARE OF CHILDREN CLASSIFIED AS VULNERABLE

Given that children classified as vulnerable are nested in families and communities, we locate the discussion of Getting to Zero within the systems that provide care, support and nurturing. Generally, the care of children classified as vulnerable in sub-Saharan Africa takes two forms: formal and informal care (see Figure 1). Formal care normally falls outside the traditional intervention provided by the immediate and extended family. Generally, services provided range from basic provisions (such as feeding programmes and respite) to a more complex continuum of services (such as system strengthening and cash transfers to meet basic needs) and social services, including immunizations and education, early childhood development interventions and prevention of acute vulnerability (Santa-Ana-Tellez, DeMaria, & Galárraga, 2011). Informal care, on the other hand, represents a private arrangement often located within the jurisdiction of the family and may include fostering by relatives



and grandparent-headed households, along with various forms of domiciles, such as child-headed households (Roby, 2011). It is important to point out that the two systems of care, formal and informal, often interface and feed into each other. It is therefore not uncommon to see children living on the street receiving food from feeding programmes as well as support from the community and extended family (Desmond & Gow, 2001).

Informal care

The burden of caring for orphaned children falls heavily on the extended family and communities. These account for about 90% of the total care of children classified as vulnerable (UNAIDS, 2010; UNICEF, 2005). The rationale is that in many parts of Africa, the extended family is seen as well-positioned to provide long-term, stable and balanced care for children in the absence of biological parents (UNICEF, 2011; International HIV/AIDS Alliance, 2014). Typically, Africans practise kinship care where the extended family may play an integral role in the nurturing of children; hence the adage, it takes a village to raise a child (Freeman & Nkomo, 2006; Maclean, 2003; Ndebele, Kasese-Hara, & Greyling, 2012). In fact, African history is alive with examples of provision of care and support to defenceless and susceptible groups, including children, the poor, the sick and the elderly. Strong familial and communal bonds are, in fact, at the core of Africanness, which is defined by the spirit of *Ubuntu*.

Although experiences of children within the informal system are not well-captured due to data shortcomings, there is some evidence to suggest that the consequences of the HIV and AIDS epidemic—loss of adults in their most productive years—has compromised the capacity of the familial system to provide adequate care (Taraphdar et al., 2011). Coupled with this is the lack of resources that define many households in the region. Furthermore, stories of abuses of children nested within the informal system of care are not uncommon.

The issue of child-headed households needs to be pointed out. This type of domicile defines a sibling-unit living under the care of an older child, who may be under the age of 18. Although child-headed households ensure continuity and emotional well-being, the normalization of permitting a sibling unit to live together in their home is problematic in that it places the responsibility to nurture children on the shoulders of another child. In fact, the evidence in place suggests that such households are often victims of abuse and multiple forms of exploitation (Nyamukapa et al., 2010). Despite the observed challenges, some characteristics of the informal system of care may provide important lessons in Getting to Zero (see Table 1, overleaf).

Formal care

This is characterized by a variety of living arrangements including statutory adoption, statutory residential care, orphanages and a hybrid of familial/community-based care. It is often organized under the umbrella of the label OVC. As is the case with the informal system, challenges are evident in the formal system of care. For example, programming that targets

Table 1 Informal care and areas of intervention

Strengths of familial system	Area of support	Intervention
Strong support system	<ul style="list-style-type: none"> ▪ Protection against abuse and discrimination ▪ Offers psychosocial and emotional support 	<ul style="list-style-type: none"> ▪ Educating primary stakeholders—communities and families—about challenges and benefits of stakeholding
Ability to keep children within community	<ul style="list-style-type: none"> ▪ Fosters identity ▪ Promotes cultural appreciation 	<ul style="list-style-type: none"> ▪ Educating stakeholders about the benefits of involving communities and families in the welfare of affected children
Ability to keep sibling units together	<ul style="list-style-type: none"> ▪ Ensures stability ▪ Fosters positive adaptation 	<ul style="list-style-type: none"> ▪ Providing families and communities with tools to enable them to become effective participants in the care and protection of affected children
Capacity to nurture within cultural context	<ul style="list-style-type: none"> ▪ Provides intergenerational transfer of values and social skills ▪ Sends strong message of unity, love and support 	<ul style="list-style-type: none"> ▪ Providing families and communities with tools to enable them to become effective participants in the care and protection of affected children

Source: Authors

children categorized as vulnerable tend to rely on the OVC label; this makes accountability problematic as the programmes attempt to respond to multiple stakeholders, including practitioners, communities and at times governments. Further, such programmes tend to focus on self-preservation, with little commitment to the well-being of affected children. Moreover, it has been argued that programming conducted under the label OVC may have contributed to the weakening of the familial bonds that defined African communities (Lombe & Ochumbo, 2015). Indeed, the label may have made it easier for both familial and communal systems of care to abdicate their responsibility, placing it on the shoulders of external entities, including international NGOs (Table 2).

Given the resources attached to the label OVC and the potential of programming carried out under its umbrella, important lessons can be drawn from OVC programming (see Table 2 for examples). An area of emphasis may be continuity in provision of social services. This effort could also incorporate authentic dialogue and bringing together multiple actors, including affected

Table 2 Formal care and areas of intervention

Strengths of formal systems	Areas of intervention
Offers comprehensive care-package	<ul style="list-style-type: none"> ▪ Extension of focus beyond affected children to including strengthening systems of care
Controls extensive resource and technical know-how	<ul style="list-style-type: none"> ▪ Incorporation of community voices and aspirations in planning and service delivery ▪ Strengthening community capacity for collaboration and agency
Has capacity to reach large numbers of affected children	<ul style="list-style-type: none"> ▪ Development of capacity for advocacy and networking—this has potential to reduce resource wastage ▪ Skills transfer to communities and opportunities for strengthening capacity for reflection and learning
Offers platform conducive to monitoring and learning	<ul style="list-style-type: none"> ▪ Showcasing good practice and providing positive models that can be adapted to informal settings

Source: Authors

children and their communities. Affected communities may lack resources, but they have aspirations for themselves and their children; their voices need to be incorporated in efforts to Getting to Zero.

HUMAN RIGHTS AND GETTING TO ZERO

The CRC and the Charter guarantee rights to children—all children irrespective of race, religion, sex, abilities/disabilities, family background, socioeconomic status, language, geographical location and/or culture. These instruments assert that children have rights to life, survival and development. They also underscore the importance of nondiscrimination for the optimal development of the child. Guiding principles for all stakeholders when making decisions that affect the welfare of the child rest primarily on the best interest of the child. Children who have been made vulnerable by the AIDS epidemic still have the rights guaranteed under the CRC and the Charter. These rights, in fact, provide nations and communities with a yardstick stating milestones to be realized, and may be useful in Getting to Zero. In this discussion, we highlight only a few provisions, including the question of definition, the right to a family environment and the right to health and education. This is intended to underscore the interdependence and indivisibility of human rights—the principle that realization of one does not take away from attainment of other rights.

The question of definition

With respect to the issue of definition, the main question addressed is, who is a child in the context of sub-Saharan Africa? The CRC defines a child as “a person below the age of 18, unless the laws of a given country sets the legal age for adulthood younger [...]” (UNICEF, 1990, p. 1). The World Bank defines a child as a person aged 0 to 14 years, differentiating this group from youths, people aged 15 to 24 years (World Bank, 2005). Providers of services for children classified as vulnerable further problematize this by delineating childhood using a variety of standards. For example, among orphaned children the age for child is set at 14 years and under, for street children it is 18 years, and for child soldiers it is 18 years and under.

Moreover, variations in definitions of child exist among African countries and, indeed, within nations. Botswana, for instance, in its Children’s Act of 2009 defines a child as anyone under the age of 18 (Botswana Parliament, 2009). Its Adoption Act of 1952, in contrast, identifies a child as anyone under

the age of 19. Furthermore, the Botswana constitution sets the age of maturity at 21 years, yet legal provisions only allow prosecution for defilement for a girl aged 16 and under. Zambia faces similar ambiguities in definitions of child. These arise mainly from its dual legal system that permits application of customary and statutory law simultaneously. Customary law defines a child as anyone who has not yet attained the age of puberty—generally understood to be below the age of 14. Article 45 of the Constitution of the Republic of Zambia, however, defines a child as anyone under the age of 18. In contrast, the Marriage Act sets 21 as the age of legal sexual consent; whereas the penal code criminalizes carnal knowledge of a girl under the age of 16. Furthermore, customary law allows marriage, with the consent of parent or guardian, for a girl at the age of 14. Who is a child in this context?

The observed lack of clarity in definitions is problematic. By failing to clearly demarcate what constitutes a child, policies and regulatory frameworks may be misinterpreted, compromising the welfare of children. Programming that targets children classified as vulnerable may also hide behind the confusion and discriminate against older children. Furthermore, ambiguities surrounding the definition of a child may be detrimental to children's realization of rights guaranteed to them under both the CRC and the Charter. Indeed, by legally placing older children outside the protection accorded to all children, they may be made vulnerable for recruitment into armed conflict, forced into early marriages, be trafficked and/or forced into the labour market.

In the light of the observed challenges, a useful starting point in efforts to target the welfare of children may be implementation of a common definition of child. This may involve alignment of various articles that govern the welfare of children, making it easier for children to claim their rights and duty-bearers to respond.

Family environment

The CRC recognizes the need for children to develop in the context of a family setting, citing care provided by biological parents as ideal. Article 5 of the CRC also requires parties to respect the responsibility of the immediate family and/or community to exercise their rights and duties to care for the child. Furthermore, through advocacy over the years, most countries in the region now plan and deliver family-centred and protective services for affected children in line with the principles of the Child Rights Act (UNICEF, 2012, p. 12). Several sub-Saharan African countries, such as Ghana, Côte d'Ivoire, Sierra Leone, Niger and Tanzania, to name a few (UNICEF, 2012, p. 25), have developed promising strategies to strengthen systems that work

to prevent and respond to the challenge of abuse, exploitation and care, not just for children affected by AIDS but also in response to other forms of violence against children in general.

Despite these provisions, the family environment is not always seen as ideal by formal service providers, who prefer institutionalization and supported living facilities as alternatives. Justifications for this are many. For example, it has been argued that institutionalization allows for targeting, ensuring that resources reach intended recipients. Indeed, monies tagged for education for children in a family environment may be diverted to household and other needs.

Furthermore, labelled children nested in this environment often experience unfair treatment expressed in unequal distribution of household chores, preferential treatment of biological children and discrepancies in disciplining. Children in the care of familial/extra familial entities are also known to suffer various forms of exploitation. This is especially true for young girls, who may be at risk of sexual exploitation/abuse at the hands of the people who are supposed to protect and care for them (Morantz et al., 2013).

Health care

There is some evidence to suggest that children affected by HIV and AIDS have limited access to health care and immunization services, making them susceptible to diseases including opportunistic infections. Also, they generally do not receive attention for emotional needs, such as trauma, depression and related mental-health problems. In the case of health care, it is important to understand that in most of sub-Saharan Africa health care is generally reactionary and not preventative. Due mainly to limited resources, seeking treatment may not be a priority for many. Opportunistic diseases are often left untreated, resulting in prolonged suffering, trauma and premature deaths (Cluver, 2011).

Education

The CRC and the Charter guarantee children the right to education, making withdrawal from educational pursuit problematic. Completion of both basic and secondary education is essential, not only for the welfare of the child but also for society as a whole. As the saying goes, school protects children from society and vice versa (Dewey, 1907). Indeed, for affected/infected children, school is an important source of respite, protection, leisure and even nutrition.

Despite this, numerous examples exist where children have been taken

out of school to help with household chores or become involved in income-generating activities, and even to be placed into early marriages for monetary gain. Drawing upon evidence pointing to the association between educational attainment and productivity, interventions are needed to ensure that children classified as vulnerable stay in school. School-related feeding programmes provide a useful platform to build upon.

Synthesis

The main challenge to the provisions of both the CRC and the Charter lies at the community level: these provisions are not fully operationalized, nor are they well-known by primary stakeholders—entities responsible for the care of children (Olagbuji & Okojie, 2015). The CRC and the Charter tend to operate at the administrative and planning level, with little interaction with communities affected by HIV and AIDS. This omission tends to compromise the role of family, both immediate and extended, along with communities, in the care of affected children. To get to zero, the CRC and the Charter may need to be interpreted at different levels and with the involvement of multiple actors, including affected families, communities and, indeed, the children themselves (UNAIDS, 2010). Lessons learned from the experiences of affected children and their communities—from both the CRC and the Charter—may provide valuable points for reflection. This is a recognition of the fact that the CRC and the Charter, like other human rights instruments, are written in the name of the people, including children. Effort could focus on documenting and replicating effective interventions that draw upon human rights. Questions that may need to be addressed include the role of human rights in ensuring access to resources and accountability from primary duty-bearers. With respect to human rights, the issue of awareness and/or the lack of this may need to be examined so as to make rights both accessible and useful to the right-holder. This may be particularly important in sub-Saharan Africa, where children are not generally seen as subjects of rights; their rights are not acknowledged or promoted and are often not realized (Table 3, overleaf, provides examples of initiatives that could be undertaken).

WAY FORWARD: SOCIAL WORK AND INNOVATIVE RESPONSES TO GET TO ZERO

Through the years it has become apparent that Getting to Zero is not just a medical undertaking; it is also a social enterprise that requires attention from

Table 3 Human rights initiatives and Getting to Zero

Proposed initiative	Activities
Increased advocacy and awareness-raising efforts	<ul style="list-style-type: none"> ▪ Target duty-bearers including government, family and community for awareness-raising campaigns so they are aware of rights and responsibilities to the right-holder—important for accountability
Making channels of redress accessible	<ul style="list-style-type: none"> ▪ Make channels of redress accessible to rights-holders. Develop capacity of right-holder to make a claim to the people with the responsibility to fulfil claimed right/s ▪ Implement context-specific strategies that are appropriate for the child. These could reflect different levels and dimensions
Implementation of accessible and user-friendly strategies	<ul style="list-style-type: none"> ▪ Provide useful platforms for data collection and use to allow for assessment of community performance ▪ Attach required resources to these
Development of mechanisms for reinforcement	<ul style="list-style-type: none"> ▪ Provide legal aid for orphans and vulnerable children in seeking legal redress when their rights, including property inheritance rights, are violated

Source: Authors

multiple actors. Social work practitioners are well positioned to play key roles in this fight; they are at the front line and understand factors prevailing in the social environment in which interactions with the epidemic are contested/played out. Furthermore, the profession appreciates the interconnectedness among the three goals—zero new infections, zero discrimination and zero deaths. Social work also recognizes that Getting to Zero among children will require Getting to Zero in other segments of the population, especially among adolescent girls and young women—some of the most vulnerable groups. This part of the discussion draws upon initiatives that have been implemented over the years to address the plight of children affected by the

epidemic and provide some useful guidelines in Getting to Zero. Attention is devoted to three pillars—practice, policy and scholarship—because these interact to shape responses to social reality and therefore may be crucial in the effort to get to zero.

Practice

Guided by the assumption that sustainable solutions to challenges presented by the HIV and AIDS epidemic may reside within communities, Getting to Zero may require entering into a social contract with communities and unleashing the power of communities to act—committing resources to particular aspects of the AIDS response and seeing through speedy implementation (UNAIDS, 2010). The goal here is to recreate the spirit of *Ubuntu* that has been at the core of Africa’s survival for generations. It is also a recognition of the fact that communities in sub-Saharan Africa are uniquely positioned to lead the fight to Getting to Zero; they are the primary custodians of children nested within them.

With respect to addressing gaps in the care of children classified as vulnerable, given the daunting numbers of orphaned children it is tempting to look for solutions outside of communities. However well-meaning, external actors may not fully grasp the realities of the local environment. For instance, they may not appreciate that the loss of *Ubuntu* and the ensuing moral decay evident in many parts of sub-Saharan Africa are, perhaps, the single largest deterrent to Getting to Zero. *Ubuntu* suggests that my humanity is inextricably bound to yours—as such we can only be human together (Bhengu, 2006). It is apparent today that *Ubuntu*, the glue that bound communities together and protected children from societal evils, has been severely compromised, unleashing malevolence on groups considered vulnerable, especially children. Indeed, as the adage goes, it used to take a village to raise a child—those days are no more!

The HIV and AIDS epidemic has ushered in a new era, redefining the way Africans relate to groups seen as vulnerable. Duty-bearers have abdicated their responsibilities to nurture and protect. Productive assets are taken away from children by relatives putting the term property grabbing into effect. Today, communities shamelessly point out their child-headed households; yet in many parts of the world, children under the age of 15 are rarely left without adult supervision for extended periods of time. It is on their shoulders that sub-Saharan Africa has placed the responsibility to nurture and raise other children. We lament the loss of *Ubuntu*!

A useful tool that communities can employ to get to zero gaps in care may

be shaming. Communities have used and can use shaming as a powerful tool to deter individuals who would neglect their responsibilities towards children or people who would harm them physically and/or emotionally. Communities could be encouraged to share stories through truth-telling gatherings, modelled after the truth-and-reconciliation tribunal initiatives implemented in Rwanda and South Africa. For example, heads of households that have taken in orphaned children could be encouraged to give accounts of how they are handling their responsibilities—challenges faced and support needed. Children in their care could also be given an opportunity to tell their truth. This may provide space for emotional support and may be a useful mechanism to enhance the quality of care provided to children made vulnerable by HIV and AIDS.

Shaming can deter risky behaviours in youth and promote positive adaptations, minimizing exposure to HIV. Youth, a group highly susceptible to HIV and AIDS, often find themselves caught up in practices such as intergenerational sexual relationships and the sugar-daddy phenomenon, placing them at higher risk of infection. A primary correlate of this behaviour is said to be poverty and growing materialism. It is common knowledge that adolescent girls and young women engage in transactional sexual affairs for material gain, such as data and airtime or the latest electronic gadgets. It should be noted, however, that such relationships are complex, often mixed with expectations of material exchanges as inherent components of sexual relationships. Appropriate naming and shaming could be targeted at behaviours of both men and women that are risky, such as having unprotected sex with multiple partners. Communities could devise appropriate mechanisms for naming and shaming. As observed (Knoops, 2006), the truth-and-reconciliation tribunals or commissions that research and report on cases of rights abuses may offer some valuable lessons in this regard.

Another area that requires attention at the community level is addressing discriminatory practices that currently exist towards children living and affected by HIV. Evidence exists to suggest that children, especially those classified as vulnerable, are discriminated against in homes, education and health, to name a few areas. For these children, discrimination is said to be rooted in the label of OVC itself, which is seen as a heavy burden for classified children to carry given that it tends to emphasize their so-called otherness and their vulnerabilities. Achieving zero discrimination may require an appreciation of the role communities can play in this struggle—starting with the identification of positive characterization.

With respect to programming that targets children classified as vulnerable

and their communities, we call for approaches that reflect the challenges of the local environment. Positive lessons could be gleaned from models that have been implemented, including the system strengthening approach. Social work practitioners, and other actors, may need to understand that the battle of Getting to Zero in the areas of discrimination, prevention of new infections and care of affected children will be won primarily in the trenches of African villages and cities—by Africans themselves. Useful interventions may be those that appreciate community strengths and capabilities.

Models that focus on institutionalization are useful as they allow for targeting children classified as vulnerable to access specialized services. This approach, however, has the potential to heighten difference, leading to discrimination/otherization of service recipients. Social work could lead an effort to forge collaborations between external and institutional actors and affected communities to enable provision of differentiated services. Some children may need more than one form of care in their life-cycle, depending on individual circumstance, and the system best able to provide such support, whether family, community and/or formal institution, should be encouraged to provide the appropriate care. The goal is to develop a menu of services for children and to strengthen the community's capacity for agency and referral.

Given the strong correlation between poverty, inequality, risk of HIV infection and HIV-related deaths, prevention efforts could incorporate social protection, care and support, and poverty-alleviation initiatives, thus strengthening the capacity of communities to realize their aspirations and full potential. Attention could be focused on adolescent girls and young women, a group said to be disproportionately represented among people in poverty.

Policy

Responsive policies are needed to facilitate Getting to Zero. In the face of massive challenges, it may be tempting to develop broad, sweeping policy statements that do not fully capture the realities of the local environment. For instance, faced with the issue of property grabbing, it may be appealing to develop policies with the potential to curb this practice, for example encouraging making wills. In advanced-market-economy countries making wills is a part of everyday life, but this practice is uncommon in most of sub-Saharan Africa. Although this is changing, anecdotal evidence suggests that people in the region's poor communities do not make official wills because of low literacy rates, little or no knowledge of inheritance laws and/or a general fear of the legal system. Further, cultural reasons, such as discouraging

planning for eventualities like death, may influence such decisions. For instance, there is a belief among the Ganda people of central Uganda that talking about death equals inviting death itself. Indeed, it is considered culturally insensitive to plan for someone's death even when it is evident that the person is dying, leaving orphaned children susceptible to property grabbing. Given the importance of familial assets in the welfare of children classified as vulnerable, social work could lead efforts to explore culturally appropriate approaches for handling property, leading to formalization of community-driven policy decisions. This has the potential to deter would-be property grabbers and produce contextually relevant policies.

Guided by the knowledge that many countries in sub-Saharan Africa lack a clear standard to delineate childhood, a useful contribution to Getting to Zero may be a conversation on the definition of a child. This may also involve addressing some of the shortcomings evident in the way African communities engage with children, creating a shift in the way duty-bearers—families, communities, governments and international organizations—perceive and relate to children. Effort could go into enactment of policies that put children at the centre. This perspective is, in fact, articulated in both the CRC and the Charter.

Drawing upon lessons learned from the near-eradication of polio, Getting to Zero in sub-Saharan Africa may require a well-articulated and coordinated policy initiative. Social work could focus on supporting evidence-informed policies—policies backed by sound research evidence that accurately reflect the local reality and that draw upon best practices, ensuring that the decision-making process is guided by the best available research and practice evidence. Policies with the potential to promote coordination of key actors under the mandate of a central body, which could be a government ministry, should be encouraged. We further argue for a policy-making process that is transparent and accessible. This has the potential to foster stakeholding, and reduce duplication and resource wastage.

Scholarship

In relation to scholarship, we focus narrowly on two areas: 1) research to guide implementation of interventions with great potential to support Getting to Zero; and 2) systematic monitoring and evaluation of programmes and policies. This view is premised on the assumption that research produces the most reliable knowledge of whether a given strategy will produce desired outcomes, and that interventions informed by evidence are likely to be responsive to local reality if they are effectively monitored.

Useful approaches to get to zero may be based upon lessons garnered from best practices and implementation of interventions guided by relevant theoretical perspectives. The Positive Deviant (PD) theory may offer useful insight in this regard. This theory is premised on the assumption that when faced with the same or similar problems, in every community there are individuals and/or groups who exhibit uncommon behaviours and strategies to find better responses to the problem than their peers, while accessing the same resources (McNeese, 2013). Although the PD theory has not been employed to guide community-based interventions with an HIV focus, it has merit and may help identify and document contextually relevant strategies used by PDs (individuals, households and communities) to navigate the risks associated with HIV and AIDS. For instance, although Senegal and Swaziland have similar characteristics, including high rates of poverty, Swaziland exhibits a higher HIV prevalence rate—28.8% for adults aged 15 to 49—while Senegal reports a lower prevalence rate, estimated at 0.5% (UNAIDS, 2015). This observation begs a number of questions: specifically, how has Senegal maintained a low HIV prevalence rate? Could this be explained by contextual factors—cultural, economic, governmental or religious? What lessons can Senegal offer the rest of sub-Saharan Africa? The same argument can be extended to individual, household and community levels.

With respect to monitoring and evaluation, the absence of useful data warrants attention. While to some extent quantitative data exist, these are often not readily available. Furthermore, data on the psychosocial dimension of children's lives and the lived experiences of their communities are hardly the focus of data-collection efforts. For the most part, data on children also tend to be aggregated. Social work practitioners are well placed to lead efforts to collect quality data disaggregated by gender and other useful categories. These data could also incorporate the lived experiences of children and communities made vulnerable by HIV and AIDS. Such effort could be guided by community-informed indicators and/or measures, enhancing the capacity of communities for learning; it may influence community stakeholding and involvement in evidence-informed policies and practice.

CONCLUSION

Getting to Zero will require a paradigm shift, starting with the conceptualization and implementation of initiatives that view communities as social actors with the potential to influence outcomes in their favour. This may involve entering into a social contract with communities, including

youth and adults, so that all are part of the agenda and aspiration to get to zero. This effort could be guided by evidence-informed policies and practices that reflect local realities. Such undertakings may also demand taking into consideration human dignity, and paying deliberate attention to the responsibilities and obligations of key actors—both helpers and children classified as orphans and vulnerable. Past events have taught us that there is no limit to what can be accomplished when the power of community is unleashed. African communities have shown remarkable resilience in dealing with natural disasters, such as floods, famines and droughts. With financial assistance, political commitment and will, they are capable of effectively contributing to efforts to get to zero.

Models that incorporate lessons learned from the lens of children affected by HIV are needed. Their experiences are a valuable source of data. This agenda may demand a shift in perceptions of children—to start looking at children as subjects of rights whose points of view deserve attention and respect. This call does not in any way disregard the role of government, culture and community in the welfare of children. To the contrary, it underscores the detrimental effect of the subordinate position of children on both society and the welfare of children.

This chapter calls for authentic collaborations between actors, both local and external. Social work practitioners, both local and external, have an important role to play: they have critical resources and the technical know-how. Nevertheless, the agenda of Getting to Zero should be locally inspired—locals live with the devastation of the epidemic. Essential ingredients for authentic collaboration, in our view, include the capacity to listen to and respect local voices, the patience to learn from and efforts to bring together different actors to find long-term local solutions and the ability to reflect on both challenges and successes.

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**Challenges
experienced by social
workers in placing
children living with
HIV in foster care in
Johannesburg**

Babbot Muchanyerei and Nontembeko Bila



ABSTRACTS

Children constitute a substantial percentage of South Africa's population. The high rate of HIV infection has, however, exposed these children, particularly those already in need of care and protection, to a number of predicaments, among them the failure to secure suitable foster care. Nonetheless, foster care is still the most viable option in South Africa in the event that natural family care fails. Utilizing a qualitative approach through focus-group interviews with designated social workers and foster parents, this study sought to investigate the challenges faced by social workers in placing children living with HIV in foster care in Johannesburg. Findings revealed numerous fears and challenges regarding the foster-care placement of children living with HIV. The challenges in placing children living with HIV in foster care are a result of a complex combination of factors. Recommendations are made to improve the placement of children living with HIV in foster care.

约翰内斯堡市社会工作者在寄养所安置儿童艾滋病患者时所面临的挑战

南非人口中儿童占相当的比例。然而，较高的艾滋病感染率使这些孩子，特别是那些需要照顾和保护的孩子，陷入到一些困境中，这些困境包括不能获得合适的寄养。尽管如此，在自然家庭照顾缺失的情况下，在南非寄养仍然是最可行的选择。本研究利用定性研究的方法，以焦点小组的方式对特定的社会工作者和寄养父母进行访谈，希望找出约翰内斯堡市社会工作者在寄养所安置儿童艾滋病病毒携带者时所面临的挑战。调查结果显示，在寄养所安置儿童艾滋病病毒携带者时存在大量的恐惧和挑战。这些挑战是由诸多复杂因素所引起的。本文针对改善儿童艾滋病病毒携带者在寄养所的安置状况提出了若干建议。

Obstáculos experimentados por los trabajadores sociales al colocar a niños que viven con el VIH en adopción en Johannesburgo

Los niños constituyen un porcentaje sustancial de la población de Sudáfrica. Sin embargo, la alta tasa de infección por VIH ha expuesto a estos niños, en particular los que ya tenían necesidades de cuidado y protección, a una serie de situaciones difíciles, entre ellos el fracaso para asegurar una atención adecuada de adopción. No obstante, la adopción sigue siendo la opción más viable en África del Sur, en el caso de que falle el cuidado natural de la familia. Utilizando un enfoque cualitativo a través de entrevistas de grupos de debate con trabajadores sociales designados y los padres adoptivos, este estudio trata de investigar los obstáculos a los que se enfrentan los trabajadores sociales al colocar los niños en adopción que viven con el VIH en Johannesburgo. Los resultados revelaron numerosos temores y obstáculos en cuanto a la colocación en adopción de los niños que viven con el VIH. Los obstáculos son el resultado de una compleja combinación de factores. Se hacen recomendaciones para mejorar la colocación en adopción de los niños que viven con el VIH.

ヨハネスバーグでHIVに感染している子供たちを、里子として縁組する際に、ソーシャル・ワーカーが経験した課題

子供たちは、南アフリカの人口の相当な割合を構成しています。しかし、HIVの高い感染率により、ケアと保護を必要とする子供たちは特にいくつかの苦境にさらされ、その子供たちの中には安全で適当な里子の養育を受けることができないものもありました。それにもかかわらず、生まれた家庭での養育ができない場合、里子としての養育はまだ南アフリカで最も現実的なオプションです。指定されたソーシャル・ワーカーと養父母のフォーカスグループ・インタビューを通し、定性的なアプローチを利用して、この研究は、ヨハネスバーグでHIVに感染している子供たちを里子に出す際に、ソーシャル・ワーカーが直面する課題の調査を試みました。調査結果では、HIVに感染している子供たちを里子に出す際の多数の懸念と課題が明らかになりました。それらの課題は、複数の要因が複雑に合わさった結果です。HIVに感染している子供たちの縁組を増進するための推奨を提示します。

Les défis rencontrés par les travailleurs sociaux dans le placement des enfants vivant avec le VIH en familles d'accueil à Johannesburg

Les enfants représentent un pourcentage important dans la population sud-africaine. Cependant, le taux élevé d'infection au VIH a exposé ces enfants, notamment ceux ayant déjà besoin de la prise en charge et de la protection,

à un certain nombre de situations difficiles, notamment à l'échec à sécuriser des familles d'accueil appropriées. Néanmoins, les familles d'accueil sont l'option la plus viable en Afrique du Sud, en cas d'échec de la famille naturelle. Grâce à une approche qualitative par des interviews des groupes de discussion avec les travailleurs sociaux et les parents d'accueil désignés, la présente étude s'est efforcée d'analyser les défis auxquels les travailleurs sociaux sont confrontés dans le placement des enfants vivant avec le VIH en familles d'accueil à Johannesburg. Les résultats obtenus ont révélé la peur et les nombreux défis liés au placement des enfants vivant avec le VIH en familles d'accueil. Les défis liés au placement des enfants vivant avec le VIH en familles d'accueil sont le résultat d'une combinaison complexe de facteurs. Des recommandations sont formulées afin d'améliorer le placement des enfants vivant avec le VIH en familles d'accueil.

INTRODUCTION

HIV does not only affect individuals' immune systems, it also has a profound impact on people's belief systems, as well as their social, sexual, economic and political lives (Van Dyk, 2012). It is undisputed that Africa continues to be heavily affected by HIV, and children are always at the receiving end of the devastating effects of the epidemic (Mwebembezi, 2016; World Health Organization, 2015). When family care is inadequate, the onus is on other members of society to care for children. This is the case because negative experiences in childhood can have long-term effects into adulthood, and on the future of a society (Deacon & Stephney, 2007). Therefore, it is vital to secure alternative placement for children living with HIV who need care and protection. Thus, foster care has become an alternative form of care in both developed and developing countries.

Nonetheless, some prospective and existing foster parents remain sceptical and reluctant to foster children living with HIV. Among many people, there is a perception that the child will eventually die and the foster family will have to bear the emotional consequences and the cultural responsibilities associated with the death of a family member (Mupedziswa, 1995). These sentiments are not baseless, given that foster parents develop meaningful relationships with the children in their care (Johannesburg Child Welfare, 2013). This chapter, therefore, seeks to establish some of the challenges faced by social workers, as well as the views of foster parents, regarding the placement of children living with HIV in foster care.

BACKGROUND TO THE STUDY

HIV infection has left many South African children's futures in uncertainty (Deacon & Stephney, 2007). Nationally, of the estimated 6.4 million people who were living with HIV by the end of 2011, about 460 000 were believed to be children (Human Sciences Research Council, 2014; UNAIDS, 2012). Although there has been a substantial decline in mother-to-child transmission of HIV lately, the number of children living with the virus remains an area of concern (Human Sciences Research Council, 2014).

HIV and AIDS in children result in medical and social problems that cannot be overlooked (Cohen & Nehring, 1994). One of the most troubling effects of the HIV and AIDS epidemic is that it leaves many children orphaned and infected with the virus. These children face an uncertain future, thus disrupting their lives, especially where there are no means to assist them (De Jager, 2011). The provision of alternative care has become an acceptable option for many governments, including the South African Government. Foster care is one such option of alternative care for children in need of care and protection, inclusive of those living with HIV. Based on their work experience, the researchers were perturbed by the increasing number of designated social workers in the Johannesburg area seeking placements in child and youth care centres for children diagnosed with HIV, and the subsequent institutionalization of these children. Simultaneously, institutionalized children are also struggling to secure foster parents once the social workers disclose the child's HIV status to the prospective foster parents. If this trend continues unabated, UNAIDS' Getting to Zero Strategy will remain a mammoth task to achieve in South Africa.

Special needs of children living with HIV who are in need of care and protection

It is essential to stress that living with HIV and being a child in need of care and protection at the same time is not easy (UNAIDS, 2001). Children living with HIV and their families or caregivers often find themselves in complex situations as they try to navigate their "illness and treatment as well as the adverse psychological circumstances and poverty in which many live" (Vranda & Mothi, 2013, p. 19). In addition to health needs, such as regular medical attention and good nutrition, Vranda and Mothi add that children living with HIV are also subjected to life stressors such as illness and death of parent(s), stigma and discrimination, abuse, loneliness and isolation, and family conflict and disintegration. Depending on the child's age, disclosure

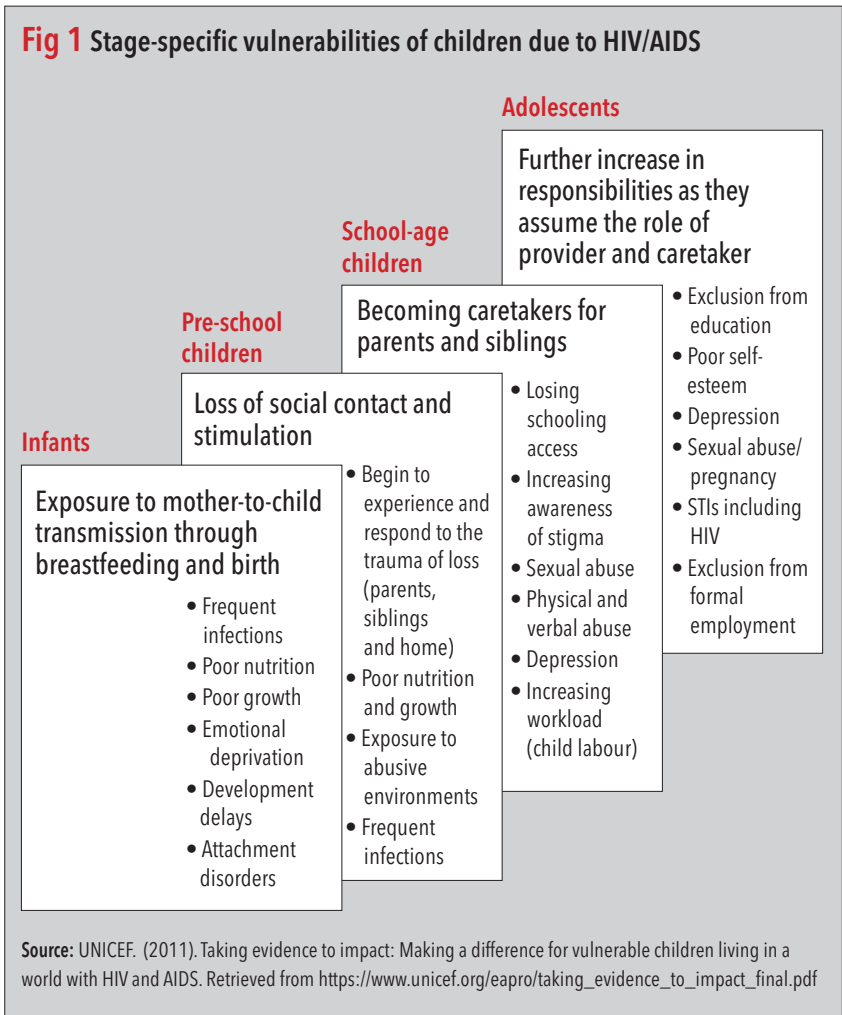
of one's HIV status to peers, friends and significant others can be troubling. Consequently, children with chronic illnesses in general, and those living with HIV in particular, are at greater risk for psychiatric problems and psychological distress, including depression, anxiety and feelings of isolation (Department of Social Development [DSD], 2011; Vranda & Mothi, 2013). Depression and anxiety may, as a result, undermine adherence to treatment (Mukasa & Namuwonge, 2016).

Ross and Deverell (2010) point out that although many chronic illnesses are stigmatized, HIV carries a double stigma—that of being a terminal illness and a sexually transmitted disease. As a result, many children living with HIV and their families prefer to live in what Vranda and Mothi refer to as a “conspiracy of silence” and shame (2013, p. 21). The children and families become “withdrawn, socially isolated and emotionally cut-off from traditional support systems” (p. 21). This self-imposed secrecy and reaction to social stigma “may preclude families from procuring necessary treatment and seeking assistance with permanent planning for infected children, and obtain needed forms of social support” (Vranda & Mothi, 2013, p. 22). Nevertheless, as children living with HIV move through adolescence and become sexually active, disclosure to friends and significant others becomes vital. These children require significant support through continuous education so that they can manage the complex issues of integrating healthy sexual development with living with HIV, as well as making informed decisions regarding their actions and life choices (Vranda & Mothi, 2013).

Research has established that psychosocial support is critical for the health and development of children living with HIV, as this may increase treatment adherence (DSD, 2011; Van Dyk, 2012; Vranda & Mothi, 2013). At this juncture, it is worth stressing that psychosocial support for these children's caregivers is equally essential, since caring for a child living with HIV is a gargantuan and stressing task (Charlesworth & Newman, 2006; UNAIDS, 2001). The caregiver or foster parent of a child living with HIV deals with crisis, illness, lack of resources and social isolation. Therefore, these caregivers or foster parents need medical, psychological and social services (UNAIDS, 2001; Vranda & Mothi, 2013). Vranda and Mothi (2013) propose interdisciplinary interventions oriented to improving the quality of life for these children and their caregivers. They also advocate for family-centred approaches to address family stressors and adaptation and cultural factors affecting the whole family, as well as connecting the family to services, community resources and respite care through case management. All of this needs to be done within an empowerment framework.

The South African Government recognizes that the psychosocial support

of children affected by HIV and AIDS is fundamental and has formulated various policies to this effect. The DSD (2011) identifies core principles that underpin psychosocial care and enhance the psychosocial well-being of all children, including those living with HIV. These principles are: protection from harm; the best interests of the child; child participation; family-based care, *Ubuntu*, social and community integration; social development; inter-sectoral collaboration; mainstreaming psychosocial support; prevention; cultural appropriateness; gender sensitivity; and age and developmental appropriateness (DSD, 2011). Through the Children’s Act No. 38 of 2005 (as amended) and other policies, the South African Government has ensured that the above principles are respected.



Policies regarding foster care of children living with HIV in South Africa

The United Nations Convention on the Rights of the Child (CRC) and the African Charter on the Rights and Welfare of the Child (the Charter) are some of the international and continental legal documents that set minimal acceptable standards for the well-being of all children (UNAIDS, 2001; Van Dyk, 2012). The South African Government is a signatory to both the CRC and the Charter, committing itself to conform to their guiding principles.

In short, both the CRC and the Charter recognize that all children have the right to survival, protection, development and participation (Smart, 2003; Van Dyk, 2012). This includes children living with HIV. Both documents further recognize the importance of a family environment in the healthy upbringing of a child. As such, foster care remains an important option when natural family care fails, despite the challenges faced by designated social workers in placing children living with HIV in foster care.

The Sustainable Development Goals (SDGs) adopted by Member States in 2015 also play a pivotal role in the achievement of the Getting to Zero Strategy. Although the SDGs should not be viewed independently of each other, SDG 3 speaks directly to the health needs of all, including people infected and affected by HIV and AIDS. Among the issues addressed by SDG 3 are efforts to end paediatric HIV, as well as addressing gender-based inequalities, exclusion, discrimination and violence (United Nations, 2016).

To show its commitment to children's rights and the guiding principles of both the CRC and the Charter, the South African Government put in place a piece of legislation on children that emphasizes the best interests of the child as well as participation in decisions that concern the child (UNAIDS, 2001). This legislation is also in line with the SDGs. The Children's Act No. 38 of 2005 (as amended) ensures that the rights of all children, including those living with HIV who need care and protection, are not infringed. Such legislation is meant to empower vulnerable children by addressing stigma, discrimination and labelling, which operate against these children's well-being (Vranda & Mothi, 2013). Similarly, the placement in foster care of children in need of care and protection is meant to protect the child's right to survival, protection and development (Van Dyk, 2012).

In spite of the obvious strengths of the Children's Act No. 38 of 2005 (as amended), there are also some loopholes with regard to the placement of children living with HIV in alternative care. The said Act vaguely mentions in Section 156 1 (g)(i) and (ii) that a children's court may issue an order placing a child found to be in need of care and protection in a facility, provided that the court finds that the child has "a physical or mental disability or

chronic illness” and if it is in the best interests of the child to be cared for in such a facility. It remains a matter for conjecture whether HIV is among the chronic illnesses referred to in this section of the Act. Moreover, it is debatable whether such facilities exist in many parts of the country and/or are adequately equipped to deal with children living with chronic illnesses such as HIV.

Foster care remains the most viable option for the care of children in the event that family care fails in South Africa (Johannesburg Child Welfare, 2013; Mawere, 2009). The intention is that, in liaison with social workers, the foster parent/s will be able to provide adequate care and protection for these children, thus filling the gap left by the children’s biological parents (De Jager, 2011). Available literature on foster care states the important aspects of effective foster care. In their conclusions, De Jager (2011), Kganyago (2006), Manukuza (2013) and Swanepoel (1999) concur that a lot still needs to be done in order to improve the current foster care system within South Africa.

Approximately more than half a million children are currently in foster care in South Africa (Dlamini, 2014; Skelton, 2012). Nevertheless, a review of the literature on policies revealed that there are no specific policies and services in South Africa regarding the recruitment and special training of prospective foster parents of children living with HIV. The current policies and legislation in South Africa do not adequately address the plight of children living with HIV in terms of securing suitable foster-care placement. In other words, HIV-positive children are regarded as akin to other children in need of care and protection, in spite of clear evidence that these children have unique and specific care needs (De Jager, 2011; Warwick, 2013). Added to these needs are issues of stigma and fear (Deacon & Stephney, 2007; Warwick, 2013) that could influence potential foster parents’ willingness or unwillingness to foster. Generally, there is a shortage of foster parents in South Africa (Mawere, 2009; Skelton, 2012; Swanepoel, 1999). Thus, the children’s unique needs and the associated stigma and fear further complicate the situation of securing foster parents for children living with HIV.

METHODOLOGY

Research questions

The study’s primary research question was:

- What are the challenges experienced by social workers in placing children living with HIV in foster care in Johannesburg?

The subquestions were:

- What are the specific policies regarding the placement of HIV-infected children in South Africa?
- What are the views and concerns of foster parents regarding fostering children living with HIV?
- To what extent do these views and concerns contribute to the challenges faced by social workers in placing children living with HIV in foster care?

Research goals and objectives

The goal of the study was to investigate the challenges experienced by social workers in placing children living with HIV in foster care in Johannesburg.

The specific objectives were as follows:

- To conceptualize HIV in children within the empowerment theory.
- To explore the policies (if any) regarding the placement in alternative care of children living with HIV in South Africa.
- To identify the challenges faced by social workers in placing children living with HIV in foster care.
- To establish the views and concerns of foster parents regarding caring for children living with HIV.
- To examine the contribution of these views and concerns towards the challenges in placing HIV-infected children in foster care.
- To propose strategies that will improve the placement of children living with HIV in foster care.

Research strategy

This was a qualitative applied research, using collective case study design. The case study design was used in this study mainly for its popularity in qualitative research, as well as its use of focus-group discussions with a number of participants (Fouché & Schurink, 2011). Focus-group interviews were conducted with designated social workers and foster parents.

Study sample

The researchers used purposive sampling to select designated social workers as well as foster parents. Participants were selected because of some defining characteristics that made them “the holders of the data needed for the study” (Nieuwenhuis, 2007, p. 79). Thirteen social workers and 11 foster parents in the service of Johannesburg Child Welfare (formerly Johannesburg Child Welfare

Society) participated in the study. The researchers first sought permission from the organization's management to interview the participants. The researchers selected participants whom they believed were informed and information-rich because they had experience of the phenomenon under investigation, and thus were the most suitable to answer the research questions (Alpaslan, 2010). Tables 1 and 2 set out the characteristics of study participants.

Data collection

Focus-group interviews or discussions were selected for primary data collection with the social workers and the foster parents. Two focus-group meetings were held with the foster parents and another two with social workers. An interview guide (Alpaslan, 2010; Greeff, 2011) was used during the focus-group discussions. The interview guide assisted the researchers in resolving some of the common shortcomings of unstructured interviews. The interview guide had themes that the researchers constantly referred to

Table 1 Demographic profile of foster parents ($n = 11$)

Biographical information	Subcategory	Number of participants
Age (in years)	Below 30	3
	41-50	3
	51-60	2
	Above 60	3
Gender	Male	1
	Female	10
Race	African	11
Marital status	Never married	4
	Married	1
	Divorced	1
	Widowed	5
Foster care experience (in years)	3-5	6
	6-10	3
	11-15	2
Foster parents with children who are HIV-positive in their care	Children HIV-positive	2
	Children HIV-negative	9

Table 2 Demographic profile of social workers (n = 13)

Biographical information	Subcategory	Number of participants
Age (in years)	20-30	6
	31-40	7
Gender	Male	7
	Female	6
Race	African	13
Qualification	Bachelor of Social Work	8
	Postgraduate (master's)	5
Experience as a social worker (in years)	3-5	5
	6-10	7
	11-15	1
Experience in rendering foster care services (years)	3-5	5
	6-10	8

during the focus-group discussions. All the interviews were tape-recorded (after first seeking both verbal and written consent from the participants) in order to allow the researchers ample time to analyse and interpret the participants' "perceptions, attitudes, understanding, knowledge, values, feelings and experiences" about the phenomenon (Nieuwenhuis, 2007, p. 99).

Data analysis

Data were analysed using Creswell's (2009, p. 186) "step-wise format" for qualitative data analysis.

- The audio-taped interviews were transcribed word-for-word and typed on A4-sized paper.
- The transcripts were read several times in order to get a sense of the whole and deduce meaning from the transcribed data. Notes of ideas and thoughts were written in the margins of the transcripts. This was done together with the field notes that were collected during the data-collection phase in order to group similar views together. Data from foster parents were organized separately from the social workers' data.
- Recurrent views were identified and similar topics were grouped

together (Schurink, Fouché, & De Vos, 2011). A comparison of the information collected from designated social workers and foster parents was made in order to identify the similarities and differences in the views expressed by these groups.

- These similar topics were regrouped into themes and subthemes.
- The themes were grouped according to their categories (Schurink et al., 2011). Data themes were allocated different codes in the form of numbers and colours.
- The researchers reexamined themes that emerged from the discussions. This was done in order to ensure that there was no redundancy of the same information contained in the themes.

The researchers ensured that the findings “as closely as possible” reflected the meanings as described by the participants (Lietz, Langer & Furman, 2006, p. 444) by applying Guba’s (1981) criteria when pursuing trustworthiness of qualitative data. These constructs are credibility, transferability, dependability and conformability. Credibility, for instance, was enhanced through peer debriefing, member checks and triangulation (Nieuwenhuis, 2007; Schurink et al., 2011; Shenton, 2004).

Ethical considerations

The researchers took cognizance of the following ethical issues:

- Informed consent and voluntary participation. Consent was sought from the designated social workers and foster parents prior to the study. Before the focus-group discussions commenced, the researchers presented the participants with letters of informed consent where the research process was described as well as consent to tape-record the interviews. Each participant was given an opportunity to read the letter, ask questions for clarity and sign the informed consent letter if s/he was willing to take part in the research. The participants were reminded about their right to withdraw at any point of the process if they so wished.
- Avoidance of harm. The researchers made an effort to minimize risks prior to the commencement of the study (Strydom, 2011). Thus, measures to assist participants to access services particularly in the event of any emotional harm were made available.
- Privacy, anonymity and confidentiality. All the information from participants was kept private and the results and findings of the study are presented anonymously in order to protect

the participants' identities. The participants were assured that confidentiality was going to be maintained in the study in order to protect the privacy of participants, even when their identities were known to each other (as was the case among most of the participants) and the researchers (Strydom, 2011). Participants were also assured that any information, such as names and addresses that might physically identify them, would not be included in the transcriptions or any publication, bearing in mind that views on HIV could be a sensitive matter.

- Debriefing of participants. The researchers ensured that participants got “the opportunity to work through their experience and aftermath” (Strydom, 2011, p. 122) of their participation in the research. They had to freely discuss their experience and express and share their feelings. Debriefing further served the purpose of clarifying any misconceptions related to the research.
- Deception of participants. The researchers did not use any form of deception in this study.

Study limitations

All the participants in the study were Africans, therefore their views on the topic under investigation might not reflect the views of other racial groups in South Africa. Nonetheless, the majority of foster parents and social workers in South Africa are Africans, given the racial distribution of the country's overall population. Furthermore, gender representation of the foster-parent participants was skewed, as only one out of eleven was male. The views of females regarding the foster care of children living with HIV might be different to those of males. Finally, the study utilized a small sample, which might not represent the views of all foster parents and social workers in the Johannesburg area and South Africa at large.

FINDINGS

There were notable similarities between most of the findings in this study and related studies on the foster care of children living with HIV, especially regarding the perspectives of social workers (Manukuza, 2013) and views of foster parents (Warwick, 2013). This study unearthed numerous fears and challenges regarding the foster care of children living with HIV. It was revealed that these fears and challenges emanate from a complex combination of

sociological, psychosocial, medical and economic factors. Findings from focus-group discussions with participants are discussed below.

Motivation to foster children

Prospective foster parents were motivated to take foster children into their care by several motives. The factors mentioned during the discussions were the foster parents' personal or life experiences, understanding that it is their social responsibility to help the needy, and the financial benefits associated with foster care. This can be corroborated by the following quotes from some of the participants:

The reason why I chose to foster children was my upbringing. I grew up without my biological father but my mother and stepfather. As a result my stepfather was maltreating me because I was not his biological child. I used not to get food and would eat at my friends' family. My stepfather even raped me when I was eight years old. Therefore I said to myself I should take care of children who are in need because I know how it is like to grow up without your parents.

There are people who are foster parents because it's a calling to them; they are committed to that because they believe it's their responsibility to help the needy, even children living with HIV.

At times you find out that we have people who are foster parents because they have a lot of other hidden agendas, chief among them being the financial reward which is associated with fostering a child.

This multiplicity of motives plays a fundamental role in the quality of care the child will get. As Delaney (2009, p. 1) cogently states, "foster parents' motives for bringing children can be complex and range from positive to problematic."

Views on fostering children who are living with HIV

The majority of foster parents interviewed noted that they did not have problems in fostering children living with HIV, as these children are also human beings who need love and dignity. One foster parent, for example, had this to say:

My view is that there is no problem with fostering a child with HIV and AIDS because those children need love and care from us. We need to show them that even if you have this disease it's not the end of the world, at least there is someone out there who loves you.

However, these sentiments were in sharp contrast with what the social workers reported. The social workers said they still find it very difficult to place children living with HIV in foster care as foster parents often give various excuses as to why they cannot take care of children who are living with HIV. The few foster parents who were fostering children living with HIV were of the view that many prospective foster parents are scared and wary of the challenges associated with caring for a child living with HIV. Responding to the question, "What are some of the challenges that you are facing in terms of placing children who are living with HIV in foster care?" one social worker responded as follows:

Placing HIV-positive children in foster care has been a huge and gigantic challenge. Every time when there is a new child that needs to be placed and we phone a foster parent and ask for placement from that particular foster parent, the first question that the foster parent asks is whether the child is HIV-positive or negative and the moment we say he is HIV-positive, the next statement you will hear is that "let me start by discussing the issue with my relatives" and so on. For some reason foster parents during recruitment and screening processes would actually agree that they will be able to look after children with HIV but when it comes to the practicality of placing the child there that's when they will start giving you excuses.

The responses from the majority of foster parents on their views on fostering children living with HIV support the findings of Warwick (2013, p. 72) that foster carers of children living with HIV "felt their foster child was 'their' child and that they were the parent." However, unlike in Warwick's study, in which the participants were already foster carers of children living with HIV, the majority of the participants in this particular study did not have children living with HIV in their care. Consequently, one cannot safely conclude that the responses of participants in this study sincerely represent their views on the subject. It is debatable whether the fact that the majority of the participants did not have children living with HIV in their care was mere coincidence or if it was a reflection of their perceptions of fostering children

who are living with HIV. If the above quotes from the social workers have an iota of truth and are to be considered, it means that most foster parents are still sceptical about taking care of children living with HIV.

Fears and challenges in fostering children living with HIV

It was clear from the participants' responses that there are still a lot of fears surrounding HIV in general, and caring for a child who is living with HIV in particular. While some of the fears were genuine, there was also evidence of myths and misconceptions with regard to HIV. Some of the fears are also a consequence of the challenges associated with caring for a child who is living with HIV. Some of the concerns raised by the participants include: myths and misconceptions about HIV; losing the child through death; physical and emotional stress; financial issues; lack of education and information on HIV; stigma and discrimination; disclosure of a child's HIV status; and compliance and adherence to medication. This is what the participants had to say regarding some of the issues:

I know that most people believe that when you have that kind of disease then it means you were sleeping out or things like that.

Part of my fear is that after bonding with the child for two, three or more years and all of a sudden something happens to him, the child passes away. I think it's going to traumatise me a lot, but you have to accept it.

You can also note that some of these foster parents are not fulltime foster parents. They are actually men and women who also go to work. So if you are to place an HIV-positive child with them and now to them there will be that fear of saying it means "I have to be constantly absent from work so that I can take this child to the hospital for medication, also for the doctor's appointment." As a result that becomes another issue.

The other challenge is financial issue because the child needs attention and also that the child needs to go to the clinic for medication, so money for transport is a problem. The grant that we get is not enough because she also wants to eat, wear, money to go to school, so the money is not enough. The other challenge is the issue of the grant because 800 Rand is not enough to look after

a child, you cannot raise a child with 800 Rand, even your own children you cannot. That's why some of the foster parents end up maltreating these kids, taking their own stress to the children and say that this child is like this or that but it's because of the money that we are talking about because in the middle of the month the foster parent can't do anything.

One of the challenges that we face as foster parents of HIV-positive children is being judged by the community because there are people who discriminate people who are HIV-positive. Maybe you may have told your neighbour that you are fostering a kid who is HIV-positive and they will maybe judge you or even judge that child. Or sometimes even in the same house you will find out that even your own children might also discriminate this child because they don't understand why the other one is taking medication or because of the influence of the community. This makes it very difficult especially for the infected child even to adjust to the environment.

Some foster parents have come forward and they have said that the child is not taking medication. I want to talk about the age of the child in question because if it's a smaller child, maybe the child is 5 years old, it's very easy for a parent to be looking after that child because the child depends largely on the adult. But if it's somebody who is 13 and above then sometimes the responsibility is given to the child to take the medication. But then there is a case that I dealt with of a child of about 14 or 15 years who stopped taking medication and we were looking at the medication, here is the medication, the child has not been taking medication. So at least a child of that age has to be told to take his meds, let him know that this is your health we are talking about and that your life depends on the medication, so you are supposed to take it. And it's not like the child forgot as such, remember we said that earlier there are issues that we tend to normally think about, issues of shelter, issues of clothes and whether the children are going to school, but there are psychosocial aspects, taking the medication has got bodily changes and psychologically it affects you. So just taking the medication every day you will be asking yourself questions that "I was born HIV-positive: What is that I did wrong?" So that can also affect you in terms of adherence.

The role of social workers in the foster care of children living with HIV

Another theme that emerged from the discussions, mainly with foster parents, concerned the role that social workers play in the foster care of children in need of care in general, and those living with HIV in particular. It was evident that social workers play a fundamental role in terms of the screening, recruitment, training, education and supervision of foster parents. Foster parents also indicated that they rely on support from social workers, whom they regarded as pillars of strength and courage in the foster-care process, particularly with children who are living with HIV.

The role of social workers is well documented in several national and international publications, and in statutes by the National Association of Social Workers, International Federation of Social Workers, and South African Council for Social Service Professions, as examples. The National Association of Social Workers (2008, p. 1) states that “the primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people with particular attention to the needs and empowerment of people who are vulnerable, oppressed and living in poverty”. Put differently, social work strives towards enabling “all people to develop their full potential, enrich their lives, and prevent dysfunction through intervention at the points where people interact with their environments” (International Federation of Social Workers [IFSW], 2012, p. 1). Equally, the purpose of social work includes the promotion of social change, problem solving in human relationships, and the empowerment and liberation of people to enhance well-being (IFSW, 2012).

The role of social workers remains critical in securing alternative care for children in need of care and protection in general, and those living with HIV in particular. Working with these children in foster care “will remain a demanding and rigorous aspect of social work practice as difficult decisions in fast moving and often complex situations have to be made with a vast array of legislation, law and social policy to understand” (Brown, 2014, p. 1). Social workers provide, among other things, supportive and cognitive therapy to children living with HIV and their foster parents—bearing in mind that these children and their caregivers are most vulnerable to mental-health problems, separation and loss (Vranda & Mothi, 2013). They perform these functions while recognizing the central importance of human relationships (Hepworth, Rooney, Rooney & Strom-Gottfried, 2013).

The majority of social workers who participated in the study felt that there was need for more support from all relevant stakeholders, so that social workers could perform their responsibilities with minimum obstacles.

An important issue raised by some of the participants pertains to the critical importance of enhancing the competencies of social workers in responding to the special needs of children living with HIV. This, they noted, may be achieved through specialised in-house training on HIV issues as well as the legislative framework relating to the foster care of children in need of care and protection. Some of the social workers had this to say:

I think the main problem is generalization or generic social work. You know when you put a child in foster care you won't have a lot of knowledge but when you are specialized it becomes easier or better. Maybe social workers need to have a department within an organization that actually specializes in issues such as HIV, I think it will help.

I would like to add to the issue of curricula that most schools of social work do offer that education, especially on HIV and AIDS, and most social workers will have that knowledge, but in terms of exposure because one may say that I have been working for the past seven years—but have you worked with people who are HIV-positive? I may have more than four years' social work experience right now, but if I were to give a client or foster parent knowledge on how to care for a child with HIV or special needs, to be honest I am blank and chances are that many social workers are also blank. So we have superficial knowledge ... but there is also much more that still has to be done ...

Empowerment in the foster care of children living with HIV

Suffice to note that the issue of empowerment regularly arose during the discussions with participants. All the participants indicated that they needed to be empowered in order to effectively deal with the challenges encountered in the foster care of children living with HIV. Some of the concerns raised by participants included providing

[C]omprehensive HIV education and training, support groups, incentives for foster parents and social workers, involvement of child's biological parents and collaboration by all role players.

LESSONS LEARNED

The challenges in placing children living with HIV in foster care are a result of a complex combination of sociological, psychosocial, medical and economic factors. They emanate from societal perceptions about HIV. These factors are also related to the profiles of the social workers placing the children and the foster parents who care for them. Since these factors are interconnected, they should not be viewed in isolation. The Getting to Zero Strategy of “revolutionizing HIV prevention; catalysing the next phase of treatment care and support; and advancing human rights and gender equality for the HIV response” (UNAIDS, 2010, p. 7) may only be fully recognized if issues raised by participants in this study are addressed adequately.

The study established that foster parents bring children in need of care and protection into their care for various reasons. The reasons include personal issues and experiences, and a passion to help the needy, and financial reward. Thus, the motivation to foster can directly or indirectly contribute towards the challenges of placing children living with HIV in foster care, given that the quality of care that a foster parent can provide to a child depends on their motivation to foster. Therefore, issues of compliance and adherence to medication may depend on the commitment of the foster parent regarding providing quality care to the child.

Although the majority of foster parents did not view fostering a child living with HIV as a problem, social workers maintained that foster parents had problems in bringing children living with HIV into their care. Consequently, one may conclude that foster parents are still sceptical of taking care of children living with HIV, although they may want people to believe that they do not have problems with the issue. This could be due to a fear of being judged. The fact that the majority of the participants (foster parents) did not have children living with HIV in their care is evidence to support this conclusion. This shows that issues of discrimination are still rampant among many people, which in turn affects revolutionizing HIV prevention.

Related to the above issue was the revelation of numerous fears and challenges regarding the foster care of children living with HIV. These include myths and misconceptions about HIV, fear of losing the child through death, stress, financial concerns, lack of education and information on HIV, stigma and discrimination, lack of support from social workers, disclosure of a child’s HIV status, compliance and adherence to medication, shortage of foster parents, and the shortcomings of the Children’s Act No. 38 of 2005 (as amended). Thus, the foster care of children living with HIV is marred by the fears and challenges described above. These fears and challenges constrain

the successful placement of these children with seemingly committed foster parents.

It was further revealed that social workers play a critical role in the foster care of children living with HIV, in terms of recruitment and screening of prospective foster parents as well as educating, training and supervising these foster parents. Similarly, foster parents are also crucial role-players in the foster-care process. The empowerment of these key role-players in the foster care of children living with HIV is therefore critical to the effective placement and care of these children, and will thereby help achieve the goals of the Getting to Zero Strategy. This includes provision of comprehensive HIV education and training for both foster parents and social workers, support groups, incentives for social workers and foster parents, and collaboration by all role players.

RECOMMENDATIONS

In the light of the aforementioned findings and conclusions vis-à-vis the challenges in placing children living with HIV in foster care, the following recommendations are proposed:

- Social workers who recruit and screen foster parents should thoroughly examine the foster parents' motives for bringing children into their care. This will help to identify foster parents with the passion and ability to care for these children, instead of those only interested in the financial rewards that accompany child fostering.
- Social workers and other relevant professionals and authorities need to address foster parents' fears and challenges regarding HIV in general, and the fostering of children living with HIV, through information dissemination seminars and awareness campaigns on HIV-related issues. These fears and challenges, whether they are genuine or mythical, cause prospective foster parents to become pessimistic about caring for children living with HIV; as a result, the pool of those willing to foster these children shrinks.
- Both the government and child protection organizations need to provide comprehensive HIV education and training for foster parents and social workers. This education and training should focus, among other issues, on the vulnerabilities of children living with HIV. This will enable social workers to provide accurate and detailed information on children living with HIV to prospective

foster parents. Similarly, the foster parents will be able to deal with any concerns and problems regarding the foster care of children living with HIV. The foster parents will also be able to distinguish between myths, misconceptions and facts about HIV. They will then become more able to deal with stigma and discrimination, which will eventually assist in achieving the goals of the Getting to Zero Strategy.

- The government should incentivize the foster care of children living with HIV, as these children are not akin to other children in terms of their physical and psychological needs. The incentives may include food parcels as well as making the children eligible for both the foster child grant and the child dependency grant accessible to children with disabilities. Given the current shortage of foster parents, if this recommendation is enacted, the number of foster parents available for children living with HIV will definitely increase. Moreover, social workers working in child protection organizations need to be remunerated at the same level as those in government departments in order to motivate them to render quality services, as well as ensuring staff retainment.
- There is a need to formulate and implement specific policies for the care of children living with HIV who are in need of care and protection. The current policies are insufficient to address issues affecting children living with HIV and their caregivers.
- Government, social workers, foster parents, biological families, donors and other service providers need to collaborate to make the child fostering process successful. All these stakeholders should specifically focus on the vulnerabilities of children living with HIV and address them adequately. Some, such as social workers and foster parents, need to be empowered through adequate resources.
- There is need for further research in the area of foster care of children living with HIV, and those with other special needs, especially in other provinces of South Africa. This will generate numerous views and recommendations to address the challenges faced in this area.

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**A communist legacy:
The untold story of
nosocomially infected
children with HIV from
Romania becoming
adults and the role
of social workers
throughout their lives**

Florin Lazăr



ABSTRACTS

The fall of communism in 1990 revealed the largest cohort of children nosocomially infected with HIV living in Romania; meanwhile, social work education was being rebuilt after 25 years of absence. From the perspective of social work practice, we use an ecosystems approach to explain the challenges faced by these children throughout their transitions to adult life, and highlight the role of social workers in providing services to them. At the macrolevel, in order to illustrate the structural challenges in getting to zero new infections and zero discrimination, we analyse the changing values, existing social policies and administrative data available. At the microlevel, based on research data, we discuss the empowerment approach and its theoretical relevance in explaining the move from a biological-citizenship perspective in social work practice. While this cohort is unique, the challenges encountered during their transitions from childhood to adults living with HIV are common.

一个社会主义国家的遗产：在罗马尼亚医院受到感染的艾滋病毒阳性儿童长大成人过程中不为人知的故事以及社会工作者在他们的生活中所扮演的角色

由于1990年罗马尼亚社会主义制度的解体，在罗马尼亚医院受到感染而罹患艾滋病的最大儿童群体被披露出来，与此同时，缺失了25年的社会工作教育也得到重建。从社会工作实践的角度来看，我们可以使用生态系统的方法来解释这些孩子从童年过渡到成年生活的过程中所面临的挑战，并且我们也着重研究那些为他们提供服务的社会工作者所扮演的角色。在宏观层面上，为了说明在实现零感染率和零歧视率的过程中所面临的结构性的挑战，我们分析了价值观的变化、现行的社会政策和管理数据。在微观层面上，基于研究数据，我们讨论了从社会实践中给予（他们）权利的方法，以及从一个“生物公民”的角度，解释其理论意义。虽然这一群体是独一无二的，但是，他们从罹患艾滋病的童年到成年生活的过渡

过程中所面临的挑战却是共同的。

共産主義の遺産：自らの人生を通して大人とソーシャル・ワーカーの役割を変えたルーマニアの院内感染したHIV陽性の子供たちの語られない話

Un legado comunista: la historia no contada de los niños de Rumania con infección nosocomial de VIH que se convierten en adultos y el papel de los trabajadores sociales a lo largo de sus vidas

La caída del comunismo en 1990 reveló el mayor grupo de niños con infección nosocomial de VIH que viven en Rumania, mientras que la educación del trabajo social fue reconstruida después de 25 años de ausencia. Desde la perspectiva de la práctica del trabajo social, usamos un enfoque ecosistémico para explicar los retos a los que se enfrentaron estos niños a través de su transición a la vida adulta, y destacamos el papel de los trabajadores sociales en la prestación de servicios para ellos. A nivel macro, con el fin de ilustrar los desafíos estructurales para llegar a tener cero infecciones nuevas y cero discriminaciones, analizamos el cambio de valores, las políticas sociales existentes y los datos administrativos disponibles. A nivel micro, basado en datos de la investigación, debatimos el enfoque de empoderamiento y su relevancia teórica para explicar el movimiento desde una perspectiva de “ciudadanía biológica” en la práctica del trabajo social. Si bien este grupo es único, las dificultades durante su transición de la niñez a la adultez con VIH son comunes.

共産主義の遺産：大人になりつつあるHIVに院内感染したルーマニアの子供達の明らかにされていない話と彼らの人生を通じたソーシャル・ワーカーの役割

1990年に共産主義が倒れ、25年の不在の後、社会福祉教育は再建されましたが、ルーマニアではHIVに院内感染した子供たちの最多の集団が浮上しました。社会福祉実践の視点から、成人期への移行を通じて、これらの子供たちが直面する課題を生態系のアプローチを使って説明し、彼らにサービスを提供するソーシャル・ワーカーの役割を強調します。マクロレベルでは、新たな感染をゼロに、そして差別もゼロにするために、構造的な課題を例証し、変わりゆく価値観、現在の社会政策と入手可能な管理データを分析します。ミクロレベルでは、研究データに基づき、社会福祉実践において「生物的市民権」の視点からの動きを説明する際、権利拡大アプローチとその理論的な関係性を検討します。この集団は固有ですが、HIVを抱えて幼児期から大人になる移行期間に起きる課題は、一般的なものです

Un héritage communiste : l'histoire inédite des enfants atteints du VIH par infection nosocomiale devenant adultes en Roumanie et le rôle des travailleurs sociaux tout au long de leur vie

La chute du communisme en 1990 a révélé la présence de la plus large cohorte d'enfants atteints du VIH par infection nosocomiale en Roumanie, alors que l'éducation en travail social a été reconstruite après 25 années d'absence. Du point de vue de la pratique de l'assistance sociale, nous partons d'une approche écosystémique pour expliquer les problèmes rencontrés par les enfants tout au long de leur transition vers le stade adulte, et nous mettons en évidence le rôle des travailleurs sociaux dans la fourniture des services à ces enfants. Au niveau macro, afin d'illustrer les problèmes structurels liés à l'atteinte de l'objectif zéro nouvelle infection et zéro discrimination, nous analysons les valeurs évolutives, les politiques sociales actuelles et les données administratives disponibles. Au niveau micro, sur la base des données de recherche, nous examinons l'approche d'autonomisation et son importance théorique dans l'explication du dépassement d'une perspective de biocitoyenneté dans la pratique du travail social. Même si cette cohorte est unique en son genre, les problèmes rencontrés par les enfants pendant leur transition du stade d'enfance au stade d'adulte vivant avec le VIH sont communs.

INTRODUCTION

From a social work perspective, the biggest challenge for the UNAIDS Getting to Zero Strategy is zero discrimination (UNAIDS, 2010). Stigma continues to be faced worldwide by people living with HIV (Alonzo & Reynolds, 1995; Earnshaw & Kalichman, 2013; Stangl, Lloyd, Brady, Holland, & Baral, 2013). While combined antiretroviral treatment (cART) is extending the life of people living with HIV, discrimination can hamper their social integration, affecting quality of life as a whole (Liamputtong, 2013). Stigma and discrimination may prevent people living with HIV from disclosing their HIV-positive status and seeking help from public authorities (Chesney & Smith, 1999), potentially affecting them on multiple levels: psychological (e.g. depression and other mental-health problems; Fife & Wright, 2000; Lowther, Selman, Harding, & Higginson, 2014); social (e.g. fewer social interactions, isolation; Nachega et al., 2012); economic (e.g. unemployment, poverty; Liu, Canada, Shi, & Corrigan, 2012); and health-related behaviours (e.g. adherence, retention in care; Boer, Sprangers, Prins, & Nieuwkerk, 2012; Greeff et al., 2010; Logie & Gadalla, 2009). To cope with stigma, tools such as social support from peers,

self-efficacy, education or activities to increase resilience seem to be most common (Chambers et al., 2015).

HIV and social work in Romania

In the last years of communism (1987 to 1990) in Romania, the health-care system was poorly equipped and syringes were used for multiple injections across different patients, which caused the nosocomial HIV epidemic of an estimated 10 000 children (Hersh et al., 1991). Suppositions have been made about the multiple use of syringes for vaccines for newborns and the use of other blood products not tested for HIV (Apetrei et al., 1998; Buzducea, Lazăr, & Mardare, 2010). In 1990 alone, over 1000 new HIV infections were reported, almost all of them among children born in 1988 and 1989 (Ministry of Health, 2013). Over the next decade similar cases were diagnosed, Romania having more than half of all paediatric HIV cases in Europe (Buzducea & Lazăr, 2008). It is estimated that of the 10 000 children infected, about 3000 died and another 7000 have survived for over 25 years (Ministry of Health, 2015). From 1992, all transfused and donated blood and derivative blood products were tested for HIV and other blood-transmitted disease. In 2006 a Ministry of Health order established the creation of a commission to investigate the circumstances of the nosocomial infection of HIV among children (Lazăr, 2010), but its conclusions never went public. In 2014, a court decision ordered a county hospital to pay approximately €1 million compensation to a young girl for infecting her with HIV when she was a child.

People from Romania living with HIV have free access to highly active antiretroviral treatment (HAART), with a relatively high coverage at 74% (UNAIDS, 2013). While in 1990 the extension of life due to treatment was three months, with the introduction of HAART from 1996 to 1998 an increase in life duration was possible (Ministry of Health, 2013). Studies revealed that infection among children occurred after that among adults (Coul et al., 2000) and social-context factors such as parents' level of education and mother's employment status contributed to an increased survival time (Kozinetz, Matusa, & Hacker, 2006). However, in the first decade of the HIV epidemic in Romania the focus was on the medical condition while the role of social services was limited (Buzducea & Lazăr, 2008). In the field of HIV research, it is only recently that behavioural and psychosocial studies on people living with HIV have been carried out in Romania. Consequently, data are scarce on the psychosocial aspect of the daily experience of people living with HIV. Previous studies investigated risk behaviours (Buzducea et al., 2010; Johnson & Buzducea, 2007), sexual satisfaction (Lazăr et al., 2014),

adherence (Dima, Schweitzer, Diaconiță, Remor, & Wanless, 2013), access to treatment (Buzducea and Lazăr, 2011; Lazăr and Buzducea, 2012) and policy and programmes evaluation (Dan, 2009; Lazăr, 2010, 2011).

LITERATURE REVIEW

The theoretical framework adopted here is the ecosystems theory (Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 1998; Payne, 2014; Tudge, Mokrova, Hatfield, & Karnik, 2009), which combines the individual/micro-level of social work practice with the meso-level and social/macro-level of policies and social values in which social work is carried out. At the micro-level, the analysis aims to explain how the generation of children living with HIV acquired via nosocomial infection in the late 1980s became adults within the turbulent social context of transition from communism to capitalism in Romania. At the meso-level, the role played by family, community and peers as sources of social support in the lives of this generation is highlighted. The social/macro-level focuses on the evolution of social policies directed towards people living with HIV in Romania; the coverage of social entitlements in the context of changing social values.

In terms of social work practice/intervention, we suggest that the empowerment approach (Payne, 2014; Turner, 2011) can be a useful tool in helping clients be resilient and move from a biological-citizenship perspective (Petryna, 2004; Rose & Novas, 2004), which seems to have dominated the early years of HIV. The roles of social workers (Sheafor & Horejsi, 2011) throughout the transition from childhood to adult life for this group of children with nosocomial HIV infection are also discussed.

METHOD

Macro-level

In order to provide the social/macro perspective, data from the European Values Survey and the World Value Survey (1990–2012) used to illustrate changing social values—for Romania only, but also from a comparative European perspective to understand the regional context. Since the 1990 to 1993 wave, these surveys included a question about intolerance towards various social groups, asking people what people they would not like to have as neighbours. In these surveys, respondents answer spontaneously, without a predefined list, but the interviewer has a list and ticks the groups

mentioned. Descriptive statistics are used to underline evolving social values towards people living with HIV by providing the percentages of people who respond that they do not want to have people with AIDS as neighbours.

Alongside the survey data, a policy analysis is combined with secondary analysis of administrative data on people living with HIV's access to social entitlements.

Meso-level

To present the perspective of the families of people living with HIV from the generation with nosocomial infection, a critical reflection on the author's social work practice during a 10-year period as a hospital social worker with children living with HIV and their families is adopted.

Micro-level

In order to highlight the individual perspective of the challenges faced by the children from the generation with nosocomial infection, we use the research data presented below.

Participants and procedures

A qualitative research based on in-depth interviews with 11 people living with HIV from the group of those who reported themselves to be nosocomially infected was carried out between July and September 2014. Respondents were registered with an infectious disease hospital, and were recruited by the researcher with the support of their care professionals (nurse, psychologist, social worker). The semi-structured interview guide included topics related to the history of infection, means of infection, life with HIV, disclosure, treatment and perspectives on the future. Interviews were audio-taped and transcribed verbatim, and lasted between 30 and 80 minutes. Thematic analysis focused on the lived experience of stigma and the coping mechanisms used to overcome it.

The research protocol was approved by the Ethics Committee of the Faculty of Sociology and Social Work, University of Bucharest.

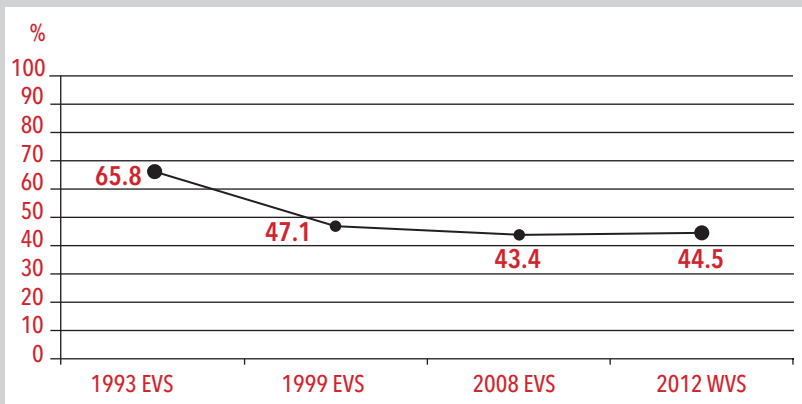
FINDINGS

The social/macro perspective

In Romania, after almost half a century of communist regimes (1947 to 1989), tolerance towards people living with HIV was low. Almost two thirds of respondents in a 1993 national survey (European Values Survey, 2015; World Value Survey Association, 2015) said that they did not want to have people with AIDS as neighbours; this figure dropped to 44.5% in 2012 (see Figure 1). The relative stability of negative attitudes towards people with HIV in the past decade suggests that despite various awareness campaigns, HIV stigma is still present among Romanians.

Compared with other formerly communist countries, Romania seems close to the regional trend of increasing tolerance towards people living with HIV, alongside Bulgaria, Baltic countries and other Latin nations, such as Spain and Portugal. However, the starting point was different in Spain and Portugal (greater tolerance in the 1990 to 1993 period) compared with eastern European countries (see Table 1, overleaf).

Fig 1 Dynamics of Romanian public opinion about people with HIV: Percentage of respondents answering “yes” to statement “Do not want people with AIDS as neighbours” 1993–2012



Notes: EVS = European Values Survey; WVS = World Value Survey

Sources: European Values Survey. (2015). *European values survey* [European Values Study Longitudinal Data File 1981–2008/ GESIS Data Archive, Cologne. ZA4804 Data file version 3.0.0]. doi:10.4232/1.12253. World Value Survey Association. (2015). *World Value Survey 1981–2014* [Official aggregate v.20150418, 2015]. Madrid, Spain: JDSystems.

Table 1 Evolution of the percentage of respondents answering "yes" to the statement "Do not want people with AIDS as neighbours" in selected European countries 1990-2010

	1990-1993 (W2) (%)	1999-2001 (W3) (%)	Change W3 v. W2 (%)	2008-2010 (W4) (%)	Change W4 v. W2 (%)
Austria	32.4	18.5	-13.9	25.5	-6.9
Belgium	24.2	11.7	-12.5	4.9	-19.3
Bulgaria	62.6	50.6	-12.0	45.8	-16.8
Czech Republic	49.3	20.8	-28.5	40.1	-9.1
Denmark	9.1	5.8	-3.3	3.2	-5.9
Estonia	62.7	41.4	-21.3	46.0	-16.7
Finland	24.3	19.6	-4.8	15.3	-9.1
France	14.7	8.6	-6.1	2.7	-12.0
Great Britain	24.2	24.1	-0.1	11.5	-12.7
Iceland	17.8	7.0	-10.8	3.8	-14.0
Ireland	34.6	24.1	-10.5	28.2	-6.4
Italy	42.3	31.1	-11.3	29.9	-12.4
Latvia	64.7	29.0	-35.7	34.5	-30.2
Lithuania	77.6	54.9	-22.7	61.4	-16.2
Malta	47.1	38.6	-8.5	32.7	-14.3
Netherlands	15.2	8.1	-7.2	15.4	0.1
Northern Ireland	27.6	31.9	4.3	20.7	-6.9
Poland	57.4	45.9	-11.5	52.3	-5.2
Portugal	47.2	25.2	-22.0	23.1	-24.1
Romania	65.8	47.1	-18.7	43.4	-22.5
Slovak Republic	58.0	44.6	-13.5	40.2	-17.8
Slovenia	41.6	33.2	-8.4	29.5	-12.0
Spain	34.8	21.0	-13.8	12.3	-22.5
Sweden	17.7	6.6	-11.1	7.2	-10.5

Notes: Only selected countries in which the survey was carried out in all three waves are shown. W = wave

Sources: European Values Survey. (2015). *European values survey* [European Values Study Longitudinal Data File 1981-2008. GESIS Data Archive, Cologne. ZA4804 Data file version 3.0.0]. doi:10.4232/1.12253. World Value Survey Association. (2015). *World Value Survey 1981-2014* [Official aggregate v.20150418, 2015]. Madrid, Spain: JDSsystems.

In the 1990s, many children living with HIV were denied access to education (Lazăr, 2010). For instance, when they became adolescents (15 to 19 years of age) about 40% of this generation had interrupted schooling or dropped out (Buzducea & Lazăr, 2008; Buzducea et al., 2010).

From 1968, social work education was banned in Romania for ideological reasons. The first new generation of social workers graduated in 1994 (Lazăr, 2015), and social work intervention in the first few years after this period was charitable, with social work services being less developed.

Until 2000 only a few nongovernmental organizations (NGOs) provided social work services to children and families affected by HIV in hospital settings. People living with HIV were by legislation included in the group of people with disabilities, receiving mainly cash benefits unaccompanied by support social services. In 2000, a federation of NGOs of people living with HIV (National Union of Organisations of People Living with HIV) was created. In 2002 a special law was issued concerning people living with HIV (Law no. 584/2002), which recognized some human rights (e.g. health care, education, employment, protection from discrimination, privacy), and a monthly food allowance for every person living with HIV was introduced. Also, legislation for people with disabilities (Law no. 448/2006) included another daily food allowance for children with HIV if they lived at home with their carers/parents (but not for the time when hospitalized), besides other (mainly) cash benefits.

In order to be registered with a certificate as a person with disabilities, a social inquiry report needs to be prepared by social workers from public social services at the local level, and the decision is made at the county level, which carries a risk of breach of confidentiality (especially as at the local level, qualified social workers are rare; unskilled personnel are usually working in these services). The food allowance is granted based on a request submitted at the county level and the monthly benefit is transferred into a bank account, ensuring a higher level of privacy. Table 2 provides a brief overview of the take-up of these two social entitlements over a period of 10 years, and reveals the role played by a policy measure that ensures higher confidentiality when increasing access to social protection measures: consistently, the percentage of those receiving a food allowance was higher than those choosing to access the local social services and receive a disability certificate.

The roles played by social workers at this level were mainly advocacy for the (social) rights of people living with HIV, and education/awareness campaigns to change discriminatory attitudes and negative social values towards people living with HIV.

Table 2 Take-up of social entitlements by people living with HIV in Romania from 2005 to 2014

	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Number of people living with HIV*	11 187	8379	9540	9669	10 041	10 405	10 903	11 581	12 273	12 886
Percentage with disability certificate (%)**	38.6	56.5	47.4	52.1	53.7	53.7	53.1	52.2	51.0	51.5
Percentage receiving food allowance (%)**	45.2	68.1	65.3	65.3	63.2	65.9	65.8	65.8	65.9	68.5

Note: the food allowance was introduced in 2003.

Sources:

* Ministry of Health. (2015). *Evolutia infectiei HIV/SIDA in Romania - 31 decembrie 2014*. National Institute of Infectious Diseases "Prof. Dr. Matei Balș", Compartment for Monitoring and Evaluation of HIV/AIDS Infection in Romania. Retrieved from http://www.cnlas.ro/images/doc/31122014_rom.pdf

** Author's calculations, drawing on the following documents:

Ministry of Health. (2015). *Evolutia infectiei HIV/SIDA in Romania - 31 decembrie 2014*. National Institute of Infectious Diseases "Prof. Dr. Matei Balș", Compartment for Monitoring and Evaluation of HIV/AIDS Infection in Romania. Retrieved from http://www.cnlas.ro/images/doc/31122014_rom.pdf

Ministry of Labor, Family, Social Solidarity and Elderly. (2015). *Buletin Statistic Trimestrial anul 2005-2014*. Retrieved from <http://www.mmuncii.ro/j33/index.php/ro/transparenta/statistici/buletin-statistic> and from <http://www.mmuncii.ro/j33/index.php/ro/transparenta/statistici/buletin-statistic/1252>

The meso-level perspective: the roles of the families

In the early years after the fall of communism, people who were living with HIV or affected by HIV (e.g. family members) were highly stigmatized. Media coverage of HIV was mostly from a negative perspective. As a result, a negative social representation of people living with HIV and their families was created. Sometimes families also adopted this approach, with many of them believing that their children will not live for long. The reactions of the families with nosocomially infected children can be classified into three categories:

- **The fatalist perspective** is based on the assumption that their children might not live too long/until adulthood. In an attempt to protect the child from the risk of stigmatization (learned through stories in media or from other parents), the child was withdrawn from school. In addition, families tried as much as they could to protect the child from disruption—the whole family being centred on the needs of the so-called sick child, sometimes neglecting other members of the family (children, spouse). All energy was directed to caring for and protecting the child with HIV. Also, being afraid of the child's reaction, parents often postponed the moment of disclosure of an HIV-positive status to the child, sometimes until they became adults or turned 18. To justify the long-term hospitalization, treatment, regular medical check-ups and periodical illness, another serious disease was used as an argument for those outside the family.
- **The victim perspective** was present among those families where the diagnosis was disclosed to the public and they faced discrimination from the community or in the school system. Sometimes the public disclosure was due to a breach of confidentiality from professionals in the health, educational or social services, while in other circumstances it was the family who voluntarily disclosed the diagnosis, either to the school to explain long absences or to social services when accessing some social entitlements/welfare benefits. It is worth mentioning that until 2000 (when ordinance 137/2000 was issued), there was no specific legislation to prevent discrimination, and only in 2002 was HIV specifically included as a criterion for discrimination (Law no. 48/2002).
- **The resistant perspective** was adopted by those parents who decided to try to carry on their life despite HIV—they tried to support the child to continue education, either by disclosing

the status at school but keeping it confidential/within a limited group (e.g. nurse, school director/principal, head teacher), or not disclosing it outside of their nuclear family. In many cases, the child was not aware of their HIV status, and was told they had another serious disease (e.g. cancer, hepatitis, tuberculosis, etc.). This group of nosocomially infected children, who are now young adults, is relatively homogenous (Johnson & Buzducea, 2007) and have benefited from family support throughout their lives (Buzducea et al., 2010).

Irrespective of the perspective adopted, families tended to be overprotective of their child with HIV. Except when the diagnosis was not disclosed abruptly by a third party, families tried to hide the HIV diagnosis from the child as much as possible. But in fact most of the children knew, or at least suspected. Some talked with other children when they were hospitalized; some saw medical records with their diagnosis or HIV status, or were aware that something significant was wrong with their health.

The roles of social workers at this level included providing support counselling to families and clients (e.g. about disclosure and managing stigma, adherence), health education (e.g. sexual education at adolescence, healthy lifestyle) and advocacy (e.g. to fight/prevent discrimination).

The micro-level perspective

The final sample comprised five men and six women from the generation of nosocomially infected people. There was a mean age of 25.5 years, a mean time since diagnosis of more than 17 years, and a mean time of awareness of diagnosis of 11.7 years (see Table 3). The gap between diagnosis and awareness is due to families delaying disclosure of HIV status to their children.

From stigma to coping and resilience

All respondents experienced stigma, albeit differently. In the group of young people infected during childhood, stigma was experienced more severely in the early years of the infection, and was more likely to have been experienced by their family and less by the children (now young adults). However, some experienced the effects of stigma severely—being rejected and insulted during their childhood.

Better resilience was observed by those managing the stigma better (i.e. controlled disclosure), who have family support and are socially active.

Table 3 Characteristics of the study sample

	Name	Gender	Age	Years since diagnosis	Age at disclosure
1	Gabriel	Male	26	16	14
2	Radu	Male	25	17	19
3	Andreea	Female	27	20	13
4	Aura	Female	26	17	12
5	Aurel	Male	25	18	13
6	Dragos	Male	26	24	14
7	Georgiana	Female	25	9	16
8	Aurelia	Female	27	24	7
9	Sorina	Female	25	18	14
10	Irina	Female	24	14	19
11	Ilie	Male	25	18	12
Totals		5 males 6 females	Mean: 25.5	Mean: 17.4	Mean: 13.8

Family seems to be the most important social support for those infected in childhood. Support from family permits a more active involvement in later life.

Three types of reactions to adversities/stigma were revealed. The first is those who were protected by family and lived (mostly) in secrecy managed to have a so-called normal life and continued their education. They are now well connected socially (with a job, family, social support).

Georgiana (25 years old) was diagnosed with HIV in high school and is currently enrolled in university to become a teacher. She says that nobody except her parents knows her HIV status:

[B]ecause, let's be serious, there are people who, if they find out that someone has cancer, already they stop talking to, they stop

[...] and cancer is not transmissible/contagious. HIV cannot be transmitted so easily, but there is this mentality ... so better no. This is what I think now ... Only my family knows. I don't care about other people, since they are not important to me. I discuss [about AIDS] with those who matter." (Georgiana, 25 years old)

My family knows. It's not somebody else's business ... When I need help I ask/discuss with my family, my aunt and my partner. (Gabriel, 26 years old)

Some, in order to avoid making their HIV status public, preferred to transfer to another school or even another location entirely. Some attended the courses of a special education school within a hospital until eighth grade.

Another area where people living with HIV experienced stigma is within the workforce. In some work situations, the respondents were witness to negative discussions among colleagues about those with HIV:

Once at work there were discussions that we will have to do a medical control and colleagues said something like, "it's not like I have AIDS" and I didn't said anything, but I kept quiet. I saw what my coworkers believed ... Soon after I found a reason to quit job. (Gabriel, 26 years old)

Another important social support factor is religion, which seems to be more important for those more vulnerable and for those socially active: "Yes, I believe in God, but it's not like I go every week to church." (Georgiana, 25 years old)

The second type of reaction to stigma was revealed by those who suffered discrimination and/or family separation and found their strength in peer, religion and professional support, and who are now the most vulnerable (e.g. insecure job and housing, living in poverty, emotionally unstable/immature).

One of the children who was abandoned in a residential institution after being diagnosed with HIV in early childhood remembers people in the village where the institution was situated calling the children names as they were on their way to school. They experienced stigma crudely:

The first couple of years were dramatically, dramatically because every time we went to school, neighbours were throwing at us ... It was very ugly [...] Yes, it was an extremely difficult time back then. I mean [grades] 5-6-7-8. Then we moved to [...] to high school,

and there, again I changed four high schools, just because of this [rejection]. (Andreea, 27 years)

Another young girl tells of repeated interruption to her education and the struggle with the community and family to continue school (she completed high school):

They were yelling at me “Sidoasa” [AIDSist] or these sort of things. But I bounced back, I was crying, I was coming home and mom was telling me “Don’t go to school anymore” and so on ... I continued with high school, but I interrupted several times, but in the end I graduated. (Aura, 26 years old)

Dragos, 26 years, blames his family for withdrawing him from school after the diagnosis. Now he is enrolled in a second-chance programme to continue school, reaching the sixth grade after three years.

Most of the respondents were, at least once, in the position of having to hide their diagnosis and pretend they did not have HIV for fear of stigma and other people’s reactions. Ilie, 25 years old, remembers that

A few days ago, someone came to us asking for a light [for a cigar] and then asked: “Do you have AIDS?” and I looked at him and replied, “No, we have other problems, we have problems with legs...”.

Since this group infected in hospital settings is relatively young, support from peers (both those living with and living without HIV) plays an important role in their current lives.

When I need to talk to someone, I speak with [...]. They are my best friends. (Aura, 26 years old)

Aurel, 25 years old, goes to church with his family every Sunday and finds comfort in going to the monastery, where he also tries to make himself useful:

I feel very good, there among the monks. I try to do little things, to help set the table, or through [working in] the garden. The monks are like my friends.

Those from the generation of nosocomially infected children who were

overprotected by the family strive for normality (wish to have a family, children, a job).

My greatest wish is to have children. If I get married and don't have children, is worst than having HIV[...] I'm sure there is a girl for me too, somewhere, waiting. (Aurel, 25 years old)

I feel left aside [by the family]. I wish they treat me like the others [normal]. (Ilie, 25 years old)

The third type of reaction to stigma was revealed by those who, despite adversity (e.g. family break-up, multiple health challenges), and with support from their family, peers and professionals have chosen HIV as a moral career and have become AIDS activists.

Irina, 24 years old, for example, is now a peer counsellor for other people living with HIV, having being in contact constantly with other NGOs and chosen to disclose her HIV status publicly.

Despite adversity, some respondents have managed to develop resilience, based on internal psychological resources. For example, Sorina, 26 years old, answered the question, “Where do you find your strength?” with, “Only in a strong psychic.”

At the micro-level, some of the roles of the social worker include being a counsellor for the person living with HIV, an advocate of his/her rights, an educator during the transition from childhood to young adult life, and, as case manager, mobilizing multiple resources (e.g. other professionals) to overcome discrimination and its negative effects. To progress towards zero new infections, it is essential that social workers also support an individual's self-efficacy in using protective measures—using condoms when having sexual intercourse, preventing mother-to-child transmission and adhering to a specific antiretroviral treatment (ART). As the children in their study grew up, social work practice also changed constantly to adapt the new realities (e.g. needs), from emergency interventions in the early years to more specialized practice (e.g. motivational interviewing for adherence or behaviour change techniques). This maturation process was found to be developing in parallel across the profession of social work and its clients.

DISCUSSION

In this chapter the use of ecosystems theory in social work has been

demonstrated, proving that it can be a robust explanatory perspective of the process of transition from childhood to adult life for people living with HIV. The dynamic nature of a chronic infection such as HIV can be efficiently approached from this theoretical perspective.

Data from surveys and qualitative research reveal that stigma is a continuous threat faced by people living with HIV in Romania. Those included in the qualitative study all experienced some kind of stigmatization—some more directly, when they went to school or work or were looking for work, while others in everyday situations were confronted by allegations of being infected. The fear of the reaction of others, based on what is defined as vicarious stigma (Steward et al., 2008)—namely hearing about episodes of stigma experienced by other people living with HIV—contributes to an internalized stigma (Berger, Ferrans, & Lashley, 2001) and fuels isolation and exclusion from the labour market. Many prefer to reduce social interaction (Nachega et al., 2012).

To cope with these adversities, people living with HIV in Romania rely mostly on family support and religion. Support from religion seems more important for those who are more vulnerable (Maman, Cathcart, Burkhardt, Omba, & Behets, 2009), and is also used as a coping mechanism alongside family and peer support (Gore-Felton, 2006; Jia et al., 2004; Sanjuán, Molero, Fuster, & Nouvilas, 2013; Skovdal & Daniel, 2012).

LESSONS LEARNED

At the macro-level, ensuring that social policies allow for greater privacy in accessing social work services creates the premise for higher uptake rates of social entitlements, as has been proved in Romania and as is recommended in order to get to zero discrimination. Instead of empowering people living with HIV and their families to face the social consequences of the disease, the lack of social work services in the early years after the 1989 revolution disempowered them and made some dependent on cash benefits. However, the best practices, promoted mainly by NGOs, created the possibility for social inclusion and (still) low prevalence rates of HIV infection.

At the meso-level, the family having a resistance perspective in providing support to the person in need seems to have had a positive impact in that person's adult life. Moreover, reflective practice from a social worker increases his/her understanding of the client perspective and of the practice itself.

At the micro-level, focusing on the strengths perspective and empowering

clients to be resilient can enhance their chances of overcoming the negative effects of stigma and discrimination. Contrary to the public health perspective, which encourages people living with HIV to disclose their HIV status, at an individual level controlled disclosure seems to have more beneficial effects than not disclosing or having a reduced social network, as it builds resilience and a relatively good quality of life compared with those who disclosed their status and were rejected.

While this generation of children with nosocomial infection is unique, the challenges encountered during their transitions from childhood to becoming adults living with HIV are common, and known to be found in other cases of HIV among children (such as vertical transmission).

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**Listening to the
voiceless: Lived
experiences of asylum
seekers living with
HIV in Scotland and
the implications for
social work practice**

George Palattiyil and Dina Sidhva



ABSTRACTS

HIV thrives in conditions of powerlessness, poverty and inequality; the very issues that mark the lives of asylum seekers, making them vulnerable to HIV. Drawing on a recent study, this paper explores the lives of asylum seekers in Scotland—a country they call home today. The study uncovered conditions that continue to present a real threat to the human rights and health of HIV-positive asylum seekers: stigma, human rights violations, detention, deportation and posttraumatic stress disorder (PTSD). While some reported positive stories of support from voluntary agencies, any reference to frontline statutory social work was conspicuous by its absence. In the current environment of austerity, managerialism and neoliberal approaches, the paper argues for mainstream social work and policy-makers to reengage with this most vulnerable group to develop culturally sensitive, inclusive and rights-based practices to facilitate timely access to support, care and treatment, so that their voices are heard in informing policy and practice.

聆听无权发言者的心声：生活在苏格兰的HIV阳性寻求庇护者和社会工作实践的启示

艾滋病病毒（HIV）在无能为力、贫困和不平等的条件下更易滋生蔓延；使寻求庇护者更易于感染艾滋病病毒（HIV）的，正是那些能代表他们生活的关键问题。。基于最近的研究，本文探讨了苏格兰艾滋病病毒（HIV）阳性寻求庇护者的生活，今天他们将苏格兰称之为自己的‘家’。本研究发现，对艾滋病病毒（HIV）阳性寻求庇护者的人权和健康构成威胁的生存条件仍然继续存在—即社会性的侮辱、人权侵犯、拘留、驱逐出境和创伤后应激障碍（PTSD）等。虽然有一些关于志愿机构援助的正面报导，但是很明显，提及基层正规社会工作的报导非常缺乏。。在当前的紧缩、管理主义和新自由主义做法的环境中，本文主张社会主流工作者和决策者应该与这个最脆弱的群体重新合作，采取文化上敏感、包容和尊重权利的做法。

法，以便使这些寻求庇护者及时获得援助、护理和治疗，使他们的声音在资讯政策和实践中被听到。

Escuchando a los sin voz: Vivencias de las personas con VIH que solicitan asilo en Escocia y las implicaciones para la práctica del trabajo social

El VIH se desarrolla en condiciones de indefensión, pobreza y desigualdad; los mismos problemas que marcan la vida de los que solicitan asilo, lo que los hace vulnerables al VIH. Basándose en un estudio reciente, en este artículo se explora la vida de los solicitantes de asilo en Escocia, el país al que ellos llaman “casa” en la actualidad. El estudio descubrió las condiciones que siguen presentando una amenaza real para los derechos humanos y la salud de los solicitantes seropositivos-estigma: violación de los derechos humanos, detención, deportación y trastorno de estrés postraumático (PTSD en inglés). Mientras que algunos informaron de historias positivas de apoyo por parte de los organismos voluntarios, cualquier referencia a la primera línea del trabajo social institucional brillaba por su ausencia. En el entorno actual de austeridad, gestionismo y enfoques neo-liberales, el artículo argumenta a favor del trabajo social y los responsables de políticas fundamentales para volver a participar con este grupo más vulnerable para desarrollar prácticas culturalmente sensibles, incluyentes y prácticas basadas en los derechos para facilitar el acceso oportuno a la ayuda, atención y tratamiento, de tal manera que sus voces sean escuchadas en informar a la política y a la práctica.

声なきものを傾聴する：スコットランドのHIV陽性の亡命希望者の生きた経験と社会福祉実践の意味合い

HIVは、無力、貧困と不平等の状況下で繁茂します。亡命希望者をHIVの被害に遭いやすくし、亡命希望者の命を狙うまさにその問題です。最近の研究に基づき、本論文では亡命希望者が今日「母国」と呼ぶスコットランドでの、彼らの生活を調査しました。研究により、エイズウイルスに感染した亡命希望者の人権と健康への真の脅威となる状況（汚名、人権侵害、拘留、強制退去とPTSD）が続いていることが確認されました。何人かはボランティア組織からの支援について肯定的な内容を報告をしましたが、最前線の法的な社会福祉が不在であることは顕著に言及されました。現在の緊縮財政、管理主義と新自由主義的アプローチの環境のもとで、本論文は、支援、ケアおよび治療へのタイムリーなアクセスを容易にするために、主流となる社会福祉と政策立案者が再びこの最も被害を受けやすい集団と面談し、文化的な配慮がなされている、参加制限のない、権利に基づく活動を開発することで、彼らの声が政策と実践に反映されるという点を主張します。

À l'écoute des sans-voix : Expériences vécues par les demandeurs d'asile qui vivent avec le VIH en Écosse et implications pour la pratique du travail social

Le VIH se développe dans des conditions d'impuissance, de pauvreté et d'inégalité ; les problèmes mêmes qui déterminent les vies des demandeurs d'asile, les rendant ainsi vulnérables au VIH. Inspirée d'une étude récente, le présent article examine les vies des demandeurs d'asile en Écosse — un pays qu'ils appellent à l'heure actuelle leur « domicile ». L'étude a révélé les conditions qui continuent de constituer une réelle menace aux droits humains et à la santé des demandeurs d'asile infectés par le VIH — notamment la stigmatisation, les violations des droits humains, la détention et la déportation, ainsi que les troubles de stress post-traumatique (TSPT). Malgré certains récits positifs rapportés sur la prise en charge offerte par des agences bénévoles, toute référence au travail social statutaire de première ligne brillait par son absence. Dans l'environnement actuel d'austérité, du gestionnariat et d'approches néolibérales, le présent article encourage les principaux travailleurs sociaux et les décideurs à reprendre contact avec le groupe vulnérable afin de développer des pratiques culturellement sensibles, inclusives et axées sur des droits. Ceci dans le but de faciliter l'accès à temps aux services de prise en charge, de soutien et de traitement et pour que leurs voix soient entendues dans l'information de la politique et la pratique.

INTRODUCTION

The connected global issues of state fragility and forced migration have recently become critical domestic- and foreign-policy topics for several nations. Millions of people have been displaced due to war, conflict, poverty, political instability, human rights violations and environmental factors, and find themselves living as forced migrants (Amnesty International, 2011; Human Rights Watch, 2015; Zetter, 2015). Global migration is vast and continues to grow (Human Rights Watch, 2009). According to the United Nations High Commission for Refugees (UNHCR, 2015), on average 24 people worldwide were displaced from their homes every minute of every day in 2015. Data from the United Nations (2013) suggest that some 232 million people are living outside their countries of origin due to such push factors.

Migration is a powerful symbol and consequence of global inequality. In many low-income countries, the poor are most vulnerable to the forces of structural inequality that impel people to migrate (Minter, 2011). They are also the least able to access forms of accountability, thereby perpetuating the structural inequalities that lie at the heart of poverty and migration (Farmer,

1999; Waquant, 2007). In recent research commissioned by the International Organization for Migration (IOM, 2015a), the most significant push factor for migration was seen as the need to flee from instability—war, conflict or economic or social pressures that inhibit a stable life. The war in Syria is currently the single most important factor contributing to forced migration flows across the Middle Eastern region (Gartenstein-Ross, Barr, Willcoxon, & Basuni, 2015; Manrique Gil, Barna, Hakala, Rey, & Claros, 2014), what the UNHCR (2014) has called the biggest humanitarian emergency of our era.

Migration can often have serious health consequences for migrants.¹ Due to their unique legal status, they may be vulnerable to discrimination and may experience language and cultural barriers and other economic and social difficulties (Amon & Todrys, 2009). Moreover, migrants are likely to experience specific challenges that influence their health as a result of the migration process itself. Commonly referred to as the social determinants of migrants' health, these relate to reasons for migrating, mode of travel, length of stay and migrants' language skills, and the social and legal status in the destination countries (IOM, 2015b). Since the emergence of the HIV epidemic, migrant populations have received considerable recognition from the international community in the context of risk, transmission and prevention of HIV. Asylum seekers are an integral constituent of this international migrant population who may be at risk of HIV.

A considerable number of asylum seekers have come to the United Kingdom of Great Britain and Northern Ireland (UK) during the past few years, although policies of successive governments have attempted to cut the overall number. For example, the UK received 262 400 asylum seekers during the period from 2002 to 2006 (UNHCR, 2007). The Joint Committee on Human Rights (2007) states that asylum applications within the UK increased from 32 505 in 1997 to 84 130 in 2002. Aspinall and Watters (2010) highlight that in 2008 there were 25 930 applications for asylum, with 19 400 initial decisions made (11% fewer than in 2007). The latest available data indicate that there were 25 771 asylum applications in the year ending June 2015, an increase of 10% compared with the previous year (Home Office, 2015).

The increase in asylum applications and the demand for services led to a rethink by the Home Office in the UK about how best to manage asylum seekers. One of the consequent developments from this paradigm shift led to the dispersal policy of the UK Government: asylum seekers are dispersed

1 Migrants in the context of this paper refers to asylum seekers, refugees and other internally displaced persons, who have been displaced due to war, conflict, poverty, political instability, human rights violations and environmental factors and find themselves living as forced migrants.

to different parts of the UK, with significant ramifications for the care and treatment of those living with HIV.

Since the introduction of the dispersal policy by the UK Home Office in 2000, many asylum seekers who were living with HIV were relocated to Scotland. A Health Protection Scotland report (2011) estimated that there were 4033 people living with HIV in Scotland, which includes a number of asylum seekers with uncertain immigration status who have been relocated to Scotland since the introduction of the above policy in 2000 (Creighton, Sethi, Edwards, & Miller, 2004; Johnson, 2003). Research indicates that, compared with any other group within the UK, African men are at a greater risk of contracting HIV (Health Protection Scotland, 2008). Within a Scottish context, the highest prevalence of HIV in both sexes is among those who have risked exposure in sub-Saharan Africa. A Health Protection Scotland (2010) weekly report suggested that most cases of HIV infection among nondrug-using heterosexual individuals in Scotland were among individuals moving to Scotland from countries where there is a high prevalence of HIV, particularly sub-Saharan Africa. However, the actual number of asylum seekers who are living with HIV remains unclear.

Current research on the impact of HIV-positive asylum seekers in Scotland is relatively limited. Tallis (2002) argues that programmes designed to tackle HIV must include the lived realities of those affected and ensure that they are involved in both defining the problem and reaching a resolution. Yet there remains a significant absence of empirical data that explore asylum seekers' experiences (Bowes, Ferguson, & Sim, 2009), and particularly of those living with HIV.

Asylum seekers living with HIV are a truly hidden population in Scotland; even invitations to participate in research are often met with reluctance owing to the fear of being exposed as HIV-positive and the resultant stigma. Despite a growing awareness of the need to understand issues that affect this marginalized and vulnerable group, both qualitative and quantitative data remain limited.

Asylum seekers living with HIV

HIV disproportionately affects marginalized groups, and the risk of HIV transmission is known to be greater in situations of poverty and inequality (Cherfas, 2006). Large numbers of asylum seekers travel from poorer countries where there is a high prevalence of HIV, and they also have individual experiences of persecution, conflict and human rights violations. Consequently, they are at a greater risk of contracting HIV. The instability

and destitution many experience upon entering a new country heightens risks and increases their vulnerability.

Policies that lead to poverty and insecurity place significant amounts of stress on asylum seekers and affect their physical and emotional well-being (Crawley, Hemmings, & Price, 2011). This stress, compounded with previous experiences of loss, grief and trauma, makes asylum seekers more vulnerable to physical and mental health issues and exploitation (Sinyemu & Baillie, 2005).

Many asylum seekers are fleeing areas where there are few legal protections of individual rights, and where conflict, violence and abuse are all too commonplace. It is obvious that the very issues that compel people to seek asylum are those that drive the HIV epidemic and make asylum seekers particularly vulnerable to HIV (Haour-Knipe, 2003). HIV thrives in conditions of poverty, conflict and inadequate living conditions (Davies, 2006; Spiegel & Nankoe, 2004). The lives of asylum seekers are very much characterized by these issues; therefore, they can be more susceptible to the disease as they are often placed in positions of powerlessness. Asylum seekers living with HIV experience poverty, isolation, vulnerability, stigma and discrimination, which when coupled with a lack of support and access to appropriate medical care have the potential of denying fundamental human rights and dehumanizing people who are already fleeing circumstances threatening their very existence.

Immigration and asylum are under the jurisdiction of the UK's central government and the various policies in relation to asylum in the UK have affected asylum seekers in different ways, with significant human rights implications. Threats of dispersal and/or detention and restrictions to health care, combined with policies that enforce poverty and wider social inequalities, exacerbate health difficulties associated with HIV (Anderson, 2008; Aspinall & Watters, 2010). Additionally, the policy of charging refused asylum seekers for HIV treatment and deporting them back to countries where there is insufficient medical treatment raises concerns on humanitarian grounds (Aspinall & Watters, 2010). "Not only is it inhumane to diagnose but not treat HIV, it also undermines the Government's commitment to managing the spread and effects of HIV worldwide" (Davies, 2006, p. 4).

The quality of accommodation and services offered to asylum seekers is limited and in some cases appears to contradict European Convention on Human Rights (ECHR) Article 8, which upholds respect for family and home (Aspinall & Watters, 2010). A recent newspaper report points to brutal practices by landlords in Glasgow who locked asylum seekers out of their accommodation by changing door locks when their applications were turned down, in clear breach of the UK Home Office guidelines (Carrell, 2016).

Moreover, denying medical care based on immigration status runs counter to ECHR Article 14. Davies (2006, p. 20) points out that denying asylum seekers affected by HIV the right to health care “is ethically indefensible, unlawful from a human rights perspective and extremely damaging to individual and public health”. Additionally, the separation of other STIs and HIV for the purpose of free treatment is discriminatory (Gazzard, Anderson, Ainsworth, & Wood, 2005).

Moreover, asylum seekers in the UK have no recourse to work, and a report by the Joint Committee on Human Rights (2007, p. 35) concluded that refusing permission for asylum seekers to work and operating a system of support that results in widespread destitution breaches the ECHR Article 3 threshold for “inhuman and degrading treatment”.

Da Lomba (2010, p. 431) argues that the immigration process prevents integration of asylum seekers, as it is determined by “inferior legal status that lacks certainty.” She avers that the differential treatment of asylum seekers could constitute a violation of Article 34 of the Refugee Convention, which requires participating states to facilitate naturalization of refugees (Da Lomba, 2010, p. 432).

The immigration and asylum policies of the successive UK governments have created conditions that make management of HIV particularly difficult. Research indicates that the ability of asylum seekers to physically manage HIV postdiagnosis is particularly challenging, because they experience a wide range of practical problems compared with non-asylum-seekers (Weatherburn et al., 2003, as cited in Cherfas, 2006). Examples include the inability to eat appropriate foods due to inadequate financial support, the inability to prepare meals and conceal medication due to overcrowded housing situations, and the anxiety created by uncertainty over whether treatment will continue due to fear of deportation. Additionally, having to share bathrooms and inadequate living conditions with many people—while experiencing difficult symptoms associated with HIV treatment—can make living with the disease less manageable (Fortier, 2003). Crawley et al. (2011, p. 6) argue that “overwhelming lack of access to institutional, social and economic resources denies asylum seekers a sustainable livelihood and results in a life that is robbed of dignity and unacceptable by human rights standards”.

RESEARCH DESIGN AND METHODOLOGY

This paper uses qualitative methodology to examine the experiences of asylum seekers living with HIV in Scotland who are struggling to manage

the process of seeking asylum along with the challenges of living with HIV. Researching vulnerable, hard-to-reach populations—such as asylum seekers living with HIV—brings a number of complexities, challenges and dilemmas to the fore. Many HIV-positive asylum seekers—and in particular those whose applications have been refused—very often are unwilling to engage with people outside of their known support systems. Therefore, accessing HIV-positive asylum seekers for interviews has been a complex and challenging experience, often fraught with uncertainty and limited success. To understand the complexity and uncertainty that marked the lives of asylum seekers living with HIV, the research methods chosen were required to be inclusive and participatory, allowing flexibility and openness for participants to tell their stories. The methodology helped to explore the perspectives and experiences of the respondents in their own words and encouraged an exploratory and descriptive analysis that stressed the importance of context, setting and the respondents' frame of reference (Marshall & Rossman, 1995; Mason, 2002).

Sample

Given the sensitivity of the study, identifying participants was challenging and time-consuming. The researchers began by contacting a number of voluntary organizations in Scotland that worked with people living with HIV. The large majority of the sample came from the Waverley Care's African Health Project in Glasgow, which provides support to people living with HIV, the majority of whom originate from sub-Saharan Africa. All participants lived in Glasgow and received support from the above project; some of them were also service users at another voluntary organization in Glasgow, the Terrence Higgins Trust Scotland.

Based on a purposive sampling method, 19 Black African asylum seekers living with HIV (15 women and 4 men) participated in this study. Participants hailed from varied nationalities; eight came from Zimbabwe, with others from the Ivory Coast, Burundi, Ethiopia, Malawi, South Africa, Nigeria, Tanzania and Kenya. Fieldwork for data collection was complex, often fraught with the uncertainties that mark the lives of the asylum seekers, with interviews often cancelled at very short notice.

Data collection

In-depth interviews, utilizing an open-ended interview guide, and two focus groups were held with the participants, generally in the premises of the African Health Project. A few interviews were held in unconventional

venues, such as a café or the researcher's own automobile, where the participants felt safe. All interviews were audio-recorded with prior consent of the participants and lasted between one and a half to three hours. Some of the interviews extended over multiple sessions.

Ethical concerns

Central to the research were critical issues of informed consent, confidentiality, voluntary participation and anonymity. Ethical approval for conducting the research was obtained from the Research Committee of the university where the researchers were based, prior to commencing the interviews. Participants were assured that they could discontinue the interview at any point that they felt necessary and that they were not obliged to answer anything they felt uncomfortable with or did not choose to answer. In fact there were a few occasions where participants felt totally overtaken by their emotions and the researcher had to discontinue the interviews immediately. After a pause, and in discussion with the participants, these interviews were resumed, with a few of them being rescheduled to another date. It was evident from the outset of the study how difficult it was to gain access to this otherwise very hard-to-reach population, as some of the failed asylum seekers lived essentially as fugitives, fearing deportation. Therefore, ensuring anonymity and protecting the identity of the participants were central to the research process.

Data analysis

Analysis began with the transcription of interviews. The researchers used narrative analysis (Riessman, 1993) to comprehend the participants' everyday experiences and the way they perceived the world. Each transcript was read and analysed for content, which was classified into categories that recurred across participant accounts or were unique to a particular participant's account. These categories were then developed into themes that described the lived experiences of the participants. The data analysis was designed to portray the participants' experiences as accurately as possible and to preserve the richness and uniqueness of the data, enabling deeper understanding of the particular phenomenon being explored (McLeod, 2000).

FINDINGS

Through the individual and focus group interviews, participants shared their thoughts and feelings on four topic areas: why they came to the UK, the experience of seeking asylum, their experience of being an asylum seeker or refugee living with HIV, and their hopes for the future.

Coming to the UK

Fleeing violent situations, being in search of treatment and overstaying on a student visa were cited as the three reasons why respondents left their countries of origin and came to the UK. A significant number of the respondents left their native country because of some form of violence that they or their close family member(s) had experienced or were in fear of experiencing. Respondents spoke about fleeing violence that was either engineered by tyrannical political regimes or perpetuated through a personal relationship.

One respondent from Zimbabwe described the routine terror and panic created by the ruling party and how she was forced to flee from her country because she feared for her life. Another woman from Uganda, whose father and brother had been vocal against the ruling regime, left her two young children with a friend because of a perceived threat to her life after her father disappeared and her brother was murdered. She said, “I left to save my life. My brother was forced to drink poison and he was killed that way ... I thought if I am to survive I will need to run away for my safety.” One woman from Kenya spoke about the continuing horror she lived through for almost a decade after she was raped in front of her son by the supporters of the ruling party. She spoke about the humiliation and pain of being gang-raped in front of an adult son and how that gave her the strength to flee her country.

The narratives of three women focused on the gender-based violence that forced them to leave their homes. They referred to the maltreatment they had suffered just because they were women: being beaten by their husbands or partners, being raped with impunity and being ritually mutilated. One woman from Malawi spoke about the constant violence she experienced from her husband because she did not get pregnant. Two respondents came to the UK to seek treatment for non-HIV-related issues. Both women were unable to access appropriate treatment in their countries of origin because of their political affiliations. One woman from Zimbabwe came to access treatment after being shot in the leg and gang-raped. She became very emotional when she recalled the gang-rape by political party

thugs. She said, “I was dumped on the roadside and lay there for hours before I was hospitalized. I do not know who took me there. My leg became so bad that they were talking about amputating it ... I knew that my only chance was to try and get some proper treatment.” Two respondents came as students and overstayed after their visas ran out, when they discovered that they were HIV-positive.

Seeking asylum

Three key areas emerged in relation to the asylum-seeking process: bewilderment and uncertainty about the present and future; issues in relation to the United Kingdom Borders Agency (UKBA); and dispersal and detention.

Bewilderment and uncertainty

All respondents described a sense of bewilderment and uncertainty, about both their present and their future. One man said that he found it difficult to sleep and eat and that he felt as though he was living on the edge of a cliff. One woman described the process of asylum-seeking as a dark, interminable tunnel with little hope. Another woman likened the process to being in a deep well. She said: “You are trying to get someone to save you, but they don’t even want to hear your cries ... they think somehow you deserve to be there.” One woman asked the researcher if she had heard of the shifting sands in Tanzania. She likened the process to the sands that kept blowing you “further and further, but you don’t know when you’re going to be able to settle down”.

Issues related to the United Kingdom Borders Agency

Respondents without exception spoke about the UKBA as an all-powerful entity with extra-human propensities. They referred to it as the Home Office, which is “neither a Home nor an Office” but some kind of omniscient power, capable of harm and destruction. One respondent explained that every week when she needed to go to the Home Office to sign to ensure that she received her payment, she experienced severe panic reactions.

Dispersal

Respondents varied significantly in their experiences of dispersal. Some looked upon it as a routine procedure of being transferred from one location to another. Others felt that their basic, fundamental right to family life had been snatched from them. One woman with three children spoke about the utter misery she felt being dispersed to Glasgow and separated from her husband. Another respondent who had just lost her asylum claim spoke

about her misery because she was dispersed to Glasgow, separating her from her daughter and grandchild, who were both living with HIV. She said, “I find it unbearable to live by myself and am on medication for I cry a lot every day. I feel helpless, so powerless.”

Detention

Two respondents spoke about their experiences of detention. One woman’s account was ironic; it reflected the harsh reality of failed asylum seekers in the UK. She likened the Dungavel Detention Centre to a five-star hotel with “fantastic facilities” and “fantastic food from all over the world”. Another respondent’s narrative was in stark contrast; he recounted that he was meant to take medication with specifically prepared meals, yet the routine at detention centres made this problematic.

Being an asylum-seeker living with HIV

The majority of respondents emphasized the immensity of their lives as asylum seekers. Among the themes that recurred were fear of disclosure; being a failed asylum seeker and the unfathomable asylum system; access to medical care; pain, shame and stigma; multiple jeopardy; and finally the solace gained from support networks.

Fear of disclosure

An overwhelming majority had not disclosed their HIV status to any of their family or friends. This was partly because they were afraid that their confidentiality would be breached and partly because they were afraid of rejection and any other adverse effects associated with HIV-disclosure in Africa. It is ironic that individuals who have fled persecution or have come in search of treatment to the UK then need to live in constant fear of disclosing their HIV status to fellow Africans within their own communities, or within the more informal social support systems that they have managed to forge in their new host country.

Being a failed asylum seeker

Respondents who described themselves as failed (refused) asylum seekers were in a particularly vulnerable situation because they are not entitled to any rights or supports. They become homeless, with no recourse to any money, and are often forced to sleep rough and go hungry. One respondent said,

They think we are scavengers, not humans, but I say we still have blood flowing through our veins and you and me we all have the same colour of blood. We came here to live in freedom, to see the human side of life.

Homelessness, hunger, depression, anxiety and poor physical health are all glaring characteristics of the failed asylum seeker experience.

Access to medical care

Several respondents felt they were discriminated against by dental practices and spoke with anger about their experiences. A few respondents spoke about feeling discriminated against when medical professionals became aware of their HIV status. Another woman said that she felt discriminated against by the ambulance service and recalled not being offered a hand when she was unable to walk.

Pain, shame and stigma

The three words pain, shame and stigma were present in the narratives of the majority of the respondents in both the individual and focus-group discussions. The narrative of one of the respondents encouraged us to think of the three aspects together. He said, “HIV-positive plus asylum seeker means you have pain, shame and stigma. Stigma because you are made to feel dirty and shameful by others, stigma because you make yourself feel shameful and dirty.”

A recurrent theme through all interviews was the pervasive stigma experienced by individuals in relation to their HIV-positive status and being an asylum seeker. The majority of the respondents were only obliged to disclose their status to doctors, dentists and immigration officers at the UKBA, and these were the sources of stigma they described. One asylum seeker’s experience of stigma from her doctor encapsulates the stigma experienced by HIV-positive asylum seekers. She said, “I remember that time I was feeling dizziness ... so I went to her and I said that I’m feeling dizzy. And she said, ‘Oh so you are AIDS.’ I said, ‘I am not AIDS, I am HIV.’”

Multiple jeopardy

Living with HIV and being an asylum seeker were seen by participants as having to cope with two major and difficult life circumstances at the same time, which was described as a position of double, and at times multiple, jeopardy. As one woman put it, “I have so many problems, I ask myself so many questions ... Is it just because I am Black? Is it just because I am

a woman? Is it just because I am HIV? Is it just because I am an asylum seeker?”

Solace from social support networks

The accounts of the majority of respondents reflected how a little social support goes a long way when it comes to fostering strength and resilience. One woman said, “I have gone through a lot, but the support and help from my own church has helped me and given me hope to go on and struggle and still go on.” Friends, mainly fellow Africans (either from their own country or other African countries), were the other source of support.

Hopes for the future

Aspirations for freedom, medical care, being united with their families, having the right to live and work freely and be productive members of society were the hopes for the future shared by the respondents. They were keen that this research would help to have their voices heard. One said, “We want a life where people are human to all humans whether they are black, whether they have HIV or whether they come from Africa or whether they have a permanent leave to remain.”

DISCUSSION

A range of premigration factors, such as conflict, war, poverty, trauma and powerlessness, make asylum seekers more vulnerable to various illnesses, including HIV (Davies, 2006; Norredam et al., 2005; Spiegel & Nankoe, 2004; UNAIDS, 2010a). The narratives of the asylum seekers living with HIV in this research provide a chilling glimpse of the lives that these individuals left behind: persecution, violence, gang-rape and discrimination as they fled their country, seeking to find a place of safety.

However, a combination of postmigration factors (such as discriminatory and authoritarian policies, negative media coverage, stigma and discrimination, breakdown of families due to dispersal policies of the state, false perceptions and inadequate representation) continue to affect the ways in which asylum seekers’ lives are shaped. Thus, these vulnerable individuals continue to experience further vulnerability and marginalization within the host countries (Crawley et al., 2011; Fortier, 2003; Malloch & Stanley, 2005).

Many asylum seekers living with HIV were forced to make difficult choices about staying in the UK to access treatment or returning to their country of

origin, where an early death is more likely. This result is consistent with the findings of Sinyemu and Baillie (2005). Many participants in the current study also reported the government's argument regarding the availability and accessibility of HIV prevention, care and treatment in their country of origin, notwithstanding the other critical factors that would increase their vulnerability if they were deported. For example, all asylum seekers living with HIV in this study had faced significant housing and financial difficulties, stigma and discrimination, with some assuming the role of a fugitive because they had no place to stay. This increases their vulnerability and ability to cope with the illness, and denies them their fundamental human rights. The narratives of asylum seekers living with HIV in this study clearly portrayed a life that is "profoundly degrading and dehumanizing" (Sinyemu & Baillie, 2005, p. 33).

The narratives of asylum seekers living with HIV in this study bear out the deep and complex relationship between HIV and human rights. Despite the advances in care and treatment of people living with the illness, HIV continues to be a major social and public-health concern across the world, shining a glaring light on the human rights of those affected by the virus, especially in relation to access to health care. Vulnerability to HIV infection feeds on violations of human rights, including discrimination against women, and conditions that create and sustain poverty. Given the importance of human rights in HIV prevention and treatment, the international human rights system has explicitly recognized HIV status as a prohibited reason for discrimination. Either through legislation or litigation, many countries have recognized that their people have the right to HIV treatment as a part of their human rights, confirming that economic, social and cultural rights are justiciable (UNAIDS, 2006).

The UK Human Rights Act (1998) guarantees to protect the rights enshrined in the ECHR. However, the accounts of the asylum seekers illustrate several instances where their rights have been breached.

The accounts of the majority of the participants in this study have highlighted the impact of forced migration, leading to increased risk of marginalization, discrimination and human rights abuses. The current study has highlighted the many difficulties of living with HIV while trying to cope with the variety of problems associated with the immigration system; this places asylum seekers living with HIV in a position of multiple jeopardy, a finding that echoes the findings by Sinyemu and Baillie (2005).

One of the most palpable issues that emerged from the interviews was the posttraumatic stress (Palattiyil & Sidhva, 2015) experienced by almost all the respondents. The interviewer found that respondents initially spoke

in a very matter-of-fact/limited way and reported difficulty remembering some experiences. It almost appeared as though they were unwilling to fully engage. Talking about their memories to the researcher seemed to be the first stage of triggering traumatic reexperiencing. It is an understandable coping mechanism. Why would you want to go there? The very nature of traumatization makes it difficult to recall but also to verbally access the issues of the traumatization. When the respondents talked dispassionately, they did not have to access this pain; it was hard for them to express themselves in a verbally accessible way. One of the respondents described having nightmares, and another flashbacks, before fortnightly visits to the UKBA.

Chantler (2011) argues that international human rights policy instruments and national policy processes for determining refugee status present particular challenges for female asylum seekers who have experienced sexual assault. Legal processes for those seeking asylum require individuals to share their story but ignores the power structures and interplay between race, gender, culture and ethnicity. In determining the credibility of asylum seekers' applications, most officials rely on the applicants being able to share their story (due to a lack of concrete evidence), yet psychological and cultural barriers can affect perceived credibility of stories (Melloy, 2007). For example, research indicates that many women have difficulty with detailed disclosure and are more likely to experience shame/posttraumatic stress disorder (PTSD) and attempt to protect themselves through disassociation (Baillot, Cowan & Munro, 2009; Chantler, 2011; Melloy, 2007; Palattiyil & Sidhva, 2015).

The hostile environment and the experience of being in a new country can also limit the applicants' capacity to recount events of their journey (Melloy, 2007). Chantler (2011) notes that women may associate male authority figures with their abusers and may therefore be more fearful and less able to disclose information. As a result, judgements are often based on perceived inconsistencies in information, late disclosures and applicant demeanour (Baillot et al., 2009; Melloy, 2007). Often, decisions require subjective interpretation by interviewers who are not adequately trained or equipped to deal with people suffering from mental-health issues (Chantler, 2011).

Thus, gathering evidence of asylum seekers' premigration journeys is particularly problematic, as is expecting people to describe traumatic experiences in one interview (Chantler, 2011). As Baillot et al. (2009, p. 208) point out, "You cannot expect someone who's been here a month to go into a hostile interview environment and disclose everything, it's crazy." Encouraging people to discuss traumatic experiences too early can be psychologically damaging. Application decisions continue to be

made without taking account of the impact of PTSD and the influence of postmigration factors (Chantler, 2011; Melloy, 2007; Palattiyil & Sidhva, 2015).

Uncertainty about asylum claims preclude asylum seekers from being allowed to work and they are often dispersed to places with few support networks. This, combined with managing the health needs of an HIV-positive diagnosis, makes life particularly difficult. Fortier (2003) has also noted that asylum seekers living with HIV often cannot buy certain foods they are used to eating due to restrictions placed on them by food vouchers or lack of income, a circumstance that was reported by our participants as well. Asylum seekers therefore have to endure multiple forms of discrimination (IOM, 2013).

Living with HIV is only one of a number of difficulties experienced by asylum seekers. The UK's All-Party Parliamentary Group on AIDS (2003, p. 16) described immigrants and people living with HIV as "two of the most stigmatized groups in today's media and society". They highlight the extent of negative media coverage, which links asylum seekers to public health concerns and terrorist attacks, and argue that punitive policies are driven by electorate desires in response to false public perceptions. The evidence presented here underlines the findings of the All-Party Parliamentary Group on AIDS (2003, p. 17), who point out the dangers of setting asylum and immigration policy in response to a media agenda.

It is not surprising that asylum seekers are more vulnerable to physical and mental-health issues. The impact of their experiences of having a life-threatening illness and having to seek assistance as a vulnerable escapee from repressive conditions is a harsh reality. A major concern is the lack of cultural sensitivity (Alvarez-del Arco et al., 2013) to the difficulties that people fleeing persecution may face in being open about their HIV status at the outset of their asylum claim. As a result, people's accounts are routinely dismissed as not credible (Palattiyil & Sidhva, 2015). Moreover, the management of HIV requires financial resources in order to maintain a proper diet and adhere to medication regimens. The lives of all the participants in this study were characterized by the stark absence of such resources.

LESSONS LEARNED

Nearly four decades into the epidemic, HIV still remains a complex issue globally, causing public health concerns and social problems. While advances in treatment and care have enabled many individuals living with HIV to live longer, there is compelling evidence of the impact of HIV-associated stigma

and discrimination marginalizing them and their families and communities. Stories from around the world demonstrate the pervasiveness of this stigma, leading to a denial of basic human and civil rights.

From its very emergence, social workers have been in the forefront of this epidemic, providing support and leadership, which are vital in offsetting the impact of stigma and ensuring basic human rights. The current study has once again raised a number of issues for social workers to refocus their attention on.

One of the key issues that asylum seekers living with HIV in this study faced was pervasive stigma and continued discrimination, particularly in health-care practices. Several of the asylum seekers reported a lack of appropriate awareness and sensitivity regarding HIV, which resulted in stigmatizing and discriminatory attitudes and approaches from health-care practitioners and their receptionists at general practitioners, dentists, clinics and ambulance services. There is a clear need for culturally sensitive awareness training, targeting specifically the influencing attitudes and approaches of health-care providers and health service staff towards asylum seekers living with HIV. Such a programme should also include developing more culturally competent services, tailor-made to the needs of people who are living with HIV. Evidently, asylum seekers living with HIV would benefit hugely from having a positive-people network or a buddy system to support each other and promote resilience and adherence in otherwise difficult circumstances.

Asylum seekers in this study whose applications have been refused live from hand to mouth, in utter poverty, relying often on the kindness of others to survive, sometimes going hungry and sleeping rough. Almost all of them yearn to work and make a living, which they attribute to their worth and dignity; however current immigration policies do not permit them to engage in paid employment. Social work is well-placed to campaign for revisiting the issue of work-related rights and to give asylum seekers permission to work if they have been waiting for more than six months for their cases to be concluded, or if they have been refused asylum but cannot be returned home through no fault of their own. This will prevent vulnerable people being left in a state of limbo for prolonged periods of time, will reduce the burden on the taxpayer, and will allow a small number of asylum seekers to support themselves and their families while contributing to the economy. Those who are allowed to stay in the UK will find it much easier to become part of British society if they have been given the chance to work (Amnesty International, 2011).

The narratives of asylum seekers living with HIV in this study bear out the deep and complex relationship between HIV and human rights. There

were several instances where discriminatory practices affected the human rights of these asylum seekers. There is a need to renew our commitment to human rights as a cornerstone for informing policy and practice in relation to asylum seekers living with HIV. Government authorities should end human rights violations, such as the policy of destitution that affects the health of individuals. The authorities should allow leave-to-remain-permit asylum seekers to work, and allow for access to food and other necessities of treatment.

Some asylum seekers in this study reported that their families were separated as a result of the dispersal policies of the UK Government. This left many asylum seekers isolated and depressed, as they found themselves in a strange place, once again away from their family and friends. Right to family life is enshrined in the UK's Human Rights Act, and respect for human rights is essential for effective responses to HIV given that infringements of human rights lie at the heart of marginalization and the creation and continuation of vulnerability (UNAIDS, 2001). Furthermore, dispersal is seldom planned in advance, and no consideration is given to the health/medical needs of HIV-positive asylum seekers. There is a clear need to rethink ways in which dispersal can be improved so that the negative effects of dispersal on HIV-positive asylum seekers can be eliminated.

One of the most evident issues that emerged from this study was the post-traumatic stress experienced by almost all the respondents. Living with posttraumatic stress had a significant impact on the ability of asylum seekers to tell their stories convincingly, especially when interviewed by people in authority. Legal processes for those seeking asylum require individuals to tell their story but ignore the power structures and interplay among race, gender, culture and ethnicity (Palattiyil & Sidhva, 2015). There is therefore a clear need to engage counselling and psychological services early on in order to deal with the trauma and stress experienced by HIV-positive asylum seekers. Assessment and treatment for posttraumatic stress should be carried out as a matter of course, and asylum seekers should be provided with advocacy services that will empower them to tell their stories.

While effecting policy changes can be challenging and time-consuming, what has been very encouraging is the support and commitment that the researchers received in setting up a new platform—HIV, Human Rights and Development Network—in partnership with some of the study participants. Hosted by the University of Edinburgh Global Health Academy, the Network aims to stimulate interdisciplinary discussion, research seminars and dialogue with policy-makers, academics and practitioners in the field of HIV, human rights and development. With cross-party support, the Network has

been successful in running high-level seminars in the Scottish Parliament with a view to inform policy, specifically around the human rights of asylum seekers living with HIV in Scotland.

CONCLUSION

Forced migration is known to affect the well-being of those seeking asylum. This combined with living with HIV and experiencing varied discrimination makes their lives particularly difficult. The respondents in this study found themselves caught in a web of multiple jeopardies. Their narratives bear witness to traumatic life events: anxiety, worry, a feeling of terror and sleeplessness, hopelessness and helplessness, living with HIV and a pervasive sense of uncertainty about their immigration status, all mark their lives.

The narratives of asylum seekers living with HIV in this study provide a painful glimpse of their lived experiences as they journeyed from their own countries to a country they call home today. These themes portray their vulnerabilities, struggle and risks to personal safety juxtaposed against the backdrop of denial of support and potential deportation by the UKBA to a country where HIV treatment is limited or beyond their reach.

Allowing migrants to seek care early and to obtain medication for treatable diseases have tremendous benefits, while the consequences of failing to provide this care are significant (Amon & Todrys, 2009). Evidence suggests that migrants tend to be in better health upon arrival than native citizens (McDonald & Kennedy, 2004), yet complexities around legal status, fear of detention and disclosure, legal restrictions on care and pervasive stigma all contribute to underutilization of health services and delays in seeking care (Amon & Todrys, 2009; Palattiyil & Sidhva, 2015).

The human rights of asylum seekers living with HIV have received increased policy attention in the past few years because the human rights of people living with HIV transcend nations and borders, and the realization of their rights and fundamental freedoms is vital in reducing vulnerability to HIV (UNAIDS, 2006). There is an increasing commitment for human rights to take centre stage in the care and prevention of HIV globally; this was underscored by the *Declaration of Human Rights and HIV/AIDS: Now More than Ever* at the 2008 International AIDS Conference in Mexico City. If we are to achieve zero new HIV infections, zero discrimination and zero AIDS-related deaths (UNAIDS, 2010b), then we need a concerted global response underpinned by political will, strategic partnerships and commitment to human rights of all.

This study has uncovered the plight of asylum seekers living with HIV as they try to establish new lives for themselves in the UK. It is time for a new approach in dealing with these individuals, whose numbers are relatively few but whose suffering is great. It is hoped that the current study will help provide a voice for these individuals and that policies and procedures can be shaped around their needs so that their human rights are respected.

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The many roles of the social worker in shaping the quality of care in transdisciplinary teams as we get to zero

*Theresa Fox, Michael Hager, Adam Thompson
and Donna Van Alst*



ABSTRACTS

The United States of America has barriers to health care that span across medical conditions. HIV stigma further prevents people from pursuing diagnosis and treatment. Social work has a natural duty to respond based on its mission to enhance the functioning and well-being of individuals. Reducing HIV incidence requires a response beyond medication monitoring. Social work helps mitigate stigma while coordinating all types of professional care. By providing linkages and addressing retention in care, social work increases the impact of all interventions, effectively reducing the overall cost of care. This transdisciplinary response necessarily includes ongoing assessment of needs in order to address barriers to partnership with consumers and professionals. Quality management is the process through which desired impacts of treatment are defined, assessed and addressed to yield improvement. This chapter will describe the transdisciplinary model, the role of quality management in HIV care, and the roles social workers play in Getting to Zero.

在实现零艾滋病目标的同时，社会工作者在塑造高质量跨专业护理团队方面要扮演多重角色

美国医疗保健体系下的诸多医疗条件都存在着某些限制。艾滋病所引起的耻辱感进一步限制了患者寻求诊断和治疗。社会工作有一种自然的责任，即基于自己的使命，为了使每个社会成员都能发挥作用、为了提高他们的生活质量而做出回应。要想降低艾滋病毒的发病率，仅仅进行药物监测是远远不够的。社会工作不仅有助于减轻耻辱感，同时也能协调各种类型的专业护理。通过提供联系和提高护理的保持率，社会工作提高了所有干预的效果，有效地降低了整体的护理成本。这种跨专业的应对必然包括对需要的持续性评估，以消除消费者和专业人士之间合作障碍。质量管理是一个通过对所需治疗的影响进行定义、评估，并使之

生産改善的过程。本章将介绍跨专业的模型、HIV护理中质量管理所发挥的作用以及向零艾滋病迈进过程中社会工作者所扮演的角色。

Las numerosas funciones del trabajador social en la conformación de la calidad de atención en equipos transdisciplinarios para llegar a cero

Los Estados Unidos tienen obstáculos en la asistencia sanitaria que se extienden a través de condiciones médicas. El estigma del VIH ahuyenta el diagnóstico y el tratamiento. El trabajo social tiene un deber natural de responder en base a su misión “para mejorar el funcionamiento y el bienestar de las personas”. La reducción de la incidencia del VIH requiere una respuesta más allá de monitorización de la medicación. El trabajo social ayuda a mitigar el estigma, mientras coordina la atención profesional. Al proporcionar vínculos y hacer frente a la retención en la atención, el trabajo social aumenta el impacto de todas las intervenciones, reduciendo efectivamente el coste total de la atención. Esta respuesta transdisciplinaria incluye necesariamente una evaluación continua de las necesidades con el fin de abordar los obstáculos en colaboración con los consumidores y profesionales. La gestión de calidad es el proceso a través del cual se definen, evalúan y dirigen los impactos de tratamiento adecuados para lograr mejoras.. En este capítulo se describirá el modelo transdisciplinario, la función de la gestión de calidad en la atención del VIH y las funciones de los trabajadores sociales para llegar a cero infecciones.

患者ゼロへ向けて、学際的なチームにおける質の良いケアを形成する中でのソーシャル・ワーカーの多くの役割

アメリカ合衆国には、病状全体にまたがるヘルスケアに対して障害があります。HIVに対する汚名が、更に人の診断と治療への追及を妨げています。社会福祉には、『個人の機能と幸福を強化する』という使命に基づき対応するという当然の義務があります。HIV発症率を減らすには、薬与の監視以上の対応が必要となります。さまざまな専門的なケアを調整する一方で、社会福祉は汚名を緩和する手助けをします。つながりを提供し、ケアの保有に取り組むことで、社会福祉はすべての介入の影響を増加させ、ケアのコスト全般を効果的に削減します。この学際的な対応には、消費者と専門家との協力への障壁に対処するための継続的なニーズの評価を必然的に含みます。品質管理とは、改善をもたらすために、治療の効果を定義、評価、検討、改善するためのプロセスです。この章では、学際的モデル、HIVケアにおける品質管理の役割と、HIVエイズをゼロとするのにソーシャル・ワーカーが果たす役割を説明します。

Les nombreux rôles joués par les travailleurs sociaux dans la définition de la qualité des soins aux seins des équipes transdisciplinaires dans notre effort d'atteinte de l'objectif zéro

Les États-Unis ont des barrières aux soins de santé qui s'étendent au travers des conditions médicales. La stigmatisation liée au VIH empêche davantage les personnes à poursuivre le diagnostic et le traitement. L'assistance sociale a le devoir naturel de mener des ripostes dans le cadre de sa mission visant à améliorer la vie et le bien-être des individus. La réduction de l'incidence du VIH exige une riposte au-delà du suivi des médicaments. L'assistance sociale aide à réduire la stigmatisation, tout en coordonnant tous les types de soins professionnels. En fournissant des liens et en abordant la rétention dans les soins, l'assistance sociale améliore l'impact de toutes les interventions, réduisant efficacement ainsi le coût général des soins. Cette riposte transdisciplinaire inclut nécessairement l'évaluation actuelle des besoins afin de supprimer les barrières, en collaboration avec les consommateurs et les professionnels. La gestion de la qualité est le processus par lequel les impacts souhaités du traitement sont définis, évalués et résolus en vue de l'amélioration des résultats. Le présent chapitre décrit le modèle transdisciplinaire, le rôle de la gestion de la qualité dans les soins du VIH et les rôles joués par les travailleurs sociaux dans l'atteinte de l'objectif zéro infection.

INTRODUCTION

UNAIDS has outlined a strategy towards ending the AIDS epidemic globally (UNAIDS, 2015). The strategy describes the need to invest in interventions across disciplines in ways that expand health education, address disparities and mitigate stigma. This chapter describes why one such investment in the United States of America must be social work as part of transdisciplinary practice with uniform goals and objectives for the health and well-being of people living with HIV.

Barriers to health care in the United States of America are complex and layered. Costs, even with health insurance, can be prohibitive to some. A complicated insurance system is difficult for many people to access without navigation assistance. Transportation and language barriers are also evident. Research has shown that these barriers contribute to racial, ethnic, class and geographical disparities in access to and use of health-care services, as well as health outcomes, for patients with an array of chronic health and mental-health conditions (Alegriá, et al., 2008; Davis, Vinci, Okwuosa, & Chase, 2007; LeCook et al., 2014).

With HIV, access to care and adherence to treatment is further complicated by stigma (Arnold, Rebchook, & Kegeles, 2014; Hatzenbuehler & Link, 2014; Hatzenbuehler et al., 2014; Hatzenbuehler, Phelan, & Link, 2013; Hrostowski & Camp, 2015; Ojikutu et al., 2013; Steiner, Finocchiaro-Kessler, & Dariotis, 2013). Both internal and public stigma prevent people at risk from seeking diagnosis and people diagnosed with HIV from pursuing treatment. Stigma by association prevents close family members from supporting people living with HIV. Even when people have overcome other types of stigma, structural stigma prevents people living with HIV from easily accessing critical health-care services. Structural stigma is defined as the manner in which societal and cultural norms limit opportunities and prevent access to resources (Hatzenbuehler & Link, 2014). While effective medication has had a measurable impact on the prognosis of people living with HIV over the past 35 years, accessing medical care and necessary support services and adhering to treatment remains a challenge for many.

Social work, as part of a transdisciplinary response to HIV, is well positioned to mitigate stigma and coordinate professional care to advance the goal of Getting To Zero. Both are critical to facilitating access and adherence to treatment. Done well, the transdisciplinary model results in a system of care that integrates the medical response with educational and social interventions and demonstrates measurable impacts on every stage of living with HIV—from addressing risk behaviours through ongoing retention in care. The model can also contribute to both improved health outcomes and lower overall costs of care. Quality management—the process through which desired health impacts are defined, assessed and addressed to yield improvement—provides a useful framework for assessing the impact of the transdisciplinary approach on HIV care and Getting To Zero efforts.

This chapter begins with an overview of how HIV stigma and structural barriers prevent people living with HIV from accessing testing and treatment services and from adhering to care recommendations. Next, we describe how the social work profession, with its emphasis on working with marginalized people and improving access to services, is uniquely poised within a transdisciplinary practice framework to promote a holistic response to HIV. Finally, we use an example from a national quality management programme to demonstrate how the tenets of transdisciplinary practice ensure that those who are diagnosed with HIV are immediately linked to treatment as a method to promote prevention and treatment.

Barriers to health care

Numerous factors have been identified as barriers to accessing health care in the United States of America, including cost, a complicated health insurance system, transportation, language barriers and disease-related stigma (Brand, Smith, & Brand, 1977; Davis & Rowland, 1983; National Center for Health Statistics, 2016; Patel, Parker, Villarruel, & Wong, 2013; Pelloski, 2013).

Cost has long been documented as a primary barrier for many patients (Brand et al., 1977). In 2014, 8.2% of all people reported delaying or not receiving needed medical care due to cost, 5.6% reported not receiving needed prescription drugs due to cost, and 10% reported not receiving needed dental care due to cost in the past 12 months (National Center for Health Statistics, 2016). Health-care costs in the United States of America are strongly influenced by recommendations made to the Centers for Medicare and Medicaid Services by the Relative Value Scale Update Community, a group of physicians that meets three times a year to set costs based upon physician work, practice expense, liability insurance and geographical region (Levy, 2010). Most major insurance companies use these recommendations as well (Munro, 2013). Critics suggest that this system tends to result in inflated pricing (Munro, 2013) while the formula excludes any consideration of health-care user affordability (American Medical Association, 2016).

Relatedly, individuals who are uninsured or underinsured also tend to be underserved by the health-care system (Davis & Rowland, 1983). Implementation of the Affordable Care Act of 2010 (ACA) has addressed this issue by extending health insurance coverage. Between 2013 and 2014, the percentage of adults aged 18 to 64 who were uninsured decreased from 20.5% in 2013 to 16.3% in 2014 (National Center for Health Statistics, 2016). Although health insurance improves access to medical services, research suggests that there is a continuing need to educate formerly uninsured people about health insurance coverage options and being responsible, informed and empowered consumers (Patel et al., 2013).

The vast differences in community environments throughout the United States of America add additional barriers. Studies have found that lack of transportation in communities makes physical accessibility to health care variable at best. In rural and even suburban areas, lack of public transportation is a remarkably significant barrier to accessing care (Maes & Louis, 2003; Syed, Gerber, & Sharp, 2013). A systematic review of literature on the barriers faced by patients living with HIV in rural areas of the United States of America found that transportation needs were among the most commonly discussed concerns facing the population (Pelloski, 2013). Further, studies have found that the specialized care most likely to maximize outcomes for

people living with chronic health conditions may be absent outside of urban centres (Rosenblatt & Hart, 1992).

Studies have also found barriers related to cultural differences (Flores et al., 2003; Jacobs, Chen, Karliner, Agger-Gupta, & Mutha, 2006). People who speak a language other than English or who have limited English-language proficiency are less likely to have a consistent medical-care provider or receive preventive services. They are also more likely to leave the hospital against medical advice and be noncompliant with medication (Flores, 2006).

Finally, disease-related stigma has also received considerable attention as a public health concern affecting prevention, care and treatment adherence (Keusch, Wilentz, & Kleinman, 2006; Link & Phelan, 2006; Valdiserri, 2002).

The literature on stigma and health outcomes conceptualizes three distinct types of stigma: public stigma, self-stigma and structural stigma. Corrigan and Fong (2014) contrast public stigma and self-stigma in relationship to stigmatizers and the stigmatized, respectively. According to Corrigan and Fong, stigmatizers “harm people with illness by leading to prejudice and discrimination which blocks the life opportunities of people with these disorders” (2014, p. 111). This, particularly when it is endorsed by power groups, results in public stigma.

Conversely, self-stigma occurs when “the stigmatized internalize the public’s prejudicial statements leading to diminished sense of self-esteem and self-efficacy” leading to demoralization and hopelessness (Corrigan & Fong, 2014, p. 111). Both public stigma and self-stigma occur in a broader sociocultural sphere in which structural stigma can develop (Corrigan & Fong, 2014). Structural stigma normalizes access disparities to resources for people who are likely already marginalized in other ways (Hatzenbuehler & Link, 2014).

Stigma has been identified as a barrier to health care for people with mental illness, obesity, hepatitis C, irritable bowel syndrome, Alzheimer’s disease, attention deficit hyperactivity disorder, physical disabilities, HIV and other conditions (Beam, 2001; Beeching, 2004; Corrigan, Watson, Byrne, & Davis, 2005; Dancey, Hutton-Young, Moye, & Devins, 2002; Gray, 2005; Herek & Capitano, 1997; Holston, 2005; Pettit, 2008; Richardson, Goodman, Hastorf, & Dornbusch, 1961). Across multiple studies stigma has emerged as “a fundamental cause of health inequalities” (Hatzenbuehler, Phelan, & Link, 2013, p. e7).

HIV-related stigma: its emergence and impact

HIV stigma has been conceptualized as emerging from a combination of

the disease itself, the behaviours that lead to infection, and perceptions of the initially affected populations (Valdiserri, 2002; Xiaboin, Sullivan, Jie, & Zunyou, 2006). In the earliest days of the epidemic, little was known about what caused the disease or how it was transmitted. Fear of the unknown solidified stigma towards HIV and contributed to an environment in which discrimination against people living with HIV was rampant. As a result, people living with HIV were treated as though they were carrying a highly infectious communicable disease (Mustich, 2011). Hospital patients were quarantined. Children diagnosed with HIV were not allowed to attend public schools with students their own age. People were banned from public swimming pools and openly mistreated (Shilts, 1987).

Once the disease was better understood, HIV-related stigma was reinforced by the behaviours viewed as contributing to the infection (Xiaboin et al., 2006). Public rhetoric among some groups and communities propagated a belief that people with HIV brought their diagnosis upon themselves through immoral personal behaviour. Religious leaders seized the opportunity to condemn homosexuality and suggested that the existence of HIV was proof of their god's ire with such behaviour. Finally, HIV was initially associated in the public's perception with stigmatized groups such as gay men and intravenous drug users (Herek & Glunt, 1988).

The role of disease-related stigma has been well documented as influencing behaviours around testing, treatment seeking and treatment adherence behaviours among people living with HIV (Herek & Capitano, 1999; Malcolm et al., 1998; Yang et al., 2004). Often stigma leaves people too afraid to seek help (Kerrigan, Bastos, Malta, Carneiro-da-Cunha, & Pilotto, 2006; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007).

Several studies have found that stigma deters at-risk individuals from engaging in prevention and education services, as well as discouraging them from being tested (Herek & Capitano, 1999; Malcolm et al., 1998; Yang et al., 2004). Self-stigma has also been found to contribute to social isolation, which can foster depression, low self-esteem and other emotional woes (UNAIDS, 2006). Both public and self-stigma discourage health-care access and treatment adherence, both of which contribute to faster disease progression and poorer health outcomes (Alonzo & Reynolds, 1995).

Empirical studies have begun to emerge that link structural stigma with negative health outcomes. Hatzenbuehler et al. (2014) found that the extent of antigay attitudes in communities was positively correlated with the risk of premature death for sexual minorities. Using data from the General Social Survey and the National Death Index, the research team found that living in a community with a high level of antigay prejudice resulted in a 12-year

shorter life expectancy for sexual minorities. Specifically, sexual minorities living in high-prejudice communities had higher death rates due to suicide, homicide/violence and cardiovascular disease.

Concern about the influence of stigma on HIV is evident in the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990, which was initiated nationwide to provide gap funding to address several of the structural barriers to care and treatment (U.S. Department of Health and Human Services, 2016b). First, the CARE Act addressed barriers related to insurance. Prior to the ACA, people with HIV who lost their insurance when they became too ill to work, and those who needed insurance after testing positive from HIV were excluded from purchasing new health insurance because they had a so-called preexisting condition (Cahill, Mayer, & Boswell, 2005). Second, the legislation incorporated funding for support and outreach services to ensure treatment coordination and promote adherence. Comparisons of data from the Ryan White Program to that of programmes with other types of funding has only demonstrated that the Ryan White Program is more successful in ensuring awareness of HIV status, ongoing medical treatment (Bradley et al., 2016; Cahill, et al., 2005; Gallant et al., 2001; Weiser et al., 2015) and viral load suppression (Bradley et al., 2016; Gallant et al., 2001; Weiser et al., 2015). The most recent authorization of legislation, known as the Ryan White Treatment and Modernization Act of 2009, continues to provide medical care, case management, treatment adherence counselling, oral health, medications, mental-health support, substance abuse treatment, housing support, medical transportation, food, legal services, psychosocial support and other types of services to people living with HIV.

Transdisciplinary approach to health care and social work's role

Between 1999 and 2013, the Institute of Medicine published four reports on the need to improve health-care quality in America. *To err is human* (Institute of Medicine [IOM], 2000) focused on safety issues in health care, including hospital deaths from medical errors. *Crossing the quality chasm* (IOM, 2001) recommended aligning payment and accountability with improvements in quality, promoting evidence-based practice and strengthening clinical information systems. *Health professions education: A bridge to quality* (IOM, 2003) recommended a mix of approaches to improve the education of health professionals to enhance quality and patient safety. The impact of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) was described in the

fourth report, *Evaluation of PEPFAR* (IOM, 2013). The IOM recommends that PEPFAR support and expand community and facility-based continuum models of service delivery that increase quality and efficiency of services (p. 240) and that PEPFAR build local professional capacity across disciplines (IOM, 2013, p. 540).

Taken together, the four publications contributed heavily to a growing interest in a transdisciplinary approach to improving individual and population health by synthesizing and extending “discipline-specific theories/concepts/methods to create new models/language” that address the complexities of modern health services (IOM, 2014, p. 72).

Collaboration at this level requires alignment of competencies, shared language, integrated practices and robust quality management systems (DeBonis, Becker, Capobianco, & Salerno, 2015). Transformation activities in the United States of America have centred heavily on the dynamics of provider relationships and communication of patient information. A major goal of the process has been to build a single actionable patient record that houses all personal health information about the patient. In order to actualize the single-record environment, all medical providers must be aware of one another, informed of each other’s assessments and coproducing health outcomes with the patient as a team. Efforts are also underway to construct medical neighbourhoods, where collaborative relationships are fostered among networks.

Moving forward, systems of care and care teams must establish relationships that foster collaboration and provide integrated patient-centred care. Nurses and physicians have had long-standing relationships in their mutual efforts to deliver high-quality care. Expanding access to and competency in these kinds of relationships to other health and health-related professionals could serve to strengthen those relationships as well.

This transdisciplinary approach has been promoted to address the challenges in providing care for people with HIV that emerge through the interaction between stigma and other barriers to care (Friedman et al., 2014; Parkes et al., 2015). The complexity of identifying people at risk of HIV infection, encouraging testing, making connections to treatment providers and ensuring treatment adherence requires a mix of medical, social and behavioural science approaches.

In the summer of 2015, key leaders of the HIV community gathered in Vancouver at the International AIDS Society Conference on HIV Pathogenesis and Treatment. They issued a consensus statement highlighting some of the continued challenges to ending the epidemic: “Knowing medicine cannot work in isolation and ARVs [antiretrovirals] alone cannot end AIDS,

a comprehensive, community-driven response attentive to underserved groups is urgent” (Beyrer et al., 2015).

In the HIV field, a competent health-care team must have the capacity to address the psychosocial and system-navigation needs of patients to address barriers to care that otherwise would lead to increased morbidity and mortality (Bowen & Walton, 2015; National Quality Center, 2016b). Often, people living with HIV have multiple needs that require accessing many systems in order to ensure a complete safety net in a fragmented system (U.S. Department of Health and Human Services, 2016c). Behavioural health needs take priority when those behaviours are a barrier to sustained engagement with HIV care. Patients might be more concerned about their food insecurity or housing instability than they are about their HIV care and treatment. Other patients might present with an experience informed by layered stigma and discrimination that manifests as difficulty engaging with care systems. A competent HIV care team must have the ability to address the needs of the patient that are both clinical and social in nature. It is this complexity that requires more voices to be present in HIV care teams to adequately address known needs.

Multidisciplinary teams have long been utilized in the delivery of HIV care funded through the Ryan White HIV/AIDS Program (RWHAP). Despite this multidisciplinary approach, viral suppression rates nationwide are only 30%, demonstrating a clear gap in performance given the provision of no-cost medical care and treatment (U.S. Department of Health and Human Services, 2016a). Further analysis of the HIV Care Continuum shows challenges in diagnosis of HIV care, linkage to HIV care and treatment, and retention to HIV care and treatment. Given the relationship between viral load suppression and onward transmission of HIV infection, it is imperative that barriers to engagement be addressed to support improved suppression. Improved access and adherence to antiretroviral therapy (ART) has both an individual outcome of prevented morbidity and mortality and public health outcomes of decreased HIV incidence (Cohen, McCauley, & Gamble, 2012). HIV care systems are also undergoing transformation, with RWHAP Part F-funded AIDS Education and Training Centers actively engaged in transformation support and interprofessional education (AIDS Education & Training Center Program, 2016). These activities are focused on improving outcomes along the HIV Care Continuum to improve health outcomes of people living with HIV. By adopting medical home principles, RWHAP is optimizing health delivery systems to meet the changing needs of communities and people living with HIV.

Social work is a key component of transdisciplinary efforts to address

the health needs of people living with HIV and minimize health disparities (Nurius & Kemp, 2012, 2014; Spitzer & Davidson, 2013). Within the context of the transformation in health care that has resulted from the ACA, casework is heavily focused on access to medical benefits across service needs. Now more than ever, it has become the duty of social workers to integrate multidisciplinary teams in order to help bridge the different languages that are spoken across disciplines. With its unique focus on marginalized populations and service coordination, social work is in a unique position to address the impact of disease-related stigma experienced by people living with HIV. Furthermore, social work, with its dual focus on individual- and system-level issues, is well situated to address multiple levels of stigma.

Direct or micro-level social work practice involves direct contact with people living with, at risk of and affected by HIV. This work often includes helping to identify and address barriers to accessing care as part of case management services, coordinating benefits, providing individual and/or direct financial support, providing counselling on medical treatment adherence and offering referrals to additional services that will help address health-related issues. Social workers have also delivered prevention programmes, offered pretest and posttest counselling and, in the earlier days of the epidemic, routinely coordinated disability benefits, hospice and permanency planning efforts for individuals who were living with HIV, as there was little hope for recovery (Buckingham, 1987). Managing mental-health symptoms is a key factor in maintaining treatment adherence for HIV, and social workers bring relevant skills to the transdisciplinary team. Finally, direct practice social workers may advocate on behalf of individual clients with the end goal to promote positive outcomes, including helping consumers to feel better, emotionally and physically, following a diagnosis.

Macro-level social work practice involves working with systems, research and policy. Macro-level practice can also include administering programmes or grants that are directed towards people living with HIV, or analysing data to determine ways that policy changes will affect access to health and social services. Macro-level social work includes advocacy, education, policy development and research. Social workers have long helped to advocate for policies at the local, state and national levels that are related to positive health outcomes for people living with HIV and promote the National HIV/AIDS Strategy (National Association of Social Workers, 2015, 2016; Teeters, 2005). Finally, macro-level social workers are involved in initiatives to improve the quality of health-care services provided to people living with HIV.

Social work has adapted its practice to address changes in treatment. As public health guidelines have changed, so has the manner in which social

workers have addressed the needs of people living with HIV. People living with HIV need someone to explain how, why and when their treatment needs to change (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2016); this is particularly true when people feel healthy, as it may seem counterintuitive to take medication if you have no symptoms. Ongoing policy analysis will remain a critical component of HIV care as long as there are disparities in public access to treatment.

As a vocation, social work must continue to professionalize in order to effectively collaborate at the systems level. Without a unified understanding of values, scope, credentialing and ethical practice, it is impossible to collaborate with other health professionals to establish a shared sense of health professionalism. An understanding of social work professionalism is required to negotiate and contribute to a larger health-care contract with society. Imperative to the establishment of relationships with the community of individuals living with HIV is an understanding of the illness as well as the disease. Experiences of stigma and discrimination are still realities for many people living with HIV, and still affect access and outcomes. Financial barriers and other life-related concerns take priority until they are resolved. Social workers are equipped with the ability to assess for these barriers, support activation, develop positive health-behaviours and mitigate the impact of stigma and discrimination. Social workers are poised to have a strong voice in the health-care teams of people living with HIV.

Assessing the impact of transdisciplinary practice on service quality

As described above, transdisciplinary practice in health care emerged through a concern about improving the quality of health-care services in the United States of America. The following section describes an example of the potential of transdisciplinary work to improve quality and patient outcomes and presents preliminary findings on the effort.

The HIV/AIDS Bureau has defined quality as the degree to which a health or social service meets or exceeds the needs of established professional standards (National Quality Center, 2006). Quality improvement is the process of ongoing monitoring, evaluation and improvement that includes the review of inputs, service-delivery processes and outcomes to continuously improve systems of care for individuals who are living with HIV (National Quality Center, 2006).

The National Quality Center is contracted to provide technical assistance and support to Ryan White-funded HIV care and treatment programmes

throughout the United States of America. It offers regional training in leadership, coaching and training of trainers on HIV-specific quality management (National Quality Center, 2016b). Beginning in 2011, the National Quality Center led the in+care Campaign. The in+care Campaign identified health-care indicators that focused on retention in care. These measures included medical-visit frequency for new patients, medical-visit frequency for existing patients and viral load suppression.

The National Quality Center provided resources for improvement of these measures and a platform for nationwide data entry for patients, most of whom were Ryan White recipients and subrecipients (National Quality Center, 2016a). Participation was voluntary. Data were collected every two months beginning in December 2011. The in+care Campaign is scheduled to continue through to March 2018. As of December 2013, data have been collected from 299 federally qualified health-centres, community health centres, health departments and hospital-based clinics.

Medical care structures inherently differ in the degree to which they are poised to implement transdisciplinary practice. For example, community health centres (CHCs) are established to serve underserved populations in the United States of America, such as homeless, indigent, poor and/or uninsured populations. Federally qualified health centres (FQHC) are those CHCs that receive specific federal grants under the Public Health Service Act. They must offer a sliding fee scale for patients and are eligible for reimbursement through Medicaid and Medicare for qualified visits. Health departments are generally public health entities that exist in communities to provide basic services that no one else in the community can provide (National Association of County and City Health Officials, 2016). They vary greatly in terms of capacity and expertise. Hospital-based outpatient clinics are designed to be fully integrated within the function of care provided within the hospital. Table 1 describes the key differences as related to the context of this chapter.

The in+care Campaign identified health-care indicators based on alignment with the National HIV/AIDS strategy. All four of the indicators are related to the HIV Continuum of Care, which is used in the United States of America to promote improvements in linkage to care, retention and viral load suppression. The in+care Campaign indicators are not directly aligned with Public Health Service guidelines, which are set to shape standard practice. For example, the in+care Campaign defined retention in care as not fewer than two visits each year for both retention and gap measures for all patients, even though Public Health Service guidelines require only one visit per year for individuals who are virally suppressed. The other important difference between the in+care Campaign and standard practice is the level of focused

Table 1 Differences in transdisciplinary practice in dominant HIV health-care providers in the United States of America

Type of provider	Provide access to basic health services	Provide additional health services	Provide range of oral health and social services	Single health record for integrated services across disciplines	Public or nonprofit
Federally qualified health centres	Required	Required	Required	Required	Required
Community health centres	Required	Required	Required	Required	Required
Hospital-based clinics	Required	Required	Not required	Not required	Not required
Health departments	Required	Not required	Not required	Not required	Required

Source: Authors

attention to each of these measures that was created by participation in the in+care Campaign. Participating agencies shared not only programme-level data but also practice tools, intervention techniques, ideas for tests of change and an overall standard of measurement for improvement. Providers engaged in data reporting every two months to ensure awareness of baseline measurement and progress towards improvement on each of the four measures.

The campaign provided a data-reporting and information-sharing forum for a range of professionals, including social workers, physicians, nurses, consumers, case managers, patient navigators and other community workers. In addition to developing ways to track these indicators, the in+care Campaign was intended to encourage professionals who work with consumers to implement, develop and share new interventions that will ultimately result in quality improvement (National Quality Center, 2016a) by sharing ideas and successes in practice. These activities help agencies understand their own baselines, prioritize quality management activities, design interventions and make improvements that are reflected in data.

It should be noted that data collected for the purpose of quality management activities are used to make local programme improvements. The data described here highlight the extent to which each type of programme was able to make measurable change on the described indicators. These data cannot be used to assess whether statistically significant improvements were achieved for patients.

In order to evaluate the impact of the in+care Campaign over time, these data include those agencies that submitted at least 80% of all possible data within the timeframe and all data in the last timeframe presented. This procedure ensures that the providers being compared were participants for the entire length of the study.

Baseline data were collected at the beginning of the in+care Campaign in December 2011. The number of sites and patients for whom baseline data is presented can be seen in Table 2. The data are tracked through medical records at HIV service-provider sites where fields such as enrolment date, visit frequency and viral load are documented at each patient visit. Data from client-level tracking systems were also used to calculate numerator and denominator for each measurement period. The final measurement that is displayed in Figure 1 through Figure 4 indicates the data that were collected at the last time period within the study (October 2013). See Table 3 for the number of sites and HIV patients who participated during the final phase of this study.

The number of sites increased between the baseline and final study measurement. The number of patients within a practice varies for a number of reasons related to both scheduling capacity and patient migration to different areas and/or clinics. As such, the number of patients described varies by measure and location.

The four measures tracked were defined by the in+care Campaign as follows (National Quality Center, 2016a):

- Gap measure: percentage of patients over the age of 24 months who did not have a medical visit with a provider with prescribing privileges in the past 180 days of the measurement year.
- Medical-visit frequency: percentage of patients over the age of 24 months with a diagnosis of HIV who had at least one medical visit with a provider with prescribing privileges in each six-month period of the 24-month measurement period with a minimum of 60 days between medical visits.
- Newly enrolled: percentage of patients over the age of 24 months with a diagnosis of HIV who were newly enrolled with a medical provider with prescribing privileges who had a medical visit in each of the four-month periods in the measurement year.

Table 2 Number of patients receiving services at each type of facility at baseline

	Federally qualified health centres		Community health centres	
	Number of sites	Number of patients	Number of sites	Number of patients
Gap measure	21	9287	11	5964
Medical-visit frequency	17	7817	9	5032
New patient	21	688	12	649
Viral load suppression	19	10 613	11	6538

Table 2 (continued) Number of patients receiving services at each type of facility at baseline

	Health departments		Hospital-based clinics	
	Number of sites	Number of patients	Number of sites	Number of patients
Gap measure	28	20 045	27	22 180
Medical-visit frequency	25	15 770	22	17 083
New patient	29	1066	26	1117
Viral load suppression	27	24 637	27	26 101

Source: National Quality Center. (2013). in+care Campaign. Retention data report: Consistent submitters by facility type. New York, NY: National Quality Center.

Table 3 Number of patients receiving services at each type of facility for final study measurement

	Federally qualified health centres		Community health centres	
	Number of sites	Number of patients	Number of sites	Number of patients
Gap measure	25	11 350	12	6541
Medical-visit frequency	23	9819	10	4326
New patient	24	606	12	455
Viral load suppression	23	12 702	11	7658

Table 3 (continued) Number of patients receiving services at each type of facility for final study measurement

	Health departments		Hospital-based clinics	
	Number of sites	Number of patients	Number of sites	Number of patients
Gap measure	29	25 489	29	26 522
Medical-visit frequency	29	23 665	25	23 005
New patient	29	1736	28	999
Viral load suppression	25	32 054	28	30 087

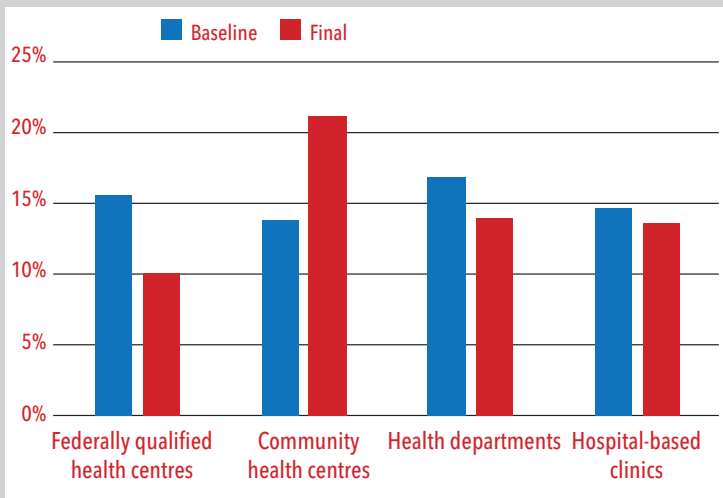
Source: National Quality Center. (2013). in+care Campaign. Retention data report: Consistent submitters by facility type. New York, NY: National Quality Center.

- Viral load suppression: percentage of patients over the age of 24 months with a diagnosis of HIV with a viral load less than 200 copies/mL at the last viral load test during the measurement year.

The campaign impact report describes several limitations to these data that should be considered before results are reviewed (JSI Research & Training Institute & National Quality Center, 2014). First, the data are reported at the clinic level, so patients who received health care at multiple locations could potentially be overcounted. Second, some clinics would only report Ryan White-funded care and treatment, even if the clinic population included other funders such as Medicaid, Medicare and/or private insurance. Third, data collection methods and quality likely varied across programmes. Not all providers tracked and reported every single performance measure throughout the course of the campaign. Data presented within this chapter represent a subset of in+care Campaign participants who submitted consistently from the beginning, representing over 25 000 patients throughout the United States of America (National Quality Center, 2013). Finally, quality management activities involve collecting baseline data and implementing interventions to improve data collection processes as the project moves forward. Hence, the quality of the data often improves as part of the quality improvement processes. As such, data are not considered experimental. Nonetheless, these data do help providers to know and understand the scope and limitations of practice and the extent to which they represent quality care.

The in+care Campaign resulted in significant improvement across all four indicators for all types of providers (JSI Research & Training Institute & National Quality Center, 2014). At the end of the campaign, data had been collected on over 90 000 patients by participating agencies. The gap measure decreased from 14.1% to 10.8%, visit frequency increased from 65.8% to 74.9%, new patient retention increased from 60.3% to 66.1% and viral load suppression increased from 70.0% to 76.4% (JSI Research & Training Institute & National Quality Center, 2014). While these findings are interesting in and of themselves, there were marked differences by provider type in the progress made in this campaign, which supports efforts for more transdisciplinary practice among HIV care providers.

The gap measure is intended to decline in order to show improvements in care. Figure 1 shows the percentage of people who were seen in the first six months of treatment and who were not seen in the second six months. FQHCs improved the number of people who were seen twice a year by 5.5%. Community health centres had the opposite trend overall, with a gap increase of 7.4%, indicating a decline in the number of clients seen twice each year.

Fig 1 in+care Campaign: Results of gap measure by care model

Source: National Quality Center. (2013). in+care Campaign. Retention data report: Consistent submitters by facility type. New York, NY: National Quality Center.

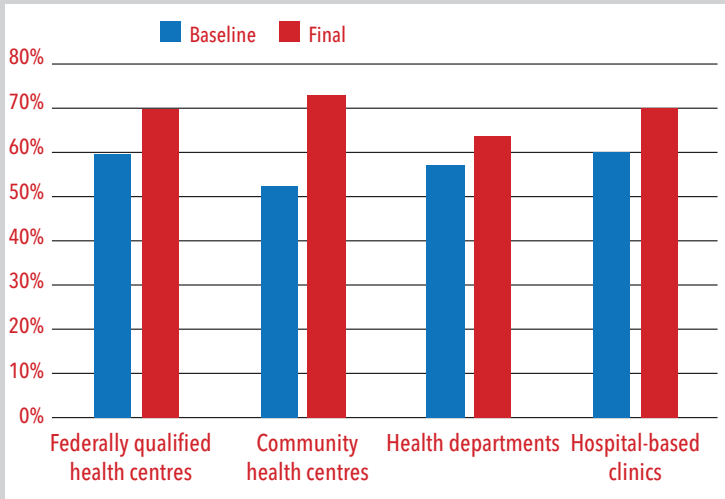
Health departments and hospital-based clinics showed some improvements, but not near the change seen by FQHCs.

The greatest gains of any indicator relate to increasing visit frequency. Figure 2 shows that FQHCs and community health centres had the greatest improvements, followed by hospital-based clinics and lastly health departments. As publicly funded entities, increasing the number of visits per patient is more feasible for federally qualified and community health centres because there is no additional coordination of insurance benefits needed in order to provide additional services. Figure 3 shows the campaign's impact on the new patient measure. With one exception, the results do not show marked differences on this particular measure by facility type. Health departments showed a decrease over time in the number of new patients who received a medical visit within four months of enrolment.

The overall difference in viral load suppression by provider type is notable. FQHCs and community health centres had increases nearly twice that of hospital-based clinics and health departments (Figure 4).

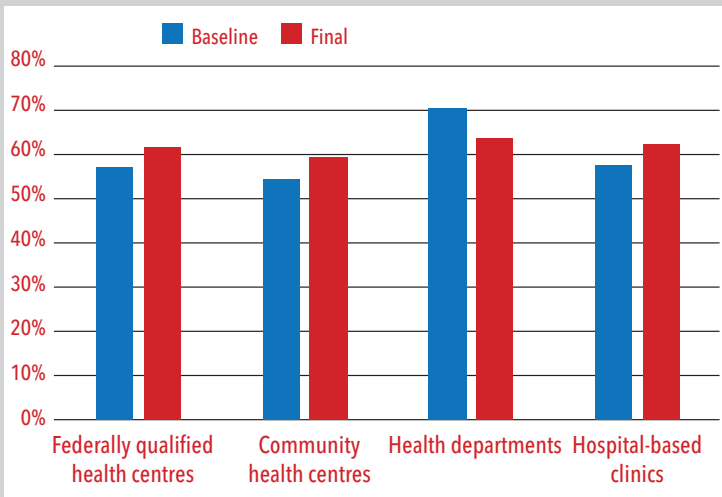
The in+care Campaign analysis by provider type demonstrates many of the points described in this chapter. Integrated care teams are vital to ensuring retention in care, viral load suppression and, ultimately, Getting to Zero.

Fig 2 in+care Campaign: Results of medical-visit frequency measure by care model



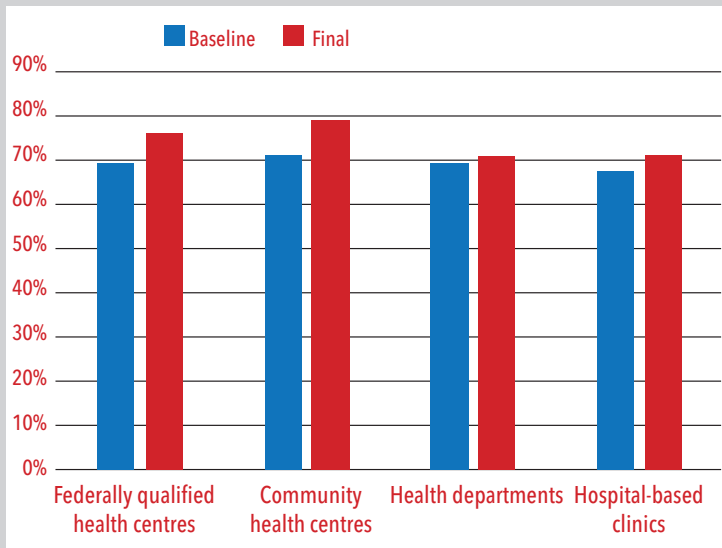
Source: National Quality Center. (2013). in+care Campaign. Retention data report: Consistent submitters by facility type. New York, NY: National Quality Center.

Fig 3 in+care Campaign: Results of new patient visits measure by care model



Source: National Quality Center. (2013). in+care Campaign. Retention data report: Consistent submitters by facility type. New York, NY: National Quality Center.

Fig 4 in+care Campaign: Results of viral load suppression measure by care model



Source: National Quality Center. (2013). in+care Campaign. Retention data report: Consistent submitters by facility type. New York, NY: National Quality Center.

Integrated care teams move towards transdisciplinary practice when they share common goals and objectives. Quality improvement activities can be implemented on a large scale across the United States of America, resulting in nationwide simultaneous positive health outcomes. While the in+care Campaign did not collect data on the role of social workers, they are understood to be vital members of the integrated care teams that have been described. The gap and new patient measures were not quite as consistent by provider type. These results indicate that the path to viral load suppression may not be directly linked to such minute quantification of visits. In other words, retention may need to be defined more broadly in order to parallel the results of viral load suppression.

FQHCs likely had the biggest gains in quality because they have requirements to provide a broader range of services beyond medical care and they utilize a single patient record. This requirement provides for opportunities to collaborate around the health needs of people living with HIV that might not be present for hospital-based clinics or health departments. FQHCs are also required to have a quality improvement plan in place that assures confidentiality and periodic assessment of service utilization and

needs to ensure that clinic services are comprehensive and address the needs of the community. The results for community health centres were mixed. These agencies resemble FQHCs in terms of the care model; however, they do not have the same funding resources, which may explain some of the variation in the data presented.

The results for these specific measures are not incidental; rather they are the result of teams of individuals working towards the common goals of increased visits and viral load suppression. It is not interdisciplinary teams that are creating this outcome, rather it is the integration of services across professions. Transdisciplinary is the vision, quality improvement is the implementation, and integration is the outcome. Transdisciplinary professionalism is one vehicle to move the needle to deeper integration, which are the models producing better patient outcomes. With its sense of collaboration, ability to adapt and focus on both people and systems, social work promotes the development of uni-disciplinary professionalism, which allows for the more sophisticated transdisciplinary professionalism. This level of coordination and collaboration addresses system barriers, including stigma and disparities, while fostering communication and service coordination.

SOCIAL WORK AND THE IN+CARE CAMPAIGN

Two elements join the in+care Campaign with social work. First, the in+care Campaign employed a clinical quality management model that required a foundational knowledge of patient characteristics. Addressing patient outcomes at the systems level requires the ability to connect with consumers and accurately assess root causes for barriers to adherence. As such, social work was a required element to ensure successes in the campaign. Second, through RWHAP, the participating providers in the in+care Campaign received federal funding. In discussing the Ryan White model, RWHAP Administrator Laura Cheever stated, “Ryan White funds a system of care versus a series of discreet services” (Aids.gov., 2015, 3:25). This system of care differs from traditional care in that supportive services are integrated into the care of people living with HIV. The supportive services and coordination of these services have been shown to significantly increase treatment outcomes (Aids.gov., 2015). A direct link between medical case management and viral suppression is demonstrated. The availability of services is only value-added when those services are also accessible. Navigation of complex health systems requires coordination and navigation of the health system itself and social services in the community. This framework is the foundation of care

coordination and medical neighbourhoods. Social workers in the RWHAP model have historically been, and continue to be, the primary driver of these service integration points. Although all of the programmes presented received Ryan White funding, the data highlight the difference in medical care models that not only include but also incorporate social work into the foundation of service delivery.

Social workers played a number of roles in the evaluation study described. Social workers provide ongoing case management services to ensure that the needs of clients are met, while reinforcing the importance and value of linkage, retention and viral load suppression. They provide valuable assistance to medical team members, who are limited in the extent to which they can address the cadre of needs experienced by consumers, whether they are linking clients to additional services or addressing stigma and providing emotional support. Social workers also have experience with a wide range of interventions that extend beyond a medical model. Social workers are trained to address barriers to treatment using a person-in-environment model of assessment and service delivery. With respect to HIV, the person-in-environment perspective that is emphasized in social work is critical to addressing stigma and ensuring linkage and retention in treatment. Additionally, the role of the social worker does not end with case management. Social workers continue to design and manage HIV programmes and help shape policy and advocate for consumers.

LESSONS LEARNED

Transdisciplinary teams are simply more equipped to address the many needs of people living with HIV. These teams usually include social workers (at the very least, elements of social work that help to integrate professions towards the common goal of Getting to Zero). Finally, quality management is the process through which we can demonstrate and monitor our progress towards these goals, as exemplified by the in+care Campaign. It will help guide practice across disciplines and determine the best measures that will result in zero new infections, zero AIDS.

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Is zero discrimination possible? Voices from Ukraine

Tetyana Semigina



ABSTRACTS

Drawing on interviews, documentary analysis and personal accounts of the author who has been working in the HIV/AIDS field for the past 15 years, this chapter discusses the issues of stigma and discrimination of people living with HIV in Ukraine. It reviews current interventions aimed at diminishing negative attitudes towards people living with HIV. Findings show that such interventions are targeting at macro-level (campaigns, trainings for medical-care personnel, etc.) and micro-level (direct advocacy during case management of people living with HIV, raising self-esteem and enhancing skills for self-advocacy) and are introduced by NGOs and supported by international donors. The problem of discrimination faced by people living with HIV is vital for many transitional countries, where human dignity is not valued and social work is underdeveloped. Looking at the research findings through the lenses of antioppressive concepts, the chapter argues for prospective action steps in overcoming stigmatization and discrimination of people living with HIV in Ukraine. This chapter views HIV activism as a push factor in advocating better social work practices.

ЧИ МОЖЛИВА «НУЛЬОВА ДИСКРИМІНАЦІЯ»? ГОЛОСИ З УКРАЇНИ

В цій статті, яка спирається на інтерв'ю, аналіз документів і особистий досвід автора, яка працює в сфері ВІЛ/СНІДу протягом останніх 15 років, обговорено питання стигми та дискримінації в Україні тих людей, які живуть із ВІЛ (ЛЖВ). У ній розглянуто поточні втручання, спрямовані на зменшення негативного ставлення до ЛЖВ. Результати засвідчують, що такі втручання засновані на макропрактиці (кампанії, тренінги для медичного персоналу тощо) і мікропрактиці (безпосередній захист прав під час кейс-менеджменту ЛЖВ, підвищення їх самооцінки і підвищення навичок для самозахисту), впроваджуваних НУО за підтримки міжнародних донорів.

Проблема дискримінації ЛЖВ має життєво важливе значення для багатьох країн з перехідною економікою, де людська гідність не цінується, в той час як соціальна робота слабо розвинена. Розглядаючи результати досліджень через призму анти-репресивних концепцій ця стаття окреслює перспективні практичні кроки в подоланні стигми та дискримінації ЛЖВ в Україні. Вона розглядає ВІІ-активізм як чинник поширення кращих практик соціальної роботи.

“零歧视”可能吗？来自乌克兰的声音

通过相关的访谈、文献分析以及翻阅笔者近15年在艾滋病领域工作的记录，本文论述了乌克兰艾滋病毒感染者被侮辱和受歧视的问题。本文回顾了目前旨在改变对艾滋病毒感染者的负面态度的干预措施。研究表明，这种干预是由非政府组织引入的，也得到了国际捐助者的支持，它们既是宏观实践（各种活动、医护人员培训等），又是微观实践（个案管理中对艾滋病毒感染者的直接宣传、在自我宣传中提高自尊心、改善技能）。艾滋病毒感染者的受歧视问题对于许多转型中国家都尤为重要，在这些转型中国家里个人尊严没有受到尊重，社会工作也未得到充分发展。从反压迫概念的视角来看本文的研究结果，本文主张，解决乌克兰艾滋病毒感染者所面临的社会侮辱和歧视问题需要采取前瞻性的行动和步骤。本章认为，在倡导更好的社会工作实践方面，艾滋病激进主义可以作为一个推动性因素。

¿La “Discriminación cero” es posible? Voces de Ucrania

A partir de entrevistas, análisis documental y relatos personales del autor que ha estado trabajando en el campo del VIH/SIDA durante los últimos 15 años, en este trabajo se tratan las cuestiones de estigma y discriminación de las PVVS en Ucrania. Se examinan las intervenciones actuales dirigidas a disminuir las actitudes negativas hacia las PVVS. Los resultados muestran que este tipo de intervenciones se basan en macroprácticas (campañas, cursos de formación para el personal de atención médica, etc.) y microprácticas (defensa directa en la gestión de casos de PVVS, elevando la autoestima y mejorando las habilidades para el auto-apoyo) introducidas por las organizaciones no gubernamentales y con el apoyo de los donantes internacionales. El problema de la discriminación de PVVS es vital para muchos países en transición, donde la dignidad humana no es valorada, y el trabajo social no está desarrollado. Buscando en los resultados de la investigación a través de los lentes de los conceptos anti-opresivos el documento sostiene los pasos de acción posibles en la superación de la discriminación social de las PVVS en Ucrania. En este capítulo se considera el activismo del VIH como un factor de empuje en la promoción de mejores prácticas de trabajo social.

『差別ゼロ』は可能ですか。ウクライナからの声

インタビュー、文書分析および過去15年間HIV/AIDS分野で働いた著者個人の記述に基づき、本論文ではウクライナでHIVと生きる人への汚名と差別の問題について検討します。また、HIVと生きる人に対する否定的な態度を減らすことを目的とする、現行の介入を再考察します。これらの介入は、NGOが開始し、国際的な資金提供者が支えるマクロレベル（キャンペーン、医療スタッフの訓練など）とマイクロレベル（HIVと生きる人の症例管理時の直接的な支援、自尊心向上、自己主張のためのスキル強化）に基づくことを、調査結果は示しています。

HIVと生きる人が直面している差別問題は、社会福祉が未発達で人としての尊厳が尊重されない体制移行国にとっては致命的です。反弹圧的な概念のレンズを通して研究結果を見て、本論文では、ウクライナでHIVと生きる人への社会的差別を解決することにおける将来の行動ステップについて議論します。この章では、HIV行動主義を、より良いソーシャルワークの実践を主唱する後押しとなる要因として見ていきます。

L'atteinte de l'objectif « zéro discrimination » est-elle possible ? Témoignages d'Ukraine

Inspirée des interviews, de l'analyse documentaire et des récits personnels de l'auteur, lequel a travaillé dans le domaine du VIH/Sida pendant les 15 dernières années, le présent chapitre analyse les problèmes de stigmatisation et de discrimination des PVVIH en Ukraine. Il évalue les interventions actuelles visant à réduire les attitudes négatives vis-à-vis des PVVIH. Les résultats montrent que ces interventions sont basées sur les macro-pratiques (campagnes d'information, formations pour le personnel de soins médicaux, etc.) et micro-pratiques (plaidoyer direct pendant la gestion des cas des PVVIH, renforcement de l'estime de soi et amélioration des connaissances pour l'auto-plaidoyer) introduites par les ONG et soutenues par les bailleurs de fonds internationaux. Le problème de la discrimination des PVVIH est vital pour de nombreux pays en transition, où la dignité humaine n'est pas valorisée, et le travail social sous-développé. En examinant les résultats de la recherche à travers l'optique des concepts anti-oppressifs, le chapitre milite pour des mesures d'intervention prospectives en vue de l'élimination de la discrimination sociale des PVVIH en Ukraine. Le présent chapitre appréhende l'activisme relatif au VIH comme un facteur pour la promotion de meilleures pratiques de travail social.

INTRODUCTION

Stigma and discrimination associated with HIV and AIDS are known and well documented in the literature (Adelekan & Edoni, 2012; Vlassoff, Weiss, Rao, Ali, & Prentice, 2012; Wolfe, Carrieri, & Shepard, 2010; Zukoski & Thorburn, 2009) as obstacles restricting HIV treatment process and effective HIV-prevention programmes.

In their declarations and actions, international organizations are striving to address the problems of discrimination related to HIV. Since the 1990s the issue of the human rights of people living with HIV has appeared on the political agendas (see World Health Organization, 1993; UNAIDS, 2003). The Declaration of Commitment, adopted by the United Nations General Assembly in June 2001, highlights global consensus on the importance of tackling stigma and discrimination associated with HIV. The political declarations adopted in 2006, 2011 and 2016 strengthened the human rights approach in combating the HIV epidemic and reaffirmed the urgent need to significantly scale up our efforts towards the goal of universal access to comprehensive prevention programmes, treatment, care and support (UNAIDS, 2016b).

In 2002, UNAIDS disseminated the document *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination*. It aimed to: 1) create a common understanding of HIV-related stigma and discrimination; 2) highlight some existing interventions targeting HIV-related stigma and discrimination; and 3) contribute to effective ways of preventing stigma and challenging discrimination (UNAIDS, 2002). In 2012, UNAIDS issued *Guidance Note on Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Response* (UNAIDS, 2012). In 2010, UNAIDS made human rights and gender equality one of three strategic directions (the other two being prevention and treatment) in its *Getting to Zero Strategy* (UNAIDS, 2010). Further development can be found in *Guidance Note on Reduction of HIV-related Stigma and Discrimination* (UNAIDS, 2014) and *On the Fast-Track to End AIDS: 2016–2021 Strategy* (UNAIDS, 2016a), which aim to address punitive laws as well as issues of stigma and discrimination.

Nevertheless, in many countries these recommendations of global actors have not yet been implemented, or have only been implemented partially (Doyal, 2013; Feyissa, Lakew, Girma, & Woldie, 2012), while stigma and discrimination continue to be major problems, even in an era when HIV treatments are more accessible (UNAIDS, 2007; UNAIDS, 2015). The vivid case in point is Ukraine, with its high levels of HIV and discrimination,

but with overall progressive legislation and public political declaration of commitments to ensure the rights of people living with HIV.

This chapter examines issues of stigmatization and discrimination against people living with HIV, reviews methods to tackle them and describes the peculiarity of the situation in Ukraine. It also critically looks at actions to counter stigma and discrimination directed towards people living with HIV in the ambivalent context of a transitional, post-totalitarian society.

THEORETICAL FRAMEWORK

This chapter is based on the UNAIDS definition of HIV-related stigma as: “[...] a ‘process of devaluation’ of people either living with or associated with HIV and AIDS [...] Discrimination is frequently caused by stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status” (UNAIDS, 2003). It also takes into account understanding of discrimination from a social work perspective based on concepts of antioppressive practices.

Much of the social work and sociology literature regarding stigma and discrimination focuses on the exercising of power by one group over others. In order to maintain positions of superiority, dominant groups may deploy processes of othering anyone deemed to be different, creating them–us divisions which “label ‘others’ as inferior and legitimate the exercise of power over them” (Dominelli, 2002, p. 18). Higgs (2015) proposes that social workers use critically reflective practice to explore the bigger political picture of power and disadvantage in society, and to consider multifarious aspects of social work interventions.

Thompson (2012) stresses that forms of disempowerment and oppression are modified over the long term: they are fundamentally affected by cultural, political and economic changes in societies. In his view, discrimination is predominantly structural and institutional in nature. But Stevelink, Wu, Voorend and van Brakel (2012) describe how structural relations of social oppression may be internalized, becoming embedded in people’s identities and their personal relationships.

A review of the literature (Adelekan & Edoni, 2012; Besonova, 2014; Stangl, Lloyd, Brody, Holland, & Baral, 2013; Stevelink et al., 2012; Thompson, 2012; Vlassoff et al., 2012) provides understanding of the interlinked levels of stigma and discrimination:

- Personal (self-stigmatization): unjustified beliefs about oneself that lead to feeling worse than peers, self-withdrawal, avoidance of

- certain activities and giving up on life activities.
- Family: manifestation of prejudice, negative attitudes, abuse; lack of support.
 - Community: manifestation of prejudice and oppression; lack of support; social exclusion and violence; denial of employment.
 - Institutions: rejection in services of care and treatment; neglecting rights.
 - Policy: punitive laws or misuse of criminal law; special demands of people living with HIV and oppressive legal practice, including prosecution and imprisonment for belonging to certain groups particularly vulnerable to HIV infection; violation of rights.

Contemporary thinking on discrimination (Ife, 2012; Sheedy, 2013; Straub-Bernasconi, 2012) notes that violation of rights might be disease (ability)-specific, gender-specific, culturally specific and/or country-specific (social, economic and political context of human rights assurance). For people living with HIV, such violations are diverse, multidimensional and multiplied (van Wormer, Kaplan, & Jubly, 2012; Vlassoff et al., 2012).

To better understand the stigma and discrimination experienced by people living with HIV, the Global Network of People Living with HIV and the International Community of Women living with HIV/AIDS, with the support of the International Planned Parenthood Federation and the UNAIDS Secretariat, developed the People Living with HIV Stigma Index. It focuses on different aspects of stigma and discrimination: social exclusion, access to work and health services, internal stigma, having children, knowledge and use of legal protection, effecting change, and HIV testing and disclosure (UNAIDS, 2007). The Index provides quite a comprehensive view on areas of inequality and inequity directed towards people living with HIV.

To tackle the issues of discrimination, social workers must base their activities on several key overarching tenets: awareness of the mechanisms of oppression, domination and injustice; acknowledgement of the structural elements influencing human behaviour; acceptance of diversity and difference; recognition of the complexity of power; and necessity for actions on different levels. Such an antioppressive framework (Ferguson, 2007; McKendrick & Webb, 2014) helps social workers to better address issues of oppression and privilege, and manifests more strongly the mandate of advancing social justice. Furthermore, Sims, de Chenu and Williams (2014) and Lombard (2016) argue that social justice needs to be underpinned by liberation, empowerment and equal rights.

Drawing from the specifics of attitudes towards people living with HIV,

UNAIDS (2014) suggests a set of steps for planning and designing programmes to reduce HIV-related stigma and discrimination: 1) in the analysis of the epidemic and response, identifying the extent to which HIV-related stigma and discrimination block the provision of services and the demand for services both beyond and within health-care settings; 2) identifying who is most affected by stigma and discrimination, and planning programmes that will address their particular needs and contexts; 3) costing and budgeting for programmes to reduce stigma and discrimination, since many planned programmes are never funded or implemented; 4) implementing programmes to reduce stigma and discrimination as critical enablers in order to ensure full access to and uptake of evidence-informed basic programmes; 5) monitoring and evaluating the impact of the programmes. These principles emphasize structural approaches with significant informational and cultural interventions, while a number of authors (DuBois & Miley, 2013; Morton & Montgomery, 2013; Moxley, 2016) also suggest empowering stigmatized individuals and groups to challenge discrimination.

Thus, the key interpretive frame of the study is that oppression serves as a master key for understanding discrimination, stigma and other unfair attitudes towards people living with HIV. This discrimination is multilevel, multidimensional, and specific to time and context. To combat it, multifaceted social work approaches (macro- and micro-levels) should be used. The proposed framework of the study is represented in Figure 1.

METHODOLOGY

The research aims to examine the discrimination of people living with HIV in Ukraine and the ways of combating it. It reviews current practices of the diminishing discriminatory professional and social attitudes towards people living with HIV and analyses experiences of the international projects funded by the United States Agency for International Development (USAID), and other donors.

The study, undertaken between March and July 2016, employs a mix-methods approach:

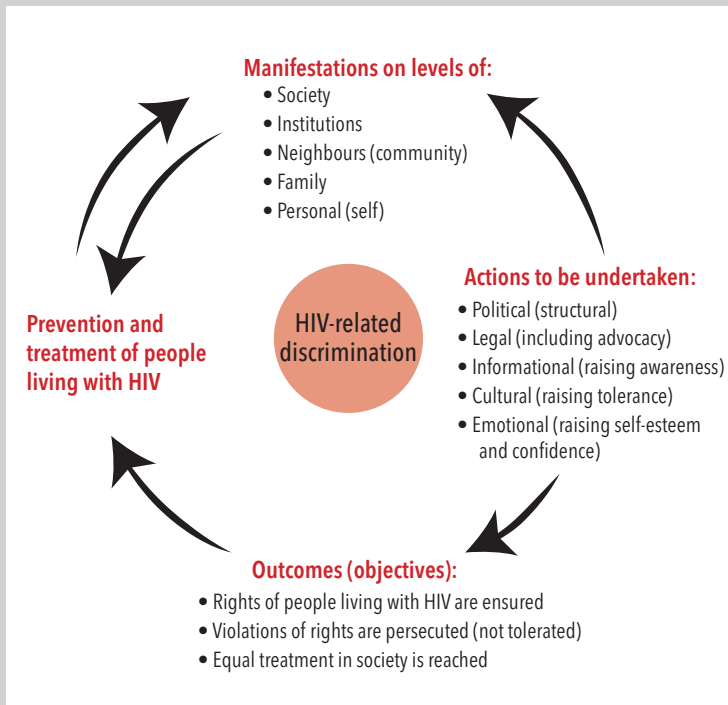
- Desk review: documentary analysis of research reports, project documentation, content of the websites of governmental and nongovernmental organizations (NGOs), as examples.
- Semi-structured interviews: 15 interviews with HIV-activists; 10 chairs of the NGOs representing people living with HIV and five social workers from such organizations in seven cities in

Ukraine (Dniepro, Chernigiv, Cherkasy, Kyiv, Lviv, Poltava and Zaporizhzhya).

- Ethnographic observations and reflections of the author, who for the past 15 years has participated in the development and implementation of different projects in the HIV domain.

Thematic analysis (Engel & Schutt, 2013) was applied to process the data. Specific considerations were given to: 1) manifestations of stigmatization and discrimination of people living with HIV; 2) how these issues are being addressed by social workers in Ukraine. The results of the research are presented through descriptive analysis; also some quotations from interviews are used throughout this chapter. Ethical dilemmas, including security and confidentiality, were taken into account.

Fig 1 Conceptual framework of the interactions between diagnosis, treatment and care of people living with HIV and actions to tackle stigma and discrimination towards people living with HIV



Source: Author's summary of the literature review

The author is aware of the limitations of research based on qualitative-analysis techniques (nonrepresentativeness and biases in selection of respondents who represent only HIV-sector views on the interventions and have also been affected by the sociopolitical context). Nevertheless, this research will hopefully appeal to those who want to understand the realities of social work practices in a postsocialist country experiencing an HIV/AIDS epidemic.

BACKGROUND INFORMATION ON THE HIV AND AIDS EPIDEMIC IN UKRAINE

Ukraine has one of the most severe HIV and AIDS epidemics in Europe. In 2015, 15 808 new cases of HIV infection were registered (2 961 of these were children under 14 years old). Between 1987 and 2015, 280 297 new cases of HIV infection were officially registered in Ukraine, and 38 128 people died from AIDS-associated diseases (Ministry of Health of Ukraine, 2016).

To date, people who inject drugs, sex workers, prisoners, street children and men who have sex with men have accounted for the majority of the reported cases. All these groups are regarded as marginal by Ukrainian society (Busza et al., 2011; Demchenko et al., 2014; Mimiaga et al., 2010).

According to the Ukrainian Center for Disease Control, 137 970 out of 264 489 Ukrainians living with HIV are registered under medical supervision (as of 1 January 2015). The highest HIV prevalence rates, according to the official registry system, are in the southern and eastern regions of Ukraine; that is, in the Dnipropetrovsk, Donetsk, Odesa and Mykolaiv regions. About 30% of new infections were in the Donetsk and Luhansk regions, now partially under rebel control, where tuberculosis—a common opportunistic infection in people with HIV—is also a major health problem (Ministry of Health of Ukraine, 2016).

The official statistics, however, do not reflect the real scale of the HIV epidemic in Ukraine, including the true number of people infected with HIV. It provides only the number of those who are voluntarily registered in the national registry of HIV patients. Many more Ukrainians may be unaware they are infected with HIV and are therefore unable to take adequate measures to preserve their health or prevent further transmission (Semigina, 2015).

The ongoing so-called hybrid war in the east of the country and a lack of public funds have further deteriorated the situation in Ukraine.

KEY FINDINGS

Attitudes towards people living with HIV in Ukraine

Data from various studies and interviews with HIV-activists in Ukraine show the population's tendency to retain extremely high levels of stigmatization and discrimination of people living with HIV, including self-stigmatization.

Assessments conducted in 2006 (Semigina, 2009), 2008 (Spicer et al., 2011) and 2012 (Bongiovanni, Sergeyev, & Semigina, 2013) suggest that stigma and discrimination were by far the biggest concern of all interviewed representatives of the key populations. Numerous people who inject drugs and many sex workers repeated harrowing stories of police brutality, corruption and abuse. Research on structural stigma (Pachankis et al., 2015) confirms unsupportive practices and policies towards sexual minorities in Ukraine, while the appropriateness of HIV-prevention services for sexual minorities is questionable (Bongiovanni et al., 2013).

Research using the People Living with HIV Stigma Index (carried out in Ukraine in 2010 and 2013) provided evidence that health care, education and employment are domains in which people living with HIV experience the highest level of stigma and discrimination (Demchenko et al., 2014). Many Ukrainian people living with HIV were either unaware of their rights and how to protect them, or did not believe that their rights could be addressed at all. The level of self-stigmatization was considerable—82% of respondents blamed themselves for having HIV, while 62% performed self-discriminatory actions.

Research conducted in 2014 and in 2015 revealed slight increases in tolerance towards people living with HIV (Volosevych, Konoplytska, & Moon, 2015). In 2015, most Ukrainians (68%) believed that people with HIV have the right to keep their diagnosis a secret. As for the belief that people only get HIV due to their immoral behaviour, the proportion of those who disagree increased significantly from 45% in 2014 to 52% in 2015. However, only 14% of respondents were ready to accept people living with HIV as colleagues, neighbours, close friends or family members. More than half of Ukrainians are intolerant of people with HIV—70% agreed to have such people only as visitors to Ukraine. Ukrainians are significantly intolerant of other vulnerable groups—for example, people who use drugs, men who have sex with men, bisexuals and sex workers. The percentage of those who accused people living with HIV of immorality increased from 18% in 2014 to 25% in 2015.

A disturbing fact is that only 37% thought it was acceptable for children who are HIV-positive to attend the same school as HIV-negative children (compared with 33% in 2014). One-third of Ukrainians (34%) believed that a

woman who is HIV-positive can give birth to a healthy child.

Interviews with HIV-activists conducted in 2016 prove the persistence of negative attitudes towards people living with HIV. Key institutional barriers to equal treatment were identified as: discharge from work; refusal of employment in the absence of a certificate confirming HIV-negative status; direct or latent denial of medical services; and refusals to attend educational institutions. Negative attitudes in communities and families are still manifested. It is not surprising that so far no well-known public figures (such as celebrities or politicians) have disclosed an HIV-positive status, while some HIV activists live with so-called open faces and become public figures.

In interviews, HIV activists stress that the main reason for discrimination is insufficient knowledge about HIV, especially how to live with the disease, as well as a stable perception of HIV as a disease of marginals. At the same time, some informants expressed the opinion that the personnel of Ukrainian health-care settings are intolerant and rude to all patients, not just people living with HIV. Various forms of institutional oppression (sexism, heterosexism and ablism) are observed towards people living with HIV in Ukraine.

Legal and policy aspects of discrimination towards people living with HIV

Nondiscrimination is enshrined in the Constitution and national legislation. Formally, no discrimination exists in the country. Overall, the HIV legal environment is regarded as supportive to people living with HIV; however, many legal and policy implementation issues are quite contradictory.

HIV has been proclaimed as a priority issue for Ukrainian public health and social care policy. Ukraine's HIV and AIDS policy covers a broad range of interventions, including prevention and treatment of HIV and the care and support of people living with HIV.

The cornerstone of Ukraine's national legislation continues to be the Law on the Prevention of the Spread of AIDS and Social Protection of Population, adopted by the Parliament of Ukraine in December 1991 and revised substantially in 2011. According to the views of a number of health-policy authors (United Nations Development Programme, 2008; UNAIDS, 2009; Bongiovanni et al., 2013), this legislation is aligned to the recommendations in the International Guidelines on HIV and Human Rights, is progressive and defines how the rights of people living with HIV to health care, social welfare and nondiscrimination can be protected. For example, it defines that HIV testing is free, voluntary and anonymous, while disclosing the HIV status of

a patient without his or her consent is a prosecutable criminal offence. This law articulates the obligations of the Ukrainian Government to ensure that the national response is “one of the priority tasks for the state in the field of health protection of the population” (Section 1). Nevertheless, the Secretariat of the Ukrainian Parliament Commissioner for Human Rights (2013) argues that Ukraine still lacks a strong human rights record for people living with HIV and at-risk groups, at least in practice.

Until 2010, this law contained outdated norms inherited from the Soviet era; for example a right to get an additional room in an apartment from the state. This right was purely a declaration—no such rooms were provided in reality. However, such legal statements supported the idea that people living with HIV are so-called others and have to be isolated and socially excluded. In 2016, HIV activists admitted in interviews that after disclosure of an HIV diagnosis they still encountered practices of personal relationships being broken, families isolating a person in a separate room, providing individual bedding, dishes, and so forth.

The rights of people living with HIV are determined not only by the above-mentioned law but also by other legislative acts. For example, the Family Code of Ukraine (adopted in 2002 and frequently revised) prohibits the adoption of children by people living with HIV. Interviewed HIV-activists regard this as a human rights violation and a manifestation of discrimination.

There is an evident gap between adopted HIV policy and its implementation. A study of the impact of the global initiatives on combating the HIV epidemic in Ukraine (Semigina, 2013; Spicer et al., 2011) brought to light unsupportive local policies regarding testing, treatment and care of people living with HIV, including social services provision by municipal agencies. An HIV policy assessment (Judice, Zaglada, & Mbuya-Brown, 2011) states that the legal environment lacks detailed mechanisms, such as operational guidelines or standards, to support the implementation of HIV laws and regulations. Insufficient resources are mobilized to implement the laws, policies and regulations. The assessment provided evidence of the lack of awareness and acceptance of legal protection for vulnerable groups among key stakeholder groups, including law enforcement, local government and health-care providers.

Informants in this study stressed the problems related to the lack of integration of different medical services (for example, HIV services and services for intravenous drug users; antiretroviral therapy and opportunistic infections treatment) and a lack of social services, including a system of social rehabilitation.

It is worth mentioning that, from the Soviet era, Ukraine inherited its

system of specialized medical centres for diagnosis and treatment of HIV and AIDS. This system has been considerably expanded in post-Soviet times (yet, no social worker positions were introduced into this service; only representatives of NGOs that have permission from the head AIDS centre may work at such centres). Moreover, special units for pregnant women with HIV and those with no certificate of HIV-negative status were opened at maternity hospitals. Thus, a segregated system of care was established for people living with HIV. For a long time, the drug procurement for it was provided by international organizations, and later by the government.

The political will to deal with the HIV epidemic is weak. It is mostly limited to declarations unaccompanied by sufficient funding for the actions and measures needed to prevent HIV transmission and to care for infected and affected people. At the same time, HIV is different from other areas of public health and social support. For instance, people living with HIV receive more free medical and social services than other groups, such as people with disabilities and people living with many chronic diseases. Research (Semigina, 2015) demonstrates the key role of Ukrainian NGOs and their international donors in this important change, as well as the lack of domestic resources. This also contradicts the declared policy of state guarantees, ensuring the rights of people living with HIV to care and social support.

All in all, the legal, political and societal factors of people living with HIV discrimination are mainly latent, based on an old-fashioned system of health and social care.

Practices and actions to counter stigma and discrimination

The first mutual support groups of people living with HIV were organized in the late 1990s, mainly in cities with high levels of HIV cases. Their main activities were concentrated on self-supportive psychological help and access to free medical care as declared by Ukrainian legislation.

In 2001, the All-Ukrainian Network of People Living with HIV (the Network) was officially registered as a charitable foundation. Nowadays the Network has about 400 employees and provides services to around 20 000 clients. It has branches in all of Ukraine's regions. It implements a number of international projects, draws the attention of public officials and tries to influence the state decision-making process (All-Ukrainian Network of People Living with HIV, 2016a). The author's analysis of its website and observations revealed that the Network's development relied heavily on international organizations, including the Elton John AIDS Foundation, the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), USAID and others. Services

changed according to the demands of donors. Observations and personal communications reveal the fact that the staff of these services have mainly ad-hoc social work training.

In 2011, a new HIV activist organization, the charitable foundation Patients of Ukraine, was established. This NGO lobbies for the interests of patients with HIV, tuberculosis (TB) and hepatitis, especially for their rights to free treatment and care. It also argues for more transparency in the implementation of public health policy. The partners of Patients of Ukraine are charitable foundations, NGOs and associations that actively protect the rights of people with HIV in Ukraine. This includes struggling against corruption and for greater levels and better use of public funds for treatment. A few campaigns were successfully implemented from 2013 to 2016 by Patients of Ukraine and the Network (Patients of Ukraine, 2016).

In recent years, numerous projects aimed at combating stigmatization and discrimination of people living with HIV have been implemented in Ukraine. In the 2000s, the private AIDS Foundation of Olena Pinchuck organized a few campaigns, mainly on television, to combat stigma and raise awareness of HIV among the general population (AIDS Foundation of Olena Pinchuck, 2016). The HIV/AIDS Service Capacity Project (USCP) was implemented and funded by USAID from 2007 to 2012; its focus was improvement of the quality of life of those affected by HIV. Helping to establish and strengthen local coordination councils, USCP also supported the involvement of people living with HIV in such councils (Bongiovanni et al., 2013). Thus, the project strengthened the ground for national and local policies where the voices of those affected by the HIV epidemic could be heard.

In 2012 to 2015, the GIZ project, supported by the Federal Government of Germany, launched the information campaign *Don't Give AIDS a Chance!* aimed at the general population but with a focus on youth. External evaluation (Vološevych et al., 2015) shows that 39% of Ukrainians have at some point heard about the campaign. Respondents recollected TV ads (24%), outdoor ads/billboards (17%), brochures (8%), newspapers (7%), Internet other than social media (6%), social media (5%), radio (5%), actions in the settlement (5%) and information from medical workers (4%). Despite all the efforts, however, the outcome was quite modest: only 20% of young people aged 15 to 24 were able to both correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about HIV transmission. Meanwhile, for example, nearly half of respondents aged 15 to 24 still believed in the possibility of HIV transmission through a mosquito bite or by sharing food with a person who is living with HIV.

In 2014, the Network, with the support of USAID/U.S. President's

Emergency Plan for AIDS Relief, initiated interventions to decrease HIV-related stigma and discrimination as a barrier to testing and treatment services. The two-year project's activities included: training for medical staff on stigma and discrimination prevention; an information campaign; development of HIV-friendly policies for health-care facilities; and implementation of specific algorithms for linking clients to care. The targeted facilities (TB, narcology, sexually transmitted infection (STI) clinics, obstetrics–gynaecology units and general hospitals), jointly with representatives of the community of people living with HIV, used a peer-to-peer approach for enrolment in testing and treatment. Training was arranged mainly by social workers and psychologists of the regional branches of the Network. The evaluation of outcomes showed that positive changes resulted from the model implementation: increased levels of HIV-transmission awareness, reduced levels of stigma caused by fear of being infected, positive dynamics in the practice of disclosure of a client's HIV status without her/his consent (All-Ukrainian Network of People Living with HIV, 2016b). However, the disturbing fact is that two years after the project's implementation, the integral index of the knowledge about HIV and AIDS increased from 54 to 64—and this is the indicator for health-care providers.

Since 2015 a new intervention known as Studio of Opportunities has been piloted in Ukraine. It is aimed at improving the quality of life of women living with HIV and who have small children. This new intervention is being implemented in four regions—Dnipropetrovsk, Cherkasy, Chernihiv and Poltava—in the framework of the USAID-funded project Improving HIV/AIDS services for key populations in Ukraine. Based on the approach of sustainable livelihoods, bringing attention to women's inherent potential in terms of their skills, social networking and access to physical and financial resources, this innovative intervention builds the dignity and self-esteem of its clients and opposes the deeply rooted self-stigmatization surrounding HIV-status through training, case management and direct advocacy.

Studio of Opportunities is based on conceptual frameworks that build on each other: 1) the Sustainable Livelihoods Framework, originally developed by the British Department for International Development in the 1990s, places people at the centre of their livelihood strategies and examines the various assets they use and have access to, as well as the structures, processes and contexts of vulnerability that affect the extent of their access to those assets; 2) the theory of self-efficacy and 90 days of motivating training (with its weekly goal cards and scores, daily actions to develop skills and new behavioural patterns, committed partners, affirmations and mediations, etc.) emphasizes what people have and not what they lack; 3) the social

ecological model, which helps strengthen and diversify people's resources by empowering them to influence and access the various aspects that make up their enabling environment. None of these concepts fits the paternalistic Soviet-style welfarism-based model that dominates Ukrainian social work (Semigina & Tymoshenko, 2016). This model holds that social workers should deal with, for example, the provision of long-term care for elderly and disabled people according to entitlement criteria and not on the basis of individual-needs assessment, payments of in-cash social assistance and so forth.

Professional social workers were involved in all of the above-mentioned projects (with the exception of the AIDS Foundation of Olena Pinchuck), as managers, experts and trainers. Nevertheless, the activists interviewed consider the role social workers play in countering HIV-related discrimination to be quite inactive. In their own words, social workers “themselves should not stigmatize people living with HIV and should guarantee the rights of people living with HIV” (respondents were talking about workers in state social agencies); they “must combat violation of rights in various facilities—educational, health care, for example, when diagnosis has been disclosed” and “should participate in public actions aimed to raise awareness among the general population”.

My observations and field interviews confirm that the main activities focused on elimination of stigma and discrimination are implemented by NGOs that are generally run by people living with HIV and HIV activists, not social workers. To advocate for the rights of people living with HIV, NGOs use both conventional and nonconventional approaches.

According to the opinions of those who were interviewed, in order to reach zero discrimination in Ukraine it is worth undertaking the following steps:

- Structural: “to ensure proper social and economic development, when all citizens will have fair payment for their work, access to quality medical and social services, the crime rate will be low, etc.”; “sound policy to combat discrimination towards any person will be adopted”.
- Social work on the macro-level: “informational work with the general population aimed at raising awareness about HIV, especially among school teachers, parents, children at schools”; “work at schools and then at universities”; “health promotion among working people”; all of these activities should be based on more modern interactive methods.
- Social work on the micro-level: active advocacy of people living with HIV and direct work with service providers; “teaching people

living with HIV the self-advocacy methods”; “empower people living with HIV to fight for their rights”; “provision of information to people living with HIV about their rights and real possibilities to utilize them”; “counselling people living with HIV and arranging group work with them to combat self-stigmatization”.

A few respondents pointed out that “the revision of legal acts is necessary”, “refusal from the segregated system of medical and social care for people living with HIV would be beneficial”. Three out of the 15 interviewed activists agreed that “public figures have to [disclose] their HIV-positive status and become ‘voices’ of people living with HIV”.

To sum up, the current action to counter HIV-related stigma and discrimination can be defined as insufficient and incoherent, while innovative projects lack sustainability and diffusion. Despite all the action taken, public and professional awareness about HIV is still low. More actions should be undertaken—by social workers and beyond social work.

DISCUSSION

The issue of HIV-associated stigma and discrimination is critical not only for Ukraine, but also for many post-totalitarian countries. In such countries, human dignity and human rights were not valued and discrimination against people with special needs was a common practice, while social work did not exist or was based on the philosophy of social pathology (Ramon, 2000; Rasel & Iarskaia-Smirnova, 2014). At the same time, the current neoliberal context in Ukraine, with its individualist perception of social problems, lays out a new foundation for a consumerist approach to social work as a service (Semigina & Boyko, 2014).

The lessons learned from this study provide some useful insights into the peculiarities of the manifestation of discrimination in Ukraine towards people living with HIV and actions needed to counteract it, noting what seems to work best for key populations.

Latent nature of HIV-related discrimination

This study shows that stigma and discrimination in Ukraine have a hidden nature and are context-specific. Overall, policy and legislation are supportive of people living with HIV, yet are not implemented fully. Public perceptions remain quite negative: people don't want to have people living with HIV as

their relatives, neighbours, coworkers or classmates; they are not perceived as people who simply have a chronic disease, but as so-called others in society. People living with HIV experience indirect refusal of services or dismissal from work for various reasons. The issue of moral superiority is believed to be a problematic stance for advocating the rights of people living with HIV.

The high level of self-stigmatization among people living with HIV creates a reluctance to fight for one's own rights at the level of institutions. Discrimination at the community level limits HIV activism and HIV advocacy programmes, given that many people living with HIV are afraid to participate in political activities because of disclosure.

People living with HIV in Ukraine have low access to resources and can be regarded as marginalized, having “clusters of disadvantages” and limited human rights (Jürgens and Cohen, 2009, p. 8). More powerful groups limit the external and internal resources of people living with HIV and of others with health problems, and thus antioppressive practice should be applied as described by Dominelli (2002), McKendrick and Webb (2014), McDermott (2014), and Ioakimidis (2015). Antioppressive practice must start from recognition of the complexity of the power exercised over people living with HIV and the necessity for action at different levels, including political action such as fighting poverty and intolerance in society.

Positive discrimination as grounds for negative attitudes

Innumerable accounts of social exclusion and discrimination and the state's lack of preparedness to deal with the HIV epidemic in Ukraine show that the institutional discourse is still in a patronizing mode regarding the relationship between the state and the people.

Ukrainian legislation grants people living with HIV a wide range of additional rights. A few of these rights have already been implemented by the state; among them are the separate state-financed medical services provided to patients with HIV. Many other Ukrainian patients experience problems with receiving medical care and have to pay for all services (Stepurko, Pavlova, Gryga, Murauskiene, & Groot, 2015), while people living with HIV receive their antiretroviral therapy for free. At times, this provokes a sort of envy in society, given that the health-care system in Ukraine is still ill-functioning (Lekhan, Rudyi, Shevchenko, Nitzan Kaluski, & Richardson, 2015).

This practice of segregated services and substantial, though declarative, additional rights strengthens the perception of people living with HIV as so-called others among the general population, professionals and people living with HIV themselves, deepening their psychological traumas and self-

stigmatization. Such positive discrimination—as Curry-Stevens (2011, p. 355) states, “[...] the privileged are somehow victims as being privileged”—can be regarded as an obstacle to viewing people living with HIV as any other special-needs group in society and is grounds for latent social exclusion. Integrated approaches ought to be promoted and introduced while preserving opportunities for people living with HIV to receive medical and social care.

This complex nature of privilege and oppression suggests that advocates should move away from binary, dualistic thinking of bad and good, and employ less discrete and more inclusive approaches. Lombard (2016)—based on the ideas of the Global Agenda for Social Work and Social Development (International Federation of Social Work, International Association of Schools of Social Work, and International Council on Social Welfare, 2014)—suggests values and principles that can help us build a positive future for all, and that open a possibility for expanding solidarity and social justice.

NGO-ization of social work with people living with HIV and combating the HIV epidemic

This research adds another layer of complexity to understanding the role of NGOs in combating the HIV epidemic.

Professional social work emerged in Ukraine at the same time as the collapse of the Soviet regime. To some extent, it inherited the paternalistic welfare model of socialist social provision, as well as populist proclamations about helping poor people and ensuring social guarantees. Until now, social work, as a relatively new profession and academic discipline in Ukraine, has had marginal status (Semigina, Kabachenko, & Boyko, 2016), and many paraprofessionals or people with educations other than in social work, if any education at all, work in social services.

Social services for people living with HIV are provided mainly by NGOs (branches of the Network) and are subsidized through diverse short-term international projects. The state proclaims the right of people living with HIV to social services, but municipal social organizations don’t provide them and professional social workers are not employed in health-care settings. Thus, NGOs are the only places where people living with HIV can find support, and only NGOs advocate for their rights. The term social worker is a loosely used title for the employees of NGOs who are responsible for social and psychological consultations; many interventions can be regarded as peer-to-peer support. However, the antioppressive practice of social work and modern interventions implemented through NGOs confront the so-called welfarism of state social services.

This process of the NGO-ization in combating the HIV/AIDS epidemic in Ukraine is quite similar to processes in countries with substantial western-donor funding. Craddock (2000) and Gray and Webb (2014) consider that NGO-ization is supported by international-organization-involved decentralization and the installation of civil society organizations as channels of influence. This can be regarded as a postcolonial soft imperialism because these activities are based on the western liberal discourse of human rights and are supported by global actors through funding, technical assistance and the adoption of international standards.

The historical evolution of Ukrainian NGOs from providing social services to political action, and from conventional to nonconventional practices, contrasts with comparable developments in many other countries where activities initially focused on antidiscriminatory policies (Gutnik, 2009; Kallings, 2008). This is because when the HIV/AIDS problem in Ukraine became visible, the epidemic's causes were already known and supportive treatment was available.

The study shows that there is a considerable urgency to advance advocacy practices for marginalized communities living with HIV. A prospective scenario for tackling HIV-related discrimination in Ukraine can be drawn from the ideas of Zhukova (2013) and Gray and Webb (2014), who stated that civil society, mindful of all the principles suggested by UNAIDS (2007), has to play a more decisive role in raising awareness, pushing for changes in the status of people living with HIV, removing economic and judicial obstacles to equal treatment for all marginal groups in society, and influencing improvements in social work education.

LESSONS FOR SOCIAL WORKERS

This study concludes with an appeal to social workers to make more extensive use of different advocacy strategies to reach the goal of zero discrimination. It is necessary to inspire practitioners to become as persuasive as possible in order to advance social justice and influence policy-makers and other political actors, including community leaders and opinion makers. The specific and challenging task in Ukraine is related to transformation of the postsocialist system of segregated care and formal privileges for people living with HIV and, instead, promoting attention to the human needs of people living with HIV.

In Ukraine (and in other countries), social workers should work more extensively with the feelings of guilt of people living with HIV. This conclusion

is congruent with the suggestions of Curry-Stevens (2011, p. 357), who looks at guilt as a positive motivator for tackling self-stigmatization and advises to use it “as long as the advocate also takes responsibility for ensuring that it does not immobilize and that actions are recommended. The most intense reactions are believed to occur when powerful arguments are made as to the complicity of the target in the oppression of others, such as intentional shaming messages.”

Ukrainian experience shows that social work educators have to look critically at educational programmes and be sure that they contain targeted courses to equip practitioners from NGOs and social work students for advocacy practice, including teaching methods of building techniques in self-advocating and empowerment, as well as preparing for modern, interactive health promotional activities. Building advocacy and informational efficacy within the field can help social work better embrace its mandates in reaching a more equitable situation and fighting societal discrimination. HIV-activist organizations have to cooperate with universities and other educational establishments to ensure modernization of training programmes.

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Part 3: Zero AIDS- related deaths

Medical case management: An ideal place for social workers

Diana Ball and Mary Edinger



ABSTRACTS

Advances in treatment have made HIV a manageable condition in many parts of the world. However, barriers to proper adherence and medical care exist among many people living with HIV. For example, distance to HIV care can be a significant barrier. Additionally, poverty, trauma, poor social support, mental illness and substance use can negatively affect one's ability to navigate complex medical and financial-aid systems. Social workers are ideally positioned to assist people living with HIV to overcome these barriers. By utilizing social work skills in advocacy, teaching and education, social workers can be most effective when working alongside the medical community, acting as a bridge between patient and provider. This chapter will discuss the medical case management programme at a publicly funded HIV clinic in central Kentucky, USA. We will discuss the practice implications of collaboration with the medical community and provide case examples to enhance application to a variety of settings.

医疗个案管理：社会工作者的理想场所

在世界许多地区对艾滋病病毒/艾滋病治疗所取得的进展，使艾滋病病毒/艾滋病治疗成为一种可以控制的操作。然而，许多艾滋病病毒携带者/艾滋病人群在坚持治疗和医疗护理方面还会受到诸多限制。例如，与艾滋病病毒携带者/艾滋病人护理之间的距离是一个重要的限制。此外，贫困、创伤、社会援助差、精神疾病和物质的使用等都可能负面地影响到某个人享受复杂的医疗和金融援助系统的能力。社会工作者最适合帮助这些艾滋病病毒携带者/艾滋病患者克服这些障碍。通过在宣传、教学和教育过程中利用社会工作技能，社会工作者在与医疗社区一起工作时可能最有效，可以成为患者和医疗服务提供者之间的桥梁。本章将讨论在美国肯塔基州中部一个公共资助的艾滋病病毒/艾滋病诊所的医疗个案管理计划，我们将讨论与医疗界合作的实践意义，并提供案例以提高对各种情景的应用。

Gestión de un caso médico: El lugar ideal para los trabajadores sociales

Los avances en el tratamiento han hecho de la infección del VIH una condición manejable en muchas partes del mundo. Sin embargo, muchas personas que viven con el VIH encuentran obstáculos para el cumplimiento adecuado del tratamiento antirretroviral (adherencia) y para acceder a la atención médica. Por ejemplo, la distancia a los servicios de atención del VIH puede ser un obstáculo significativo. La pobreza, el trauma, el escaso apoyo social, la enfermedad mental y el consumo de sustancias pueden afectar negativamente la capacidad para navegar los sistemas complejos de atención médica y financiera. Los trabajadores sociales están en una posición ideal para ayudar a las personas que viven con el VIH a superar estos obstáculos. Mediante la promoción y la educación, podemos actuar como puente entre el paciente y el proveedor de servicios de salud. Este capítulo aborda el programa de gestión de casos médicos de una clínica de atención del VIH, sustentada con fondos públicos, en el centro de Kentucky, EE.UU. Se debate sobre las implicaciones prácticas de la colaboración con la comunidad médica y se proporcionan ejemplos para mejorar la aplicación de estas intervenciones en diversos entornos.

医療事例管理：ソーシャル・ワーカーの理想的な場所

治療の進歩により、HIVは世界の多くの地域で対処可能となりました。しかし、適切な固守と医療に対する障害が、HIVに感染した多くの人の間で存在します。たとえば、HIV治療までの距離が著しい障壁となることがあります。その上、貧困、トラウマ、劣悪な社会的支援、精神疾患と薬物使用が、複雑な医療支援および財政支援制度を得るための能力に悪影響を及ぼすことがあります。ソーシャル・ワーカーは、HIV/AIDSに感染してこれらの障壁を克服しようとする人々を助けるために、理想的な立場にあると言えます。社会福祉援助技能を、政策提言と教育に役立て、医学界とともに進むことで、患者と医療提供者の間のかげ橋となり、ソーシャル・ワーカーは最大にその効果を発揮できます。この章では、米国のケンタッキー州中部において公的資金で運営されているHIVクリニックでの医療事例管理プログラムについて検証します。医学界との協力による実践のもたらす意味を議論し、いろいろな状況への適用を強化するために、事例を提供します。

Gestion des cas médicaux : Un cadre idéal pour les travailleurs sociaux

Les avancées dans le traitement ont rendu le VIH une condition gérable dans de nombreux pays au monde. Cependant, les barrières à une adhérence et aux soins médicaux appropriés sont observées chez les personnes vivant avec le VIH. Par exemple, la distance aux soins de traitement du VIH peut

constituer une barrière importante. Par ailleurs, la pauvreté, le traumatisme, la mauvaise prise en charge sociale, la maladie mentale et la consommation de drogues peuvent affecter négativement les capacités à accéder aux systèmes d'aide médicale et financière. Les travailleurs sociaux sont bien placés pour aider les personnes vivant avec le VIH à surmonter ces barrières. En utilisant nos connaissances dans le plaidoyer, l'enseignement et l'éducation, nous pouvons être plus efficaces lorsque que nous entrons en contact avec la communauté médicale, en jouant le rôle de pont entre le patient et le prestataire de services. Le présent chapitre étudie le programme de gestion des cas médicaux traités dans une clinique publique de soins du VIH situé au centre du Kentucky, É.-U.. Nous analyserons les implications de la pratique de la collaboration avec la communauté médicale et fournirons des exemples de cas en vue d'une meilleure application dans différents environnements.

INTRODUCTION

Social workers have been key professionals in the fight against HIV from the very beginning of the epidemic (Rowan, 2013). However, the rapid dissemination of highly active antiretroviral treatment (HAART, or ART) has moved HIV care from the palliative care of terminally ill individuals to the medical management of a serious but treatable chronic condition (Este & Cihlar, 2010; Rowan, 2013). This gradual shift away from supporting a dying individual and his/her friends/family to medical treatment of a chronic condition has turned the focus of HIV care away from psychosocial and environmental factors to attention on long-term medical care. Although the medicalization of HIV has increased life expectancies for this population, it may also have limited the availability of resources and support necessary for people living with HIV. Unlike medical conditions such as hypertension or diabetes, HIV diagnosis is still stigmatized and largely misunderstood by society. Many people at the highest risk of contracting HIV are already at the margins of society due to, for example, drug use, mental illness, gender identity, or racial or ethnic minority status (Blair et al., 2014; Brezing, Ferrara, & Freudenreich, 2015; Hillis, Anda, Felitti, Nordenberg, & Marchbanks, 2000; Karim, 2011; Lakdawalla, Sood, & Goldman, 2006; Zurlier et al., 1991). A diagnosis of HIV further marginalizes and stigmatizes these individuals. It is nearly impossible to divorce psychosocial factors from the treatment of HIV.

Recent research indicates that HIV providers are discovering this truth: psychosocial factors are associated with diagnosis, engagement to care and retention in care (Cox, 2013; Holtzman et al., 2015; Ware, Wyatt, & Tugenberg,

2006). Additionally, numerous psychosocial factors have been found to be associated with medication adherence. For example, mental illness including depression, anxiety and posttraumatic stress disorder (PTSD); substance use disorders; poverty and lack of social support (Cox, 2013; Gordillo, Amo, Soriano, & González-Lahoz, 1999; Mugavero et al., 2009; Nel & Kagee, 2011; Sledjeski, Delahanty, & Bogart, 2005; Ware et al., 2006; Whetten, Reif, Whetten, & Murphy-McMillan, 2008). Some HIV medical providers find that the most effective treatment for HIV includes multidisciplinary care such as mental health, substance use treatment and case management (Gardner et al., 2005).

The Joint United Nations Programme on HIV/AIDS (UNAIDS) Strategy 2016–2021, *On the Fast-Track to End AIDS*, discusses three key areas on which to focus: prevention, treatment and advocating for human rights and equality (UNAIDS, 2015). Medical case management provided by social workers focuses on providing accessible treatment; however we could argue that social work has a broader approach that includes prevention and advocating for equality. Throughout this chapter, we discuss efforts to ensure that all clients receive quality care, eliminating the barriers caused by socioeconomic status.

ABOUT THE BLUEGRASS CARE CLINIC

The Bluegrass Care Clinic (BCC) is a grant-funded HIV clinic embedded into a larger university health system. We provide comprehensive medical, mental health and case management services to low-income people living with HIV. We serve approximately 1 300 people living with HIV from a 331 000 mi² (857 000 km²) area, a southern state in the USA. Our client population comes from both urban and rural settings. The majority of BCC clients are Caucasian men who have sex with men; however, we see a disproportionate number of African American males. Additionally, we are seeing an increase in people who inject drugs. Mental illness and substance use disorder (SUD) are rampant in the clinic population, mirroring the shortage of mental health and SUD treatment in the area. The BCC employs two full-time licensed clinical social workers and contracts with outside mental-health providers to address the mental-health needs of our clients. Ten master's-level social workers assist our clients in eliminating barriers to effective HIV treatment and retention in care.

It is through the ongoing collaboration between medical providers, social workers and retention specialists that our clinic is able to provide quality HIV

care to our clients. This quality of care is evidenced by the 96.3% retention rate in 2015. Approximately 90% of clients retained in care at our clinic in 2015 had viral loads of less than 20 copies per ml.

MEDICAL CASE MANAGEMENT

Defining medical case management

Social workers are employed as case managers in community agencies to provide services for people living with HIV. Case managers are often tasked with assisting clients to gain access to much-needed resources such as housing, food, transportation and childcare. Other professions have adapted to provide case management services in the medical field. For example, nurse case managers often focus on the medical needs of the client. However, when working with highly stigmatized chronic conditions such as HIV, medical case managers must be able to balance an understanding of the medical condition along with the client's social, economic and psychological situation. Social workers bring a unique set of skills that allows us to best facilitate the combination of medical and psychosocial factors that people living with HIV often face. Social workers are uniquely positioned to enhance the medical care of people living with HIV by contributing to care through coordination of services, mental health care, advocating for the client and fostering mutual respect and understanding. These aspects of medical case management from a social work perspective will be discussed in greater depth later in this chapter.

Social work is a broad profession. Social workers are trained to manage caseloads and provide mental-health counselling. They work with children, adults, families and communities. Social workers work at the individual or community level, or advocate for social justice in national and international arenas. This broad scope of practice can be confusing for those determined to pin the profession down to a particular category. However, the broad scope of practice can be helpful in medical case management. Social workers are professional chameleons, taking on the persona of the environment while simultaneously remaining true to professional values. Social workers have become adept at adapting to their surroundings as they provide services to clients with dignity, respect and equality. In a medical setting, social workers can work with medical providers to provide education and support aimed at the client's comprehension level while also encouraging medical providers to embrace a holistic view of the client in order to provide sensitive, compassionate care that fits the client's medical and psychosocial needs.

Social workers bridge the gap between client and health provider in a way that allows each to communicate his or her needs and reduce barriers to effective treatment of the client's HIV infection. In this chapter, we will discuss social work's role in medical case management in supporting clients and providers in the medical treatment and care of people living with HIV. Our discussion will pull from our experiences as medical case managers embedded into an HIV clinic in central United States of America (USA).

Integrating medical care and social services

Through many years of serving low-income people living with HIV, the authors are keenly aware of the potential barriers to retention and treatment that many clients experience. It is fundamental to address the many potential barriers that people living with HIV face to remain in care and access ART with strict adherence (Cox, 2013; Gordillo et al., 1999; Holtzman et al., 2015; Ickovics & Meade, 2002; Sabeto, 2003). Without a holistic, person-in-environment perspective and adequate understanding of each individual's life experiences, it is very easy for professionals to work with a nonadherent HIV client and think: "Why aren't they taking their medication?" "It is just one pill, just pick a time and take it!" "Don't they know they will die if they don't take this medication?"

For many of our clients, life is more complicated than coming to the doctor a few times a year and taking a pill every day. Often, our clients are living with the effects of stigma and discrimination due to their sero-status, violence, complex trauma, generational substance use and comorbid medical conditions, in addition to poverty and low family or social support. These are problems that many medical providers are ill-equipped to solve. In fact, the very nature of medical training often places the provider in a position of feeling they need to solve problems: follow these simple steps and you will be well. Social problems are not resolved with a course of medication or surgery.

Assisting people living with HIV to navigate the complexities of life with HIV is the job of the medical case manager. A medical case manager (MCM) performs many of the tasks of a case manager: screening for and maintaining programme eligibility, providing referrals to resources, and assisting with financial needs as available through programme funding. However, the MCM is also a key member of the medical team. An MCM is often available to help explain and reinforce information provided to the client by the medical provider. Using the depth of knowledge about the individual's life, the MCM can repeat medical instructions in language that the client understands and assist the client in creating plans for medical care that work for his or her

lifestyle. The provision of case management services within an HIV clinic is one tool available for expanding uptake of health services by carefully using decentralization, reassignment of responsibilities and deployment of community health workers (UNAIDS, 2015).

At our clinic, the MCM is the go-to person for many clients. The MCM works to build rapport with each client on his or her caseload so that he or she can recognize potential barriers to treatment. The MCM helps the client to feel known as a person, instead of as a number or disorder, thus improving the likelihood that he or she will stay connected to HIV care (Beach, Keruly, & Moore, 2006). This connection also encourages the client to discuss highly sensitive or even stigmatizing information about his or her life, including homelessness, drug use, mental illness and violence in the home. The MCM provides support through, for example, brief crisis counselling, active listening, validation and motivational interviewing skills. Equipped with knowledge of both the client's situation and the basics of HIV medical knowledge, the MCM can effectively advocate for a client or assist a provider with determining the best medical care given the client's individual circumstances. As previously mentioned, every MCM in our clinic is a master's-level social worker because we understand the importance of social work training for this position. For the remainder of the chapter, we will use the term social worker to clarify our views that social workers are ideal candidates for this role.

MEDICAL CASE MANAGEMENT IN THE HIV CLINIC

The UNAIDS Strategy 2016–2021 (2015) places emphasis on reducing inequalities and providing people-centred healthcare. We eliminate socio-economic inequality in HIV care by providing social service resources at the site of care. This allows for clients to see their doctor, get medication, see a counsellor and meet with a social worker to obtain food or housing assistance in one trip. For clients who travel for several hours, this integrated service model allows clients to have all their needs met in one day.

In order to provide a better understanding of how integrated social work services work in the HIV clinic, we will discuss our clinic's procedures and a few case scenarios. Multidisciplinary teamwork starts even before a client presents for intake. Transportation is often a barrier to engagement and retention in care (Holtzman et al., 2015; Reif, Golin, & Smith, 2005). Clients who may have difficulty making it to the intake appointment are

immediately referred to the social worker. The social worker works with the client to determine the best possible route for transportation, such as reimbursement for fuel costs or public transportation. Once the client arrives for the first appointment, he or she meets with three key members of the multidisciplinary team. The financial counsellor enrolls the new client into all available financial assistance programmes in order to minimize the cost barrier to the client. Then a nurse and social worker team up to obtain a comprehensive psychosocial and medical history. This practice allows both the nurse and the social worker to work together to gather as much information as possible about the client without the client having to repeat his or her story numerous times. This set-up can also improve the rapport the client feels towards the clinic as a whole and reinforces the concept of teamwork in the clinic. The nurse and social worker provide education regarding the intake visit and subsequent visits, and fill gaps in knowledge about HIV prevention, care and treatment.

During the intake, the nurse focuses primarily on the medical history, often asking closed-ended questions aimed at gaining information of medical importance. The social worker can work open-ended questions into the interview to build rapport and gain a more holistic picture of the individual's past and present situation and context. In a world of computer-based medical records, the combination of two professionals in the intake means that the conversation and the rapport-building does not stop when one professional is focused on clicking and typing. The combined note is placed in the client's chart for the HIV care provider to review prior to his or her first meeting with the client. This allows the care provider to have important information about the client from day one of medical care. This intake note, along with results of laboratory tests also performed during intake, provides the medical provider with the information necessary to determine whether to start or delay ART at the first visit.

Staff at the BCC recognize the importance of confidentiality and cultural competence. All staff are trained at hire and annually regarding confidentiality, cultural competence and consent. There is also an additional level of confidentiality for HIV patients. In order to release any records outside of the health system, the patient must give explicit consent on a Release of Information form. Additionally, the university health system routinely monitors user access to patient records to ensure that no staff access the charts of patients not seen in their clinic. During the intake process, the patient is provided information about how information is shared within the clinic and throughout the wider health system. Additionally, the social worker informs the patient about the limitations of confidentiality. Clients

are able to use an alias, thus providing another layer of protection.

It is during intake that the social worker and the client talk briefly about possible barriers to care, such as unmet needs. The client and the social worker collaborate to create a tentative care plan that outlines goals, objectives and tasks. It is important to note that the care plan is a working document, which will likely change as the client engages into care. Following the intake, it can be helpful for the social worker to reflect on the client's situation and locate any resources that might be helpful for the client. Two case studies will set out this process.

Case study 1: Darren

Darren is an eccentric 45-year-old white male, who identifies as a gay man and lives in rural central Kentucky, USA. Darren has been diagnosed with AIDS since the mid-1990s and has struggled with mental illness, including depression, anxiety and bipolar disorder, for many years. Darren is unable to work due to his mental illness and AIDS dementia but does not receive disability income. He is well known to staff in the clinic, and is returning after living in New York City for several years. Darren completes his interview with the nursing staff and social worker while incarcerated for multiple driving-while-under-the-influence (of alcohol) convictions. During the intake, Darren asks the social worker to lend him money for bail, stating that the jail won't give him access to his money to bail himself out. Darren denies having a problem with substance use; however, he relies extensively on Xanax to control his anxiety.

Even in the brief interaction we had with Darren in the intake interview, multiple potential barriers became clear to the social worker. Darren's involvement with the legal system may be a barrier to accessing care and support. Jails in the region are legally responsible for providing medical care, including HIV medication, but few actually provide the medication. However, even more unsettling is Darren's request for money. The interaction he had with the nurse and social worker were indicative of a potential need for mental health services.

Case study 2: Courtney

Courtney is a 26-year-old white female with a history of injecting drugs and sex work. At entrance she was referred by a county jail for services after she tested positive for HIV. Courtney has a history of over 50 arrests, mostly related to drug use and sex work.

Courtney currently uses alcohol, marijuana, cocaine, methamphetamines, hallucinogens, heroin and prescription drugs. During intake, she is offered referrals to drug addiction treatment programmes but she declines for the social worker to make the referrals. Courtney requests to be given a list and states that she will call independently. She reports a tenth-grade education. She has limited work history outside of sex work. Courtney states that she is often unable to find employment other than sex work due to a combination of her limited work history, legal history and substance use.

Like Darren, Courtney has a history of incarceration; however, her legal history is more problematic. Courtney's legal history actively works against her attempting to leave sex work. Additionally, Courtney uses multiple illicit drugs, possibly in lethal combinations (alcohol and prescription opioids, for example).

Discussion

Each of these cases highlights the helpful information that can be elicited from an intake interview, in addition to the fact that clients will almost never tell their full story to one person on the initial visit. Many people living with HIV have previously experienced trauma and may be reluctant to disclose sensitive information (Brezing et al., 2015). Additionally, many people living with HIV are concerned about confidentiality. Health professionals are obligated to maintain patient confidentiality; however, many BCC patients report their distrust of local providers. Ongoing staff training regarding the importance of maintaining confidentiality and treating clients with dignity and respect can assist client trust in the HIV providers.

As a client continues to interact with the clinic, the social workers are there to assist in any way possible. Each time a client comes to see a doctor, he or she meets with a social worker. This consistent presence of the social worker in the clinic improves the likelihood that the client's needs are addressed. We would also argue that the presence of the social worker in the clinic increases the provider's understanding and improves the overall atmosphere of the clinic. Social workers provide education and model culturally sensitive behaviour to clients and staff.

Often social workers' meetings with clients are brief, a simple assessment about how things are going, inquiry about medication adherence, potential barriers to care and so forth. This conversation may last only a few minutes, or it may consume an hour or more of the social worker's time. Many clients do well with periodic check-ins and occasional intervention to reduce barriers, for example transportation assistance, referral to mental health care, assistance with paying for medication. However, each social worker has

several higher-needs clients on their caseload. These clients often present with multiple mental disorders, substance use and psychosocial barriers that prove too difficult for the client to overcome simply by free medication or a ride to the clinic. These clients often require weekly or daily contact with the social worker and intensive follow-up with community resources, medical and mental-health providers.

THERE IS MORE TO CARE THAN TREATING THE DISEASE

For many of our clients, medical treatment of HIV is the easiest part of treatment. Our clients come to us with years of trauma experience, mental illness, drug addictions and poverty. We can easily give patients a pill, but helping them achieve a stability in their lives that increases their ability to actually take that pill takes much more work.

Darren begins ART soon after his release from jail and quickly gets the HIV under control. Without social workers in the clinic setting, his providers might have believed Darren to be at low risk for falling out-of-care or non-adherence.

It is important to note that Darren's case was relatively easy to manage from a medical standpoint. Once he regained access to ART, Darren's HIV viral load quickly became undetectable (<20 copies/ml). As social workers, we understand that physical health can be affected by psychosocial stress. As such, we do not wait for a client's HIV viral load to rebound or for the client to fall out of care before we intervene. By intervening with psychosocial barriers prior to their becoming disruptive to care, we are able to prevent clients from falling out of care or developing resistance due to nonadherence to ART.

Combating stigma and mental illness

Once released from jail, Darren moves to a very small rural town far away from the city and the clinic. He is unemployed but does not yet receive income from the government due to disability; therefore he feels that he is a burden. Stripped of his driver licence due to his numerous driving convictions, Darren must rely on others to drive him several hours to and from his doctors' appointments. Each appointment will take the entire day because of the distance travelled and the wait times at the clinic itself. Additionally, Darren's identity as a gay man is something he must hide for fear of physical and social attacks.

Darren's experience with stigma is common among people living with HIV, particularly in rural locations (Karim, 2011). Darren identifies as gay, is living with HIV and has mental-health issues. All of these represent highly stigmatized identities in Darren's town. People living with HIV often identify with multiply stigmatized populations, therefore their experiences of stigma are often compounded (Fuster-Ruizdeapodaca, Molero, Holgado, & Mayordomo, 2014; Lee, Kochman, & Sikkema, 2002; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Whetten et al., 2008).

Darren chose to deal with this stigma by isolating himself, but this only worsened his depression and anxiety. Darren's social worker worked with him regularly to encourage him to seek mental health care and attend a support group for gay men and other men who have sex with men living with HIV at the clinic. Darren initially refused mental health care, stating that he can't get care near the clinic because it is too far away, but stated that quality care in his area does not exist. The social worker used listening and motivational interviewing skills to discover that Darren was concerned primarily about disclosure of his status. His fear of disclosure prevented him from obtaining care closer to his home. It also prevented him from receiving social support in the clinic support group even though the social worker could have provided transportation for him to attend these sessions. As Darren's suicidal ideation and manic symptoms increased, the social worker continued to discuss with him the importance of receiving mental health care, including counselling and psychiatric treatment. Darren agreed to see a psychiatrist for medication but stated that he had been to so much counselling in the past that he couldn't possibly get anything else out of it. Darren's social worker facilitated a referral to a mental-health clinic with a request for psychiatry services only.

Several months later, Darren's suicidality continued to intensify. The social worker referred Darren to one of the counsellors for a brief crisis counselling session, assessment for suicidality and potential need for immediate hospitalization. During this session, Darren revealed that he attended one appointment with the psychiatrist. The psychiatrist recommended Darren taper off his antianxiety medication because it can facilitate dependence and increase anxiety with regular use over a long period of time. The psychiatrist planned to replace the antianxiety medication with a newer, more potent antidepressant that has shown to be effective in managing depression and anxiety. The psychiatrist also determined that Darren did not have bipolar disorder, but was willing to watch for evidence of this closely. Darren expressed intense frustration that the psychiatrist was going to "take away" his antianxiety medication and never returned for follow-up care.

This scenario reinforces the potential for clients to fall out of care without

active communication between providers and social workers. Our facility space and funding limit our ability to provide on-site psychiatric services, thus placing our clients at risk for falling out of essential psychiatric care without anyone in the HIV clinic knowing until the client worsens or informs us.

Upon hearing that Darren was not in psychiatric care as a result of this conflict with the psychiatrist, the social worker discussed various avenues for psychiatric care with Darren. The social worker explained that the clinic worked with another psychiatrist so another referral could be made. Darren agreed to this referral. At this point, Darren also agreed to attend semi-weekly counselling sessions with the therapist who had seen him for the brief crisis session. Over the next several months, Darren's mental health stabilized. He continued to express passive suicidality but no longer reported that he had a plan or intent to commit suicide and continued to maintain adherence to ART.

Trauma

A few weeks after coming into care, Courtney calls from the emergency department where emergency medical services have brought her after she was found tied to a radiator by a client and sexually abused. Courtney is currently homeless and difficult to reach once released. She was offered counselling and agreed to meet with a therapist at her next medical doctor appointment but declined to meet beforehand.

Trauma is a common experience among people living with HIV, both before and after HIV diagnosis (Brezing et al., 2015). Traumatic experiences are associated with decreased medication adherence. However, Courtney's relationship with her social worker encouraged her to call the social worker shortly after her assault. This knowledge allowed the social worker to provide emotional support and connect Courtney with counselling. Courtney was also empowered since the police took her report seriously and treated her with dignity and respect during reporting of the attack. The social worker consulted with Courtney's provider to get her an earlier appointment to check up on any injuries sustained and to test for sexually transmitted infections. Being treated by providers familiar with Courtney's medical history and who Courtney trusts provided her with compassionate and quality care. Many articles and books have been written about working with individuals who have experienced trauma, and we cannot go into this topic in depth here.

Advocating for the client with providers

Social workers operating in the medical clinic advocate on behalf of their clients in a variety of ways. Often it is simply requesting resources from community agencies in order to provide basic necessities for the client. Social workers who work in HIV are also at the forefront of advocating for people living with HIV at both the national and international levels, working to ensure continued funding of programmes that provide assistance to people living with HIV. Medical social workers also advocate for the needs of the client with the providers themselves. Due to their unique person-in-environment perspective, social workers are able to make links between a client's apparent nonadherence to medical advice and social or environmental problems. Social workers use this knowledge to provide education to providers about an individual client's issues and common barriers to care.

Courtney came into clinic reporting that she was eight weeks pregnant and wanted to ensure that her child was born "healthy and HIV-negative". At this point, the social worker worked with Courtney to make sure that she had access to high-risk prenatal care. Courtney reported that she had been using opiates and alcohol but wants to stop using drugs. Because of the levels of her use and her pregnancy, Courtney was admitted to the hospital for medical detox. After detox, Courtney declined follow-up treatment and stated that her pregnancy was the motivation she needed to remain substance free.

Women with HIV who receive adequate prenatal and HIV care, who achieve viral suppression and whose babies are given ART during and after labour have minimal, almost nonexistent, risk of giving birth to an HIV-positive baby. Our clinic routinely cares for HIV-positive women and their HIV-negative babies. For this reason, the social worker worked intensively with Courtney to make sure that Courtney had access to medical treatment and social support and had the best possible chance of staying off drugs. However, Courtney did not think she needed residential or outpatient treatment for her substance use. The social worker was apprehensive about this, but respected Courtney's decision.

Courtney's HIV providers were less supportive of her decision to attempt sobriety on her own and voiced their frustration with Courtney's decision. However, the social worker was able to discuss with them the importance of Courtney's maintaining her autonomy and not being forced into decisions. The social worker utilized information known about trauma, the stages of change and motivational interviewing to educate Courtney's providers about the possibility of Courtney disappearing from care if she felt threatened or not respected.

Approximately one month following her release from detox, Courtney

was arrested for possession of cocaine and paraphernalia. This time, Courtney accepted treatment and the social worker advocated to allow transition directly from jail to treatment. She received a second medical detox. However, instead of entering rehab following her release from jail, Courtney travelled to another state for a “family emergency”. She returned three weeks later reporting use of Valium, crack cocaine, Loratab, Klonapin, tetrahydrocannabinol and heroin and drinking a fifth (one litre) of vodka within the previous 24 hours. Courtney was admitted for her third medical detox. During this hospitalization she was referred to another rehab facility out of the area where she could wait until a spot opened closer to our area.

After spending a few weeks at the out-of-area rehab, Courtney began having issues with her pregnancy and was encouraged to come back to the area of her high-risk prenatal care. She returned to the area and was transitioned into a rehab programme but left after having an altercation with another resident.

Courtney was again taken to the hospital, for supervised detox number four. At this point, Courtney was 36 weeks pregnant, with a history of early labour. Due to her extremely high-risk situation, Courtney and her providers decided she would stay in the hospital until she delivered. This plan was almost destroyed when Courtney was informed by a medical provider that her baby would not go home with her due to her drug use. Courtney insisted on leaving, but agreed to talk to the social worker first. The social worker was able to use her rapport with Courtney and also her understanding of Courtney’s motivation to encourage her to stay hospitalized. Courtney delivered a healthy baby at 39 weeks and 4 days. The baby was recently confirmed to be HIV-negative; however, the long-term effects of Courtney’s drug use remain to be seen.

This situation is perhaps the most frustrating and confusing situation in which a social worker can find themselves. Social work values of treating clients with dignity and respecting the client’s autonomy suggest that the social worker should provide education and understanding, but ultimately respect the client’s decisions. However, it is very hard not to also be concerned about the unborn child, whose interests may be in direct contrast to the decisions of the mother. This ethical dilemma troubled the social worker often but she always remained committed to providing Courtney with quality, trauma-informed care, even if this meant not forcing Courtney into a situation that might have been more beneficial for the unborn child.

The social worker actively worked with other professionals who came into contact with Courtney to encourage them to put their personal views of Courtney’s behaviour aside when they were working with her. She frequently

met with hospital staff during Courtney's medical detox stays. She also frequently kept the HIV doctor up-to-date on Courtney's situation. The value of the social worker's involvement in both the medical and the social service aspect of Courtney's HIV care was affirmed when the social worker was fully informed of Courtney's experience during her last hospitalization and to remind Courtney of her motivation and goals so that she decided to stay in the hospital until after delivery.

LESSONS LEARNED

Over the course of this chapter, we have discussed two scenarios where having social workers integrated into the HIV clinic provided better care than had the services been available at two separate locations. Integrated care is beginning to take hold in the USA, and is slowly expanding from grant-funded HIV clinics to primary care providers. It can be difficult to learn to integrate social work services into a medical practice for a variety of reasons. Below, we will discuss three key lessons we have learned in the course of working in an effective multidisciplinary team.

Buy-in comes with experience

Fully integrated multidisciplinary teamwork is not familiar to many doctors, nurses and social workers. Unfortunately, many medical providers do not fully understand the valuable skills social workers bring to the table. Social workers often find themselves using their skills to advocate for themselves as well as their clients. However, it has been our experience that it only takes a short time for medical providers to see and understand how valuable social workers can be to improving retention and adherence.

Our clinic trains new infectious-disease doctors through a fellowship programme. We watch each year as doctors come in with little understanding or respect for the social workers. By the end of the second year, these same doctors often request to consult with the social workers regarding a particular client or situation, knowing the importance of understanding the client's psychological and environmental situation.

Multidisciplinary teams influence each other

Perhaps medical case management by social workers is effective because social workers are highly trained team members. Social work education often

focuses on working *with* clients, levelling the power dynamic between provider and client, and believing in the client's ability to change. These values are often foreign to medical providers. However, by working with social workers and valuing the work they do, these values start to rub off on the providers. Medical providers begin practising trauma-informed, compassionate and collaborative care with people living with HIV, often with good results.

Similarly, the social workers are often able to learn medical terminology and basic information regarding treatment of HIV, medication side-effects and information about medical conditions common to people living with HIV. Social workers should never act as if they know medicine as well as trained medical providers; however a basic understanding of HIV and its treatment allows the social worker to effectively communicate with the client regarding his or her care and with the provider to convey information that is pertinent to the client's treatment.

True multidisciplinary teams facilitate retention and adherence

Often, multidisciplinary teams in medical situations operate with a very distinct hierarchy. Doctors come first, then nurses and then other health professionals, with social workers typically ending up at the bottom. This hierarchy reflects the belief that treating the disease is more important than treating the person. However, research indicates that psychosocial factors affect the ability of clients to stay in medical care and take prescribed medication (Cox, 2013; Gordillo et al., 1999). Social work values help to facilitate caring for the entire person, looking at the client's environment, psychological health and physical health. As social workers advocate for their clients with medical providers, and provide education regarding the environmental and psychological factors affecting the client, this hierarchy may flatten to reflect the importance of each discipline in the multidisciplinary team. Through interaction with each discipline and with mutual respect, HIV professionals can provide care for people living with HIV that encourages retention and adherence to treatment. Clients return to the clinic because they feel respected, listened to and understood. They sense the teamwork among their providers and trust that information they tell one person will be accessible to all of the team members. Additionally, clients are able to discuss barriers to adherence and receive help in overcoming these barriers.

CONCLUSION

Integrated social work services in our HIV clinic have been valuable services for our clients. Our clients' lives might have been severely affected by HIV, and our ability to spend ten minutes, or two hours, with clients, encouraging them, providing information and advocating for their needs, makes a difference. We do not argue that our model is the only way to provide quality care. We simply report that our model works, and works well for clients and providers alike. Social workers are key to contributing to comprehensive responses to AIDS that integrate prevention, treatment, care and support (UNAIDS, 2015).

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Policy engagements to ensure the future of antiretroviral medicines in Ethiopia: The case of associations and networks of people living with HIV

Zena Berhanu and Nathan Linsk



ABSTRACTS

Research assessing how associations and networks of people living with HIV influenced policies and programmes to provide HIV medicines in Ethiopia yielded a number of lessons for HIV social work. Findings highlighted the need to assess the views and concerns of organizations of people living with HIV regarding the continuous availability and accessibility of HIV medicines to improve the availability and quality of HIV treatment in the nation. This will help to inform interventions focusing on UNAIDS's strategy of zero AIDS-related deaths. The study highlighted the need to identify enabling and impeding factors to policy engagement for these entities, as part of civil society that are expected to play roles in the nation's policy processes regarding the future of antiretroviral medicines. Finally, the study identified the need to strategize how to enhance policy engagement roles of these entities for continuous availability and accessibility of antiretroviral medicines.

确保埃塞俄比亚艾滋病相关的病毒（ARV）药物未来的政策安排：艾滋病病毒携带者/艾滋病患者协会和网络的案例

通过对艾滋病感染者之间的关联、交际情况，以及它们影响埃塞俄比亚提供艾滋病病毒药物的政策和方案的方式的研究评估，本文为艾滋病病毒社会工作提供了一些经验教训。研究结果特别指出，需要在艾滋病病毒药物的持续供应和普及方面对艾滋病病毒携带者/艾滋病患者机构的意见和他们所关注的问题进行评估，以提高该国国家HIV医疗服务的供应和质量。这将有助于把重点放在联合国艾滋病规划署迈向零艾滋病相关死亡的战略上，以有利于采取干预措施。该研究强调需要识别这些实体政策安排的有利和不利因素，它们作为公民社会的一部分，预计会在国家制定ARV药物政策过程中发挥作用。最后，本研究确定了研究战略化的需要，加强这些实体的政策参与角色，将有利于ARV药品的持续供应和普及。

Compromisos de política para asegurar el futuro de los medicamentos antirretrovirales en Etiopía: El caso de las asociaciones y redes de personas que viven con el VIH

La investigación para evaluar cómo las asociaciones y redes de personas que viven con el VIH influyó en las políticas y programas para proporcionar medicamentos contra el VIH en Etiopía produjo una serie de lecciones para el trabajo social del VIH. Los hallazgos resaltaron la necesidad de evaluar las opiniones y preocupaciones de las organizaciones de personas que viven con el VIH en cuanto a la disponibilidad continua y la accesibilidad de los medicamentos contra el VIH para mejorar la disponibilidad y la calidad del tratamiento del VIH en la nación. Esto ayudará a informar las intervenciones centradas en la estrategia de ONUSIDA de Cero muertes relacionadas con el SIDA. El estudio puso en relieve la necesidad de identificar los factores habilitantes y los que impiden el compromiso de las políticas con estas entidades como parte de la sociedad civil que se espera que juegue un papel en el proceso político de una nación con respecto al futuro de los fármacos antirretrovirales. Por último, el estudio identificó la necesidad de elaborar estrategias sobre cómo mejorar las funciones de participación política de estas entidades para la continua disponibilidad y accesibilidad de los medicamentos ARV.

エチオピアで抗レトロウイルス薬の将来を確かなものにする政策関与： HIV に感染している人の協会とネットワークの事例

HIVに感染している人の協会とネットワークが、どのようにエチオピアでHIV薬を提供する政策とプログラムに影響を与えたかについて評価する研究から、HIVの社会福祉のための教訓をいくつか学びました。調査結果では、エチオピアでのHIV治療の質と利用可能性を改善するために、HIV薬が継続して入手できることやアクセスのしやすさに関する組織の見解と懸念を評価する必要性が強調されました。これは、AIDS関連の死をゼロにするというUNAIDSの戦略に焦点をあてた介入を広めるのに役立ちます。本研究は、抗レトロウイルス薬の将来に関し、国家の政策プロセスにおいて役割を果たすことが期待されている市民社会の一部として、これらの組織の政策関与を可能にする要因と妨げる要因を特定する必要性を強調しました。最後に、抗レトロウイルス薬の継続的な使用の可能性とアクセスのしやすさのために、これらの組織が政策に関与するための役割の強化を戦略化する必要性を確認しました。

La participation à l'élaboration des politiques afin de garantir l'avenir des médicaments antirétroviraux en Éthiopie : Le cas des associations et réseaux de personnes vivant avec le VIH

Les recherches évaluant la façon dont les associations et les réseaux de personnes vivant avec le VIH ont influencé les politiques et programmes d'offre de médicaments antirétroviraux en Éthiopie ont produit un certain nombre d'enseignements pour le travail social dans le cadre du VIH. Les résultats obtenus ont mis en évidence la nécessité d'évaluer les points de vue et préoccupations des organisations de personnes qui vivent avec le VIH au sujet de la disponibilité et de l'accès continu aux médicaments antirétroviraux en vue de l'amélioration de la disponibilité et la qualité du traitement du VIH dans le pays. Ceci permettra d'informer les interventions axées sur la stratégie de l'ONUSIDA pour l'atteinte de l'objectif zéro décès lié au Sida. L'étude a souligné la nécessité d'identifier les facteurs favorables et perturbateurs à la participation politique de ces entités en tant que partie intégrante de la société civile, lesquelles devraient, en principe, être impliquées aux processus d'élaboration des politiques du pays concernant l'avenir des médicaments antirétroviraux. Enfin, l'étude a identifié la nécessité d'élaborer des stratégies sur le mode d'amélioration des rôles de ces entités dans la participation politique en vue d'une disponibilité et d'un accès continu aux médicaments antirétroviraux.

INTRODUCTION

Country ownership of HIV/AIDS programmes and sustainability are global issues of concern (International Conference on AIDS & STIs in Africa, 2011; UNAIDS, 2012, p. 4). In Ethiopia, a variety of associations and organizations representing people living with HIV have been involved in activities related to antiretroviral therapy (ART) programmes. Thus, there was a need to assess their activities related to current systems of providing antiretroviral (ARV) medicines and the alternatives being considered for the future. This chapter addresses selected issues included in research entitled *The Involvement of Associations and Networks of People Living with HIV in Policy Making in Ethiopia Related to ARV Drugs: A Case Study* (Zena Berhanu, 2014) and addresses two questions:

- What activities have associations and networks performed regarding policies for the continuous availability and accessibility of ARV medicines in Ethiopia?
- What factors are related to the policy influence of associations and

networks regarding the continuous availability and accessibility of ARV medicines in Ethiopia?

The study was guided by a policy process consisting of stages whereby a social problem is identified, defined and made a matter of public policy concern. In this study, the five stages of the policy process are: problem formulation, agenda setting, goal-setting (policy legitimization), policy implementation and policy evaluation.

LITERATURE REVIEW

Scholars have questioned the long-term sustainability of HIV/AIDS treatment interventions funded by international donors (Getnet Tadele, Woldekidan Amde, & Kloos, 2013; Hanefeld, 2010; Kovsted, 2005; Seckinelgin, 2008; Stine, 2010; Whiteside, 2008). They argue that donors' priority interests and financial status determine the fate of programmes. Funds available from international donors may be declining. The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), for example, reported that "the financial crisis led to greater uncertainty about future contributions from donors, which ultimately resulted in the cancellation of Round 11 in 2011" (2013, p. 74). A recent report indicated that funding governments have decreased their support, which resulted in a decline of more than US\$ 1 billion in 2015 compared with the previous year (Kaiser Family Foundation & UNAIDS, 2016).

Civil society organization (CSO) responses have been a critical element in whether HIV responses are owned and sustained by local actors (UNAIDS, 2012, p. 15). The Global Fund has made the engagement of CSOs, including those of people living with HIV, a priority and has identified a variety of roles that such organizations should play (Global Fund, 2012, p. 9). UNAIDS (2012, p. 15) also expects countries to engage people living with HIV and other community groups in developing, implementing and evaluating policies and programmes. Yet, despite such policy expectations, few studies have assessed the levels of participation or the impact of CSOs' participation in HIV policy-making processes.

AIDS activists have demanded treatment, care and compassion for people living with HIV as well as an end to the discrimination and stigmatization many face (Stine, 2010, p. xiii). In the United States of America, for example, the AIDS Coalition to Unleash Power engaged in direct actions both with pharmaceutical companies and US government agencies (e.g. National

Institutes of Health), demanding rapid development, participation of people living with HIV and price reductions for ARVs. These medicines would not exist or be available had it not been for the advocacy of these groups. HIV-activism has not been limited to the United States of America and western Europe; nonstate networks have also made crucial contributions to HIV prevention, treatment and policy activities in a variety of eastern European (Spicer et al., 2011), South American (Le Loup et al., 2009), South-East Asian (Tantivess & Walt, 2008, p. 328), and African (Hanefeld, 2010; Leclerc-Madlala, 2005) countries. Tantivess and Walt's (2008) investigation found that CSOs in Thailand have participated in agenda setting, policy development and policy implementation related to the country's ART policy. In India, people living with HIV held a public rally in 2011 to demand that the Indian Parliament not give in to European Union patent protection demands (Subramanian, 2011).

A good example of CSO activism around ARV medicines is South Africa's Treatment Action Campaign (TAC), founded in the 1990s (Achmat, 2004a, 2004b; Chorev, 2012; Hanefeld, 2010; Hoen, Berger, Calmy, and Moon, 2011; Iqbal, 2009; Willan, 2004). People used TAC to make their voices heard by the South African Government. HIV CSOs in other African countries were engaged in similar activism. In November 2011, CSOs in Namibia developed a position paper on the need to have a strategy for the financial sustainability of AIDS responses (UNAIDS, 2013, p. 22).

In Ethiopia, the associations of people living with HIV engaged in a variety of activities including "professional HIV/AIDS counselling, socioeconomic provisions, orphan care and support, legal support, and home-based care for patients with AIDS and children living with the virus" (Pankhurst, Andargachew Tesfaye, Ayalew Gebre, Bethlehem Tekola, & Habtamu Demile, 2008, p. 223). They were involved in prevention activities through public education, awareness creation and media campaigns. However, more in-depth understanding of the nature of their activities and rationale has not been documented, and is thus the focus of this study.

METHODS

Given that previous studies have not described the activities of associations and networks of people living with HIV, qualitative approaches were appropriate to explore these issues. In order to protect the organizations' identities, the researcher has assigned pseudonyms (i.e. Association A, Association B, Network A, Network B, Network C) to the organizations, and has also used these pseudonyms within quotations from participants. The

researcher selected the organizations based on three criteria: 1) office in Addis Ababa (the capital of Ethiopia); 2) the number of years of experience with HIV; and 3) a mix of associations and networks.

The researcher selected two national-level associations (Associations A and B) that are pioneers in the fight against HIV and are the only national-level associations in Ethiopia. The three networks of associations of people living with HIV (Networks A, B and C) include a regional network (A), a specialized network (B) focusing on women who may be underrepresented by the other associations, and an umbrella organization of regional networks (Network C).

Key informant interviews (KIIs) included individuals with leadership positions in their organizations, which made them knowledgeable about the developments in the associations and networks. The researcher interviewed 13 key informants at the interviewees' offices and audio-taped the interviews. Key informants (KIs) were predominantly male and were generally well-educated, with several holding professional degrees. They had all served their respective organizations for years and all held paid positions in their organizations.

Four focus-group discussions (FGDs), each consisting of 10 individuals, were held with people living with HIV. Participants were recruited from the memberships of the two national associations based on the following criteria:

- Living with HIV and registered as an association member.
- Involved in the activities of the association, at least as a volunteer.
- Knowledgeable about current developments in the association.

The researcher did not reject any of the members recruited by the associations. Most of the FGD participants had worked in their respective associations for years, often as volunteers. Separate audio-recorded focus groups were held for males and females to maintain the homogeneity of the groups (Padgett, 2008).

In addition to the KIs and the FGD participants, the researcher analysed organizational documents including material that indicated the roles of people living with HIV and the policy advocacy roles of the organizations in ART programmes. Representatives of the organizations provided whatever documents they had that would show the organizations' purposes and activities in relation to ARV medicines. More publications (newspaper, leaflets and newsletters) were provided than reports and minutes. Ultimately, the researcher was able to collect and review a total of 52 documents from the organizations.

Data analysis

Data analysis included organizing and preparing the data, reading through the data, coding the data, generating themes, interrelating the themes and interpreting the meaning of the data (Creswell, 2009, p. 185). The researcher used Microsoft Word 2007 for coding and analysing the KII and FGD data. With the research questions and key concepts in mind, the researcher carefully reviewed documents looking for relevant words, sentences or paragraphs and found that 37 documents contained relevant information.

Ethical considerations

Data collection processes (i.e. interviews, FGDs and document reviews) were initiated after the research proposal was approved by the School of Social Work, Addis Ababa University. This approval constituted ethical approval. Prior to data collection, KIIs and FGD participants provided informed, voluntary consent. All participants in the study signed consent forms. All data including audio cassettes were kept in a locked cabinet accessible only to the researcher. FGD participants received 30 Birr (approximately US \$2.00 at the time of data collection) to compensate them for their time, transportation costs and other expenses associated with their participation. This amount was reasonable and was not large enough to affect people's abilities to exercise their right to voluntary participation.

FINDINGS

In the larger study, research questions included the views of association and network representatives about the current and future situation of ARV medicines in Ethiopia. This chapter, however, presents only a summary of the findings on those views, as follows. Association and network representatives viewed ARV medicines and the associated ART programme as offering significant benefits to individual people living with HIV, the community of people living with HIV and society at large. However, they identified a number of challenges and concerns related to the medicines and their provision. Several factors were identified as affecting medication users' adherence to ARV medicine regimens, including stigma and discrimination, negative rumours about the medicines, side-effects of the medicines, food and religious reasons. Fears of medicine interruption and dependence on donation were discussed as well. Service-related problems included disparity of service provision between ART sites, by geographical area and according to

personnel preparation. Finally, the association and network representatives offered opinions about the future prospects of ARV medicines, especially about alternatives that might help to sustain the availability and accessibility of the medication, such as establishing local HIV/AIDS funds and domestic production of ARV medicines (Zena Berhanu, 2014). Two other research questions are addressed below, focusing on key concepts and themes.

What activities have the organizations performed regarding policies to ensure the continuous availability and accessibility of ARV medicines?

The associations and networks reported several activities related to ARV medicine availability and accessibility. Several of the organizational documents (two strategic plans of Network B [2007, 2011] and two from Network C [2006, 2009], and a 2009 advocacy strategy of Network C), contained reports of activities to influence HIV and AIDS policies in general, but provided little information specifically about activities related to ensuring continuous ARV availability and accessibility.

Table 1 shows the related links between the key concepts, themes and codes for this research question for the first two stages in the policy process. Three themes and six codes are related to the activities of the networks and associations.

Table 1 Key concepts, themes and codes for research question 1

Key concept	Theme	Code
Problem formulation	Problem formulation	▪ Informal discussions among association and network leaders
		▪ Informal discussions among people living with HIV
		▪ Informal discussions between association and network leaders and members
Agenda setting	Reminding the government informally about the problem	▪ Reminding and promoting about the problem in an informal fashion ▪ Raising concerns informally at meetings and events
	Requesting and appreciating efforts of local production	▪ Requesting and appreciating efforts of local production

Information about activities reflecting the problem formulation stage of the policy process were available from the KIIs and FGDs; the organizational documents had very limited information to offer. According to a few of the KIs and FGD members, informal discussions had been occurring about whether or not ARV medicines will be continuously available.

A few of the KIs reported that the leaders of the associations and networks had informal discussions about their concerns regarding the future availability and accessibility of ARV medications and available solutions. A KI from an association said, “We see such issues being raised in informal discussions [more] than in a very organized situation.” Similarly, another KI from an association reported:

One of our future advocacy issues is making this ART drug and also the source of the fund[s] reliable. This issue concerns us much. At Network C level it is an issue we would like to see in the future at a higher concern.

This suggests that they consider it to be a problem that should be addressed, which according to the policy process model used in this study fits the problem definition stage.

Associations and networks serve as a place where people living with HIV can share their views about things important to them. According to a few of the KII and FGD participants, whenever people living with HIV meet each other they talk about their fears of medication interruption. As one FGD participant put it, “the users always raise this question.”

People living with HIV in the associations talked to each other, not only about their worries but also about options that might ensure the continuous availability and accessibility of medications. Topics such as the advantages and disadvantages of the local production of ARV medicines, the possibility of local funding and other options were discussed. For example, a female FGD participant reported that in relation to funding options,

We have been discussing this issue in a certain meeting. There is a kind of contingency deposited by government employees. Some of the government employees are giving a certain per cent of their salary to address the problem associated with future interruption.

A few of the KII and FGD participants indicated that concerns about availability and accessibility have been raised at more formal organizational gatherings and meetings. By using these various forums to discuss these

concerns, organizational leaders and members were able to keep attuned to each other's views. A KI from an association said,

You don't know the existing world situation and what is also coming in the future. It is difficult to predict. From this point, I have the concern that the accessibility will not be there [...] members also do raise this issue. Members have this concern because this issue [of continuous donor aid] is customary in our country.

However, FGD participants mentioned that there had not been opportunities to discuss these concerns about whether ARV medicines will be available in the future with their organizations' leaders. A few FGD participants emphasized the need to have platforms that would allow members to exchange views about medication availability and related issues. A FGD participant summed up these sentiments: "If the association gathers us, we would raise this issue [ARV medicines' future availability and accessibility] as an agenda. However, I don't think they are concerned about such issues."

A few FGD participants also asserted that associations of people living with HIV, in general, were not focusing on the future of ARV medicines because the organizations were engaged in other HIV/AIDS interventions. Representatives of associations that are network members have raised these issues with leaders of the networks. As stated by a KI at a network,

The association leaders raise this issue when they come to the [Network] General Assembly. [...] At that time, we call the leaders. They raise this issue [continuous ARV availability and accessibility and local production of those medications] in that meeting. They give their reflections and report to us that this issue is largely raised from members.

Agenda setting is a set of activities to bring an issue to the attention of policy-makers. A few of the KII and FGD participants indicated that there had been attempts to remind people from the government about ARV medicine-related concerns. They said they used available occasions, such as meetings and events, to share their concerns in an informal way. For instance, they reported telling public officials about their interest in seeing ARV medicines produced in the country. However, no organized or formal requests were made to the government in this regard.

A theme emerged around reminding the government informally about

the problem. Most strategic plans of the associations and networks clearly identified the need to develop strategies to influence policy through advocacy. The strategic plans also discussed the need to participate in decision-making processes affecting the lives of people living with HIV. For example, the term sustainability was used widely in the strategic plans of the associations and networks; for instance, Network A's 2009 plan cited sustainability of the ART programme as a concern, and listed advocacy and networking about the issue as important activities for the organization.

The strategic plans stated the concern of both associations and networks about sustainable ART service delivery, ideas about how to sustain the programme financially and a recognition of the need to provide advocacy. However, the documents provided no data about actual activities in relation to these issues. KIs described most of the activities involved in trying to get their concerns on the government's policy agenda as behind-the-scenes approaches rather than formal actions.

Association and network representatives used various opportunities to remind government officials and experts about the concerns of people living with HIV. Reminding, however, was not done in a formal way, such as by letters. Rather, the organizations' leaders used informal approaches: drawing on personal relationships, discussing things informally and raising their concerns about ARV medicine availability and accessibility as a side issue alongside other issues. Associations and networks used any available occasion to remind the government about the fears people living with HIV had about medicine interruption, and the importance of having ARV medicines continuously available and accessible. A KI from a network says:

Network C presents all its concerns on those meetings at different levels in which Network C is a member and attending. Network C facilitates the ways to make practical those issues presented in the meetings. Every time there is a chance to do so Network C reminds the government. [...] We have presented also the issue of domestic production to the government.

Representatives of the associations and networks reported that they raised their concerns at different meetings and events. As with reminding, their approach was to raise issues informally. Two KI respondents from associations reported:

We spoke a million times at different forums that I raised earlier. [...] Nothing is asked through letter[s]. It is in every forum that

we ask. [...] When we think of the fact that renowned individuals in our country are emerging to work on the area [medication production] ... there were times where we talked to them formally and also as a friendly person. But in order to say, "Do this [drug production] and that" as a right, as I said earlier, there are gaps.

There are different platforms where we could lobby so that the medicines would be produced in the country. Whenever the ART programme is raised, the issue of sustainability will be raised at the end. Even if the implementation is not done at large, raising the issue at different platforms is there.

A few FGD participants mentioned that there were several HIV/AIDS-related meetings held by an association where issues of continuation of the ART programme had been raised as a great concern of the community of people living with HIV. One male FGD participant said,

We are not able to cope when donors turn their face from us. Therefore, there is a concern both on the side of the government and also on our side. [...] This issue is always raised in every meeting. What should we do if they are going to stop? This issue is raised whenever different HIV/AIDS-related meetings are held. [...] Different questions will be raised in the meetings such as how is that we are able to cope with it.

Several of the KIs mentioned that attempts had also been made to remind government officials to push forward the idea of local production of the ARV medicines. A KI from a network stated:

Of course, the drugs are imported [...] However, Network C reminds every time that there should be encouragements from the government side regarding local production of the medicines. This is done because if in case there would be a condition where the importation of the drugs be interrupted and people living with HIV would fall into a problem.

Some KIs reported that local production issues were raised during events that focused on general HIV/AIDS issues. For instance, Network B raised the issue during an event held for parliamentarians. Government officials in attendance responded that the process to obtain a release from patent rights' restrictions was in the pipeline. A KI from a network told of how the issue was

raised also at the Global Fund Review meeting of the nation several times as a side issue but not as a formal agenda item:

In the Global Fund Review meeting achievements and challenges of the last six months will be raised by beneficiaries of Global Fund Round Seven. [...] Hence, it [the meeting] is to discuss with implementers regarding the programmes and the projects [...] But at that time many issues will be raised even if they were not proper agendas. As I said to you, they will discuss with Network C about the activities regarding local production.

A few organizational documents contained information related to ARV local production; however, these were inconsistent. For example, in its 2006 strategic plan, Network C listed one of its priority and programme areas as involving “advocacy for human rights of PLWHA (e.g. access to ARV drugs) to make them available with affordable cost or free of charge, to manufacture ARV locally and to access Global Fund for ARV drugs”. The following year, Network C’s bylaws (2007) included an objective advocating for and encouraging possible local ARV production. Network C’s intention was “to enable the PLHIV to get ARV drugs for free and also support the production of standardized ARV drugs in our country.” However, in the 2010 bylaws this objective was omitted and was not added in the most current, 2011, version. Similarly, at the time of data collection in 2010, Network B was developing a new strategic plan and the researcher was told that the document would incorporate a statement about promoting the domestic production of the medicines. However, the researcher could not find any explicit statement on this topic when the strategic plan for 2011–2013 was later reviewed.

Neither the KIs nor the FGD participants described association or network activities related to the remaining three stages of the policy process: goal setting, policy implementation and policy evaluation. The researcher found no information relevant to these three stages within the organizational documents.

To summarize, this research used the five-stage policy process framework as a way to understand the activities of the associations and networks in the policy arena. Analysis of the data suggests that the activities of the organizations were limited to informal discussions within the organization about their concerns. They also tried to share their concerns informally with government officials. Their activities reflected the problem-formulation and agenda-setting stages, but in a more behind-the-scenes way than is usually described. Association and network representatives did not identify

activities, even informal ones, that could be construed as reflecting the other stages of the policy process model.

What factors are related to the organizations' policy influence regarding the continuous availability and accessibility of ARV medicines?

This research question explored the factors contributing to the activities undertaken, or not undertaken, by the associations and networks. The larger research examined factors related to the policy-influencing activities of the organizations to ensure continuous ARV availability and accessibility. Although the KII and FGD participants reported factors related to whether the organizations influenced policies or not, data analysis revealed that most of the factors reported were those that limited the organizations' activities. The researcher classified the factors into two categories: internal factors (i.e. those within the organizations) and external factors (i.e. those in the organizations' environment; Zena Berhanu, 2014). This section focuses on one internal and one external factor.

Several of the KIs suggested that the associations and networks wanted to maintain a good relationship with the government—an internal factor—because that would allow them to continue to function. Rather than engaging in campaigns, confrontations or demonstrations, the associations and networks focused on less direct advocacy approaches, such as raising issues by asking or requesting. They attributed this to reluctance to jeopardize their positive relationship with the government by raising contentious or untimely issues. For example, a Network KI reported:

If you are going to be asked [by the government], “What is your question and what is your fear?” [while ARV drugs are currently available] the issues you are going to raise will be taken as untimely issues. The government can say that it is thinking about the issues. Therefore, you will be seen as an impediment. Hence, what we are doing now is looking positively on the progresses. We would like to see the government look upon associations of people living with HIV as opportunity. We like the government to see us positively. That’s what we call positive thinking. [...] You should be careful in raising problems. Otherwise, this will create a gap with the government. The government could also change its positive outlook. Bear in mind that [for the government] there are other more serious programmes [problems] than this one. It is

very important to care for that. When we speak and advocate we need to take precautions. [...] There are questions that you raise by waiting for the right time. Questions should be sensitive to the contemporary issues around.

The organizations' adoption of informal or behind-the-scenes advocacy approaches seemed to be based, in part, on the concern that more direct approaches might put future activities, or even the organizations themselves, at risk, as a KI from an association states:

For instance, we have [a] newspaper ... Most of our members share their experiences through that newspaper. It mainly focuses on the impacts of HIV/AIDS, how to take care and how to prevent. And we don't push farther on policy and related issues. The reason why we don't go is the point [...] If we raise such an issue, there is a fear of the risk. For instance, if you raise one of the policies and start criticizing, what will come is a fear about the future of your newspaper. The newspaper is sponsored by donors and they are telling us the areas that we should focus on.

As an external factor, the effect of positive governmental perceptions was an additional theme. According to more than half of the KIs, the government generally had good communications with the two associations and three networks and typically perceived the organizations of people living with HIV positively. Several argued that groups of people living with HIV around the country were able to engage in the activities they chose because the organizations were not seen as being involved in so-called political games, which allowed them to be perceived favourably by the government.

The Federal HIV/AIDS Prevention and Control Office (FHAPCO) and Network C (established with significant government support and supervised by FHAPCO) have worked together on a number of issues. According to more than half of the KIs, the interactions between Network C and FHAPCO have contributed to the government's positive interactions with the associations and networks.

Several of the KIs contended that the government offered its maximum support to people living with HIV and their networks. A few pointed out that the Ministry of Health was particularly welcoming and was said to have an open door and a willingness to work with the associations and networks. According to several of the KIs, the Ministry and FHAPCO had invited associations of people living with HIV and their networks to participate

whenever there was a meeting or an issue to be discussed. These KIs also reported that the government wanted the associations to participate whenever the issue of ARV medicines was discussed.

DISCUSSION

The associations and networks reported activities that can be seen as reflecting the problem-definition and agenda-setting stages of the policy process. The activities reported by the representatives tended to be informal, casual and based on personal contacts. Associations and networks used only informal approaches to formulate the problem as a policy issue and to set it as an agenda item for government consideration. There was no organized, formal effort and sometimes they did not know what to do to advance their concerns.

The discussions and interactions that took place within these groups were most closely aligned with what has been termed the problem-definition stage (Jansson, 2011; Joachim, 2003; Smith & Katikireddi, 2013): identifying and selecting an issue and framing it as a problem. They expressed concerns as well as possible solutions. For example, whenever they met at their offices they shared their concerns about whether ARV medicines will be continuously available or not. Jansson (2011) indicated that selecting a specific issue is the first step in a policy-making process; other authors, such as Joachim (2003), call this framing. These matters were never formally brought before the organizations' memberships or decision-making bodies or expressed in written documents.

Agenda setting also was undertaken informally. The organizations informally lobbied members of the parliament, specifically Social Affairs Standing Committee members. By raising their concerns about the continuous availability and accessibility of ARVs, these organizations tried to communicate to other stakeholders, and especially to government officials, not just their worries but also possible responses. To some extent they were able to influence the government's agenda, but this appears to have been dependent on an individual's ability to present the matter and on the depth and level of trust in the interpersonal connection.

These findings extend the literature about organizational involvement of people living with HIV in the policy process, challenging us to understand the apparent paradox of invited involvement. These organizations do visibly participate in the policy process, but only on matters and in ways that are consistent with the interests of the government. Although the associations and networks consider the continued availability and accessibility of ARVs

to be a major concern, the issue does not fit in with what is an acceptable advocacy focus for them at this time. Thus, they use informal, and often invisible and potentially less effective, approaches to advocate.

Although international donors and policy-makers encourage involvement of organizations of people living with HIV in the policy process, limited research has examined how they are involved. The participants in this study did not discuss activities commonly associated with goal setting or policy formulation, policy implementation or stages of policy evaluation, in spite of their concerns about the issues of medication access and sustainability. However, this should not come as a surprise given that the issue of continuous ARV availability and accessibility was not a prominent concern on the country's policy agenda, and the reluctance to advocate directly is due to a dependence on the government for related services. In the absence of a new policy initiative or a policy modification proposal, the associations and networks cannot be expected to expend effort on these other policy process stages.

Robinson and Friedman (2007) had similar findings regarding the positive relationship of CSOs with the government being important to the policy engagement process of CSOs in Uganda and South Africa. They stated that CSOs should strive to secure "perceived legitimacy among government officials" (p. 662), which supports this study's findings about the importance to these CSOs of being positively perceived by government.

This study suggests that the associations and networks have understood that bolder approaches to raising the issue of ensuring continuous availability and accessibility of ARVs is beyond their capacity, and doing so may not be acceptable to the government. Hence, they prefer not to raise this issue formally as a policy agenda item, but instead rely on informal, behind-the-scenes approaches to try to convey their concerns about the future of ARV medicines in Ethiopia. To sum up, these organizations' engagement activities associated with influencing the policy process were limited and reliant on informal interactions; they did not use formal, overt advocacy methods to advance their interests related to ARV medicines. Notwithstanding these difficulties, ensuring access and continuous availability of ARV medicines is critical to Getting to Zero, decreasing HIV-related infection and symptoms and to future prevention efforts.

LESSONS LEARNED

Strengthening and enabling associations and the networks

The efforts of the associations and networks to be involved in and to influence the policy process should be encouraged, nurtured and supported. This will bolster the idea of the need to mobilize communities, which is identified in point two of Getting to Zero (UNAIDS, 2010). These organizations represent vulnerable and marginalized segments of the population, the very groups whose lived experiences and voices need to be considered when policies relevant to them are being made. These organizations merit support that will allow them to handle the challenges they face. Support has to be given to create powerful groups of people living with HIV that can engage in the policy-making process and maximize the empowerment of people and meet their needs. This in turn will contribute to the building of country ownership and the sustainable capacity of a nation's ARV programmes. Social workers can use their knowledge and skills to contribute directly to this effort.

Increasing the involvement of people living with AIDS

There is a need to use the Greater Involvement of People with AIDS principle (UNAIDS, 2007) and its emphasis on the participation of people living with HIV to leverage involvement in discussions and activities to ensure continuous ARV availability and accessibility.

The involvement of associations and networks in influencing the country's HIV policies and programmes is inadequate. Implementing the Greater Involvement of People with AIDS principle (UNAIDS, 2007) may be a way out of this dilemma, particularly as Ethiopia has endorsed and developed a guideline for implementing this principle. Associations and networks may utilize the country's endorsement of this principle as an opportunity to frame issues of interest in the policy-making process. The principle may facilitate ensuring that people living with HIV are fully engaged in the implementation and evaluation of relevant policies, particularly those dealing with ARV medicines.

Researching other organizations and issues

Similar studies are needed with other organizations of people living with HIV as well as with civil society organizations working on related issues.

To deepen our understanding of the roles of CSOs in the HIV policy arena, studies should be carried out with other related groups. Comparable

studies should be undertaken with Ethiopian CSOs involved with other issues. Cumulatively, these kinds of investigations could help us to develop stronger roles for CSOs, as well as improved knowledge and theories regarding enhancing the engagement of CSOs in the policy-making process. Additional research on the five-stage policy process model used in this study is warranted to assess its utility for describing the policy process and to identify how it may need to be revised to better reflect policy-making in the context of Ethiopia and other developing countries.

Greater involvement of social workers

Social policy advocacy skills training should be provided to associations and networks of people living with HIV. Schools of social work could prepare and deliver different kinds of training to the members and staff of the associations and networks of people living with HIV, to enhance capacity. This research suggested the need for capacity-building training in the area of skills development for policy advocacy. Basic policy advocacy skills, such as analytical skills, ethical reasoning skills, interactional skills and evaluation skills, grounded in the Ethiopian context, are lacking. In addition, social workers could work together with the associations and networks to plan, design and facilitate events that would allow members of these organizations to freely air their views regarding the future of ARV medicines. Such efforts further stress the need to continue the commitment to work with people living with HIV and their organizations.

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**The emotional cost
of caring for patients
living with AIDS:
The experiences of
caregivers at
an AIDS palliative
care organization**

Francine Masson and Adelaide Mangena



ABSTRACTS

South Africa has one of the highest HIV rates in the world, and in the past few decades the prevention, treatment and management of HIV has received significant attention. However, the emotional effects of caring for patients living with AIDS is an area that still requires further investigation. This chapter, which is based on an empirical study, explores the experiences of 15 caregivers working at an AIDS palliative care organization and outlines the implications for social work practice of caring. The results of the study indicated that more than half of the participants experienced high levels of compassion satisfaction, with average to low secondary traumatic stress and burnout levels. Furthermore, the impact of caring on caregivers' professional and personal lives is highlighted. The social work response needs to move beyond assisting HIV-positive clients and their families and should incorporate interventions for those who care for individuals afflicted with this disease.

照顾艾滋病病毒携带者/艾滋病患者的情绪成本：在一家艾滋病病毒携带者/艾滋病患者缓解治疗组织中照顾者的经验分享

南非是世界上艾滋病病毒感染率最高的国家之一，。在过去的几十年里，艾滋病的预防、治疗和管理受到了极大的关注。然而，照顾艾滋病病毒携带者/艾滋病患者的情感效应仍然是一个需要进一步调查的领域。本章采用实证研究的方法，探讨了某艾滋病毒的缓解治疗机构的15位工作人员的经验，并概述了照顾社会工作实践的启示。这项研究的结果表明，一半以上的参与者经历了高层次的同情满意度，在创伤性精神压力和过渡疲劳方面满意度为一般或较低。此外，本章也特别讨论了关心那些照顾者的专业和个人生活所产生的影响。社会工作的响应不仅仅是为艾滋病病毒阳性患者和他们的家庭提供援助，它也应该包括为那些关心遭受艾滋病患者的人员提供干预措施。

El costo emocional de cuidar a pacientes que viven con SIDA: Las experiencias de los cuidadores en una organización de cuidados paliativos del SIDA

Sudáfrica tiene una de las tasas más altas de VIH en el mundo y en las últimas décadas, la prevención, el tratamiento y la gestión del VIH ha recibido una atención significativa. Sin embargo, los efectos emocionales de cuidar a los pacientes con SIDA es un área que aún requiere una mayor investigación. En este capítulo, que se basa en un estudio empírico, se exploran las experiencias de 15 cuidadores que trabajan en una organización de cuidados paliativos del SIDA y se señalan las implicaciones de estos cuidados por la práctica del trabajo social. Los resultados del estudio indicaron que más de la mitad de los participantes experimentaron altos niveles de satisfacción con un promedio bajo de niveles de estrés traumático secundario y de desgaste. Además, se destacó el impacto de cuidar sobre la vida profesional y personal de los cuidadores. La respuesta del trabajo social tiene que ir más allá de ayudar a los clientes seropositivos y sus familias y debería incorporar intervenciones para aquellos que se ocupan de las personas infligidas con esta enfermedad.

HIV/AIDS患者看護の感情的コスト：HIV/AIDS苦痛緩和看護組織での介護者の経験

南アフリカは世界最高のHIV感染率の国の一つです。そして、ここ数十年間はHIVの予防、治療、管理には大きな注意が払われました。しかし、HIV/AIDS患者を看護するさいの感情的な影響は、さらなる調査を必要とする分野です。この章では、実証的研究に基づいて、HIV苦痛緩和看護組織で働いている15人の介護者の経験を調査し、社会福祉実践で必要なケアの意味を概説します。研究の結果は、参加者の半数以上が高い水準の共感満足を経験し、平均またはそれより低い二次的外傷性ストレスと燃え尽きレベルにあることを示しました。さらに、介護者の専門家としておよび個人としての生活を気にかけることの大切さが強調されました。社会福祉対応はHIV陽性の患者とその家族を支援することを越えて行動する必要がある、この病気で悩む個人をケアする人のための介入を取り入れなければなりません。

Le coût émotionnel de la prise en charge des patients qui vivent avec le Sida : Les expériences du personnel soignant au sein d'une organisation offrant des soins palliatifs du Sida

L'Afrique du Sud affiche l'un des taux de séropositivité les plus élevés dans le monde ; et, au cours des quelques dernières décennies, la prévention, le traitement et la prise en charge du Sida ont reçu une attention significative. Cependant, les effets émotionnels de la prise en charge des patients du Sida

constituent un secteur qui nécessite de plus amples analyses. Le présent chapitre, inspirée d'une étude empirique, examine les expériences de 15 personnes soignantes travaillant au sein d'une organisation offrant des soins palliatifs du Sida et souligne les implications de la prise en charge pour la pratique de travail social. Les résultats de l'étude ont indiqué que plus de la moitié des participants ont expérimenté des niveaux élevés de satisfaction de compassion, avec un stress traumatique secondaire et des niveaux d'épuisement moyens à faibles. De plus, l'impact de la prise en charge sur les vies personnelles et professionnelles des soignants a été souligné. La riposte menée dans le cadre de travail social doit dépasser l'aide aux clients séropositifs et à leurs familles et incorporer les interventions pour les personnes prenant en charge les individus infectés par cette maladie.

INTRODUCTION

Despite continued HIV awareness and prevention campaigns being an item on the South African national agenda, the number of people living with HIV in South Africa continues to increase. Statistics provided by the South African Government estimated that in 2015 more than six million South Africans, or about 16.6% of the population, were living with HIV (Statistics South Africa, 2015). According to Target 10 of the UNAIDS 2016–2021 Strategy: *On the Fast-Track to end AIDS*, “75% of the people living with, at risk of and affected by HIV, who are in need (should) benefit from HIV-sensitive social protection” (UNAIDS, 2015, p. 8). Furthermore, one of the people-centred goals of the UNAIDS 2016–2021 strategy is to ensure “fewer than 500 000 people dying from AIDS-related causes” by 2020 (UNAIDS, 2015, p. 15). The number of AIDS-related deaths has significantly decreased in the past decade due to the increase in the availability of antiretroviral therapy (ART). However, in 2015 at least 30.5% of the recorded deaths in South Africa were attributed to AIDS-related illnesses (Statistics South Africa, 2015).

Furthermore, high mortality rates can also be partly attributed to the growth of multidrug-resistant tuberculosis (Alcorn, 2015). Consequently, palliative care still needs to be incorporated as part of AIDS programmes so that the care and support of people living with HIV can be sufficiently addressed. Lofgren et al. (2015) note that over the past few years, earlier integration of palliative care services into chronic disease management has become more frequent. As part of the UNAIDS strategy to strengthen the community systems that deliver services, the impact of caring for patients in the final stages of AIDS needs to be considered and addressed, as do

ways of enhancing compassion satisfaction. According to Hudnall Stamm (2010), compassion satisfaction refers to the sense of personal fulfilment experienced by people who help others. This chapter discusses empirical research that was conducted with caregivers at a hospice caring for patients with AIDS and highlights some of the challenges caregivers encounter when looking after patients in their final stages of the disease.

LITERATURE REVIEW

The HIV and AIDS epidemic and palliative care in South Africa

According to UNAIDS, globally there were 36.7 million people living with HIV in 2015 and about 1.1 million people died from AIDS-related causes (UNAIDS, 2016a). In South Africa, AIDS has been the leading cause of deaths of its citizens (National Planning Commission, 2012), and to date millions have died as a result of the disease. South Africa has not been sufficiently equipped to deal with the enormity of the epidemic and its far-reaching consequences. Numerous historical and social factors have contributed to the spread of HIV and include: high levels of poverty, inequality, unemployment and social instability; gender-based violence; disparities in access to health-care systems; and the government's initial failure to provide sufficient leadership in the fight against HIV and AIDS (AIDS Foundation of South Africa, n.d.). In South Africa it is the most disadvantaged groups and the poor that are primarily affected by AIDS. Inadequate nourishment, provision of water, sanitation and electricity are socioeconomic realities that contribute to the vulnerable position of the poor in the fight against HIV and AIDS (Demmer, 2007; Sekgoka, 2013).

However, in the past decade the government has taken significant steps to reduce the spread of the epidemic and tried to manage the devastating effects of the illness. In 2011, the South African President, Jacob Zuma, announced a government strategy to improve South Africa's fight against HIV and AIDS, which was incorporated in the South African National Strategic Plan 2030. The objectives of the plan include programmes to sustain health and wellness—primarily by access to quality treatment, care and support services, and to develop programmes that focus on wellness— and therefore reduce the self-reported stigma related to HIV and tuberculosis by at least 50% of sufferers (National Planning Commission, 2012). Despite the government's implementation of preventative and proactive measures, reducing the number of AIDS-related mortalities, palliative care and hospice services are

still an imperative component of the AIDS care continuum (Demmer, 2007; Lofgren et al., 2015).

According to Powazki, Walsh, and Shrotriya (2015), the multidisciplinary team is an essential component of any hospice or palliative care unit. In particular, members of the team can contribute knowledge about the patient's disease status, symptom management, medical complications and the possibility and timing of the patient's hospital discharge. Located within a multidisciplinary team at an AIDS hospice are the caregivers who are required to respond to the patients' physical, emotional and spiritual needs. During the last stages of the AIDS illness most patients lose their mobility and require assistance with many functions, such as bathing, dressing, feeding and mobility. Caregivers fulfil a vital role in assisting patients with these tasks and helping them to maintain a level of dignity (Juster & Marin, 2011).

Unlike many other countries that often rely on volunteers to fulfil the caregiver role at palliative care organizations, such as Canada (Jovanovic, 2012), Australia and England (Huynh, Winefield, Xanthopoulou, & Metzger, 2012), in South Africa most caregivers are employed at hospice services to provide caregiving services. Caregivers are required to have a matric education, which is the equivalent of a school-leaving certificate, and attend a six- or twelve-month course at a nursing college. The course includes training about patient care, basic anatomy and physiology, first aid and care for the elderly. Caregivers must have received their training from an institution accredited by the South African Qualification Authority (South African Government, n.d.).

The challenges and effects of caregiving

There are inherent challenges and job stresses in caring for terminally ill patients. Ross and Deverell (2010) emphasize that there has been extensive research exploring the psychosocial issues of the dying person and that what is apparent is that those who are assisting the dying patient are also psychologically affected by the dying process. Hill, Dempster, Donnelly and McCorry (2016) identify numerous emotional demands that palliative care workers may experience and that may be stressful, including dealing with difficult patients, having to break bad news, recurrent exposure to death, watching patients suffer, poorly defined roles and secondary trauma. There are additional challenges that health workers and caregivers working at an AIDS hospice may experience. Apart from the fact that there is still no cure for the disease, caregivers have to deal with the fear of being infected themselves,

losing patients, watching the progression of patients' illness and providing comfort to the patients' family and loved ones (Harber, Roby, & High-George, 2011; Sindi, 2011). Figley (1995) adopted the term secondary traumatic stress to explain the emotional and physical responses that practitioners or helpers may experience through watching or listening to the traumatic experiences of others. Carers who are suffering from secondary traumatic stress may experience avoidance, arousal and other intrusive symptoms. Yassen (1995) acknowledges the pervasive effects of secondary trauma and explains that an individual's life may be affected on a cognitive, emotional, behavioural, spiritual, interpersonal or physical level. Mutsvunguma and Gwandure (2011) emphasize that secondary traumatic stress is more psychological than physical and, in particular, is associated with feelings of helplessness, anxiety and being overwhelmed. Caregivers caring for terminally ill patients may feel overwhelmed by their responsibilities and feel helpless through watching the progression of the patient's illness.

Experiencing secondary traumatic stress could have consequences for individuals which might not only affect their work but also may result in their personal lives being negatively affected. Robinson-Keilig (2014) found that high levels of secondary traumatic stress in mental-health practitioners in the United States of America have been significantly associated with personal relationship satisfaction, reduced social intimacy and a greater use of negative communication patterns. Furthermore, caring for terminally ill patients may also raise issues for carers about their own sense of mortality, spirituality and the meaning of life. Without sufficient support in place for caregivers, the constant emotional toll of their work may result in them running the risk of suffering from secondary traumatic stress and/or burnout.

While the onset of secondary trauma symptoms can occur suddenly, burnout tends to be more gradual and occurs over time. Maslach (2001) explains that there are three identified components of burnout: emotional/physical exhaustion, depersonalization and a reduced sense of personal accomplishment. Furthermore, Hill et al. (2016) explain that burnout can be understood to be a syndrome of physical exhaustion and negative self-concept, which lead to negative job attitudes and eventually develop into loss of concern or regard for the people for whom the caregiver is responsible. Burnout can be caused by long-term involvement in situations that are emotionally demanding (Gustafsson, Eriksson, Strandberg, & Norberg, 2010).

Emotional exhaustion refers to not having the capacity to offer psychological support to others. Offering psychological support involves listening to traumatised people's traumatic experiences. Ross (2011) refers to physical/emotional exhaustion as the stage whereby caregivers feel that

emotionally they are exhausted and used up to such an extent that they have nothing to offer their patients or clients. Depersonalization brings about the psychological distancing of oneself by the caregiver. The caregiver might start treating patients as objects rather than humans. This approach may also include unfeeling, callous and indifferent attitudes towards patients. Some authors argue that depersonalization, characterized by a distanced, uncaring attitude towards patients could also be seen as a coping mechanism for the emotionally exhausted caregiver (Gustafsson et al., 2010; Ross, 2011; Ross & Devereil, 2010).

Caregivers may experience a sense of personal inadequacy in which they feel they are not achieving their professional goals or making a significant difference in the patients' lives. Juster and Marin (2011) note that when one is dealing with an illness, it is natural to experience a sense of diminished control. Carers may experience these feelings of diminished control and helplessness as they have to assist the patient to deal with often unpredictable symptoms and responses to treatment. Feelings of low personal accomplishment may also have an immobilising and demotivating effect on the caregivers, which in turn may result in depression and lowered morale (Radney & Figley, 2007). Hudnall Stamm (2010) cautions that negative feelings experienced infrequently may become more frequent and eventually have a long-term negative impact on the caregiver.

According to Ross (2011), burnout occurs at a very slow and steady pace and in different stages. The four stages of burnout are identified as: enthusiasm, stagnation, frustration and apathy. Enthusiasm occurs when the professional or caregiver has a tendency to be overly available and to have unrealistically high hopes and expectations about the job. The level of energy and eagerness to achieve goals at this stage is very high. This response usually occurs in the first year on the job (Ross, 2011). Stagnation refers to failure to develop, progress or advance in one's duties or responsibilities (Hill et al., 2016). During this stage, the energy levels are slowing down, motivation is decreased and the priorities and goals are no longer pursued with enthusiasm. Furthermore, the caregiver can start experiencing disappointment about the job. A lot of negative feelings and perceptions of self are associated with this stage. The caregiver can be seen as starting to be more interested in fulfilment outside the job, such as being with friends and taking part in sport, rather than the actual responsibilities of the job. Self-doubt becomes a dominating factor and questions around being in the right job are also asked in this phase. The caregiving role can be very demanding under any circumstances, but if one has self-doubt and has little faith, the consequences might be overwhelming and dire (Maslach, 2001).

As the difficulties seem to multiply, the helper becomes frustrated, bored, less sympathetic and might start coping by avoiding and withdrawing from relationships. Caregivers might feel frustrated and torn between sacrificing their own needs and fulfilling those of their clients. Should this process be prolonged, the caregiver might move on to apathy (Harber et al., 2011; Ross, 2011). Apathy is seen as the final and most dangerous stage as it is sometimes characterized by depression. At this stage the caregiver treats the job as a job, but does not pay any special attention to the patients. The caregiver might start presenting with a more negative attitude, associated with complaints and bickering. During this final stage of burnout, caregivers might not be seen as functioning to their best ability. In the end the relationship between the patient and the caregiver is likely to be compromised (Gustafsson et al., 2010; Ross, 2011).

Hudnall Stamm (2010) explains that compassion satisfaction is regarded as the pleasure derived from being able to offer help to someone in need, especially in the workplace. One may feel fulfilled and content through helping others, be it clients or colleagues. Compassion satisfaction refers to the sense of personal fulfilment experienced by people who help others. Figley (2002) emphasizes how compassion satisfaction could be reinforced in the workplace through support given to the caregiver and positive feedback received by the caregiver. The balance between positive support for the caregiver and the negative aspects of the role could lead to caregivers playing a more competent and caring role (Huynh et al., 2012).

Against this backdrop, and given the far-reaching effects of caregiving, the aim of this study was to explore the levels of secondary traumatic stress, burnout and compassion satisfaction in caregivers who were employed at an AIDS palliative care organization.

RESEARCH DESIGN AND METHODOLOGY

The study employed a mixed methods research design as the study incorporated both qualitative and quantitative aspects. The combination of both quantitative and qualitative approaches provides a better understanding of the research problem than applying either approach alone. By incorporating both approaches, the researchers were able to use multiple data sources, which is referred to as triangulation. Triangulation, according to Shaw, Briar-Lawson, Orme, and Ruckdeschel (2010), occurs when data from one method are used to corroborate data from a different method, both testing the same phenomenon.

Ethical clearance for the study was obtained from the Humanities Ethics Committee of the University of the Witwatersrand. Ethical research principles of confidentiality, anonymity, voluntary participation and informed consent were adhered to in the study.

Population and sampling

The study was conducted at a hospice which caters for terminally ill patients with AIDS in Johannesburg, South Africa. Although there were 45 caregivers who were employed at the hospice at the time that the study was conducted, only 15 were willing to participate. All 15 met the inclusion criteria. In order to assess levels of secondary trauma and coping, caregivers were required to have been employed at the hospice for a period of more than six months. According to Van Dyk (2010), the more experience the caregivers have of working in the field of HIV and AIDS, the better their chances of developing coping mechanisms to deal with aspects such as secondary traumatic stress.

Research instrumentation and data collection

Two research instruments were used to collect data for this study. First, Hudnall Stamm's (2010) Professional Quality of Life (ProQOL) scale was administered to measure secondary traumatic stress, compassion satisfaction and burnout levels. Although the ProQOL scale was originally developed for use with trauma counsellors, the scale has been shown to be a reliable and valid tool in various other contexts (Slocum-Gori, Hemsworth, Chan, Carson & Kazanjian, 2011). In addition, a semi-structured interview schedule was used to guide the face-to-face interviews with the caregivers in order to explore their experiences of secondary trauma and coping. The use of a semi-structured interview schedule allowed for flexibility in the interviews so that the researcher could probe and ask questions for clarification in order to gain an in-depth understanding of participants' experiences. The research tools were piloted on five home-based carers working at a different AIDS palliative care organization from the one where the data were collected. According to Strydom (2011), pilot testing of the research tool ensures that errors in the research study may be avoided. As such, the pilot study allowed the researcher to improve and adjust the questions posed in the semi-structured interview schedule. This process was particularly important taking into account that English was not the home language of most of the caregivers. The sample used in the pilot study did not form part of the actual sample of the study.

Data analysis

As the study utilized a mixed methods design, both qualitative and quantitative data analysis techniques were used. Thematic content analysis was used to identify the themes arising from the face-to-face interviews. According to Terre Blanche, Durrheim, and Kelly (2006), there are five steps in undertaking thematic content analysis: first, the researchers need to familiarize themselves with the data; second, they need to look for common themes that recur; third, they assign codes to the themes identified; fourth, they elaborate on the themes in a more in-depth manner; and finally, they analyse and interpret the meaning of the themes identified through the literature. Descriptive statistics were used to analyse the quantitative data collected from the ProQOL scale (Hudnall Stamm, 2010).

FINDINGS

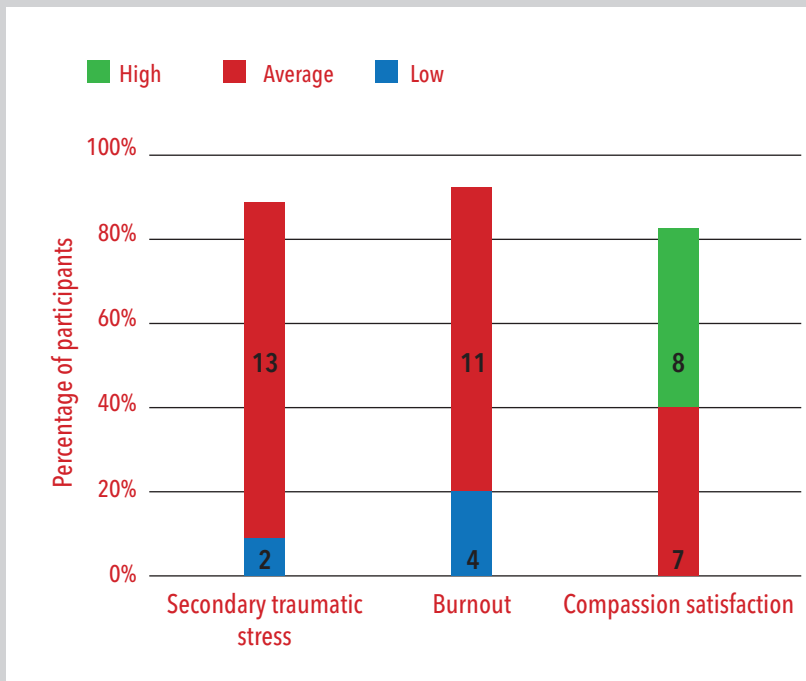
Demographic information of the participants

All the caregivers interviewed in the study were female, and their ages ranged from 31 to 60 years. None of the participants was married and most of them had children. All of them were employed in a full-time capacity as a caregiver by the hospice. In order to be equipped with the knowledge and skills required to be a caregiver, all of the participants had attended more than one training course addressing the following: home-based care, palliative care, HIV and AIDS, tuberculosis and auxiliary nursing. The average length of time participants had worked as caregivers was 10.73 years, showing that they had numerous years of experience in this role. Participants had worked for the hospice organization where the study was conducted for an average of 9.53 years, with the number of years at the organization ranging from 5 to 21 years.

Secondary traumatic stress levels

According to the results of the ProQOL scale (Hudnall Stamm, 2010), all participants had average to low secondary traumatic stress levels (see Figure 1). Thirteen of the respondents experienced average levels of secondary traumatic stress, while only two experienced low secondary traumatic stress levels. All participants felt that at times they were preoccupied with thoughts about their patients. Nine participants indicated that they sometimes or often experienced intrusive or frightening thoughts. Seven participants indicated that they avoided certain situations that reminded them of traumatic experiences that their patients had undergone. While participants appeared

Fig 1 Levels of secondary traumatic stress, burnout and compassion satisfaction ($n = 15$)



Source: Authors

to experience some secondary traumatic stress symptoms, particularly avoidance and intrusive symptoms, levels of secondary traumatic stress were average to low.

Burnout

The results of the ProQOL scale (Hudnall Stamm, 2010) showed that most of the caregivers (11) experienced average levels of burnout, while four caregivers had low burnout levels (see Figure 1). Although there were no participants who experienced high burnout levels, most of the caregivers did exhibit symptoms of burnout. According to Maslach (2001), there are three main components to burnout: emotional exhaustion, depersonalization and reduced personal accomplishment. Utilizing this framework, quotations

obtained from the interviews were grouped into these three categories and are presented in Box 1.

Participants attributed their emotional exhaustion to the demands of caring for patients with AIDS, especially as they knew that the patients were at the organization for palliative care and were in their final stages of the disease. While most of the participants spoke about their feelings of emotional exhaustion, a few felt that they did not experience signs of emotional exhaustion. One participant explained how she had never felt emotionally exhausted and how she kept motivated to ensure appropriate patient care. Designated as Participant 12, she states:

I never get emotionally exhausted because I always tell myself that I am here to work ... The fact that I am at work. I have to focus on my work, my patients need me.

Aspects of depersonalization were apparent as caregivers spoke about avoiding and distancing themselves from patients. Twelve of the participants felt that they were hardly the person that they wanted to be, and they felt that their levels of care for others had declined since they started as caregivers. Avoiding personal attachments with patients could be understood to be a necessary coping strategy that caregivers develop in order to deal with the overwhelming feelings of caring for terminally ill patients. Keidel (2002) argues that a person's vulnerability to burnout is also dependent on their personality type. People with low self-esteem, who are overly conscientious and who have perfectionist attributes are also prone to burnout. This understanding is apparent in Participant 8's response when she explained,

I feel exhausted emotionally due to the fact that I try to be perfect in my job but I do not receive any recognition or appreciation from the management, all I get are complaints.

Compassion satisfaction

Not everyone would be able to care for a patient during the last stages of life. Those who have the ability to care for a patient with AIDS are able to derive a sense of gratification from caring for these terminally ill patients. The results of the ProQOL scale (Hudnall Stamm, 2010) showed that participants had either a high or an average level of compassion satisfaction (see Figure 1). Twelve of the 15 participants acknowledged that they enjoyed their work as a helper most of the time, while only two participants rarely

Box 1 Participant illustrations of burnout symptoms (n = 15)

"It is emotionally exhausting to care for one patient for a long time but not see any improvements on their medical condition." (*Participant 7*)

"Some patients have serious and highly infectious conditions and diseases. They have dangerous diseases, so I try avoiding them so as not to get infected." (*Participant 2*)

"I do feel like avoiding the patient if there are no changes in the patient's condition." (*Participant 6*)

"I avoid patients who are in denial, for example, who do not want to accept that they are HIV-positive, making it difficult for caregivers to assist them." (*Participant 3*)

"I avoid and feel like not helping some patients because some of them are very difficult to handle and accuse us as caregivers of stealing things from their rooms." (*Participant 15*)

"Sometimes you get too attached to the patient and when you come for duty the following morning you find that the patient had died, that is so dissatisfying and traumatizing." (*Participant 2*)

"I was motivated and eager to implement what I learnt during my training days ... but I am no longer motivated." (*Participant 3*)

liked being a helper. The caregivers attributed their level of satisfaction mainly to seeing improvements in their patients coupled with the good relationships and appreciation they received from the patients' families. From the interviews, it was apparent that there were four predominant aspects that caregivers attributed to their levels of compassion satisfaction. These four themes included:

Noticing an improvement in seriously ill patients

Although patients who are admitted to the hospice are in the final stages of the AIDS illness and are not likely to improve significantly, when there were noticeable improvements in a patient's health, caregivers were encouraged. As Participant 2 shared, "I feel happy when I see a patient that was very sick getting better and being discharged."

Experiencing the happiness and gratitude of the families of the patients

Six of the caregivers spoke about how they experienced compassion satisfaction in the execution of their caregiving roles at the hospice as they noticed the family's happiness when a patient was experiencing health improvement. As Participant 3 explained, "I feel blessed when I see their families happy."

A study conducted in the United States of America by Christakisa and Iwashyna (2003) showed that there was a positive relationship between the care given to patients and the effect that it had on the families. Furthermore, a good and respectful relationship between caregivers and families contributed towards job satisfaction of the caregivers. Participant 14 spoke about how she felt appreciated by one of the families she had helped, "When you meet them [families] later on in the community, they recognize and value you as a caregiver."

Working with children

All of the caregivers spoke about how working with children was particularly rewarding. Being able to make a positive contribution to a suffering child's life had a particularly rewarding effect for caregivers. Participant 15 shared how encouraged she felt when she saw an improvement in a child's health, "What is satisfying for me is seeing a child that was once on an oxygen tank now breathing freely without an oxygen machine." Consistent with this response, working with children reminds people of their vulnerability and often brings out a sensitive and caring response from people (Figley, 1995; Geldard, Geldard, & Yin Foo, 2013).

Contributing to the fight against HIV and AIDS

Participants had selected to work specifically in an organization that assisted patients with HIV and AIDS as they wanted to play a part in the fight against the HIV epidemic. Most of the participants had personally witnessed someone they knew struggling with the disease, which had motivated them to become caregivers at an organization that assisted patients with HIV and AIDS. Participant 10 explained, "I became a caregiver when the epidemic became a huge issue in my community and after watching my neighbour suffering because of HIV and AIDS."

Two of the participants spoke about how they felt that there was still stigmatization of people living with HIV and AIDS from families and communities alike. Participant 9 related, "I have been watching poor treatment of people living with HIV and AIDS both in the hospitals and communities; as such, I wanted to help them."

These participants specifically wanted to work with this vulnerable group of people in order to help ameliorate the stigma associated with the disease. Motivated by personal experiences, Participant 2 specifically wanted to assist families, as she explained, “I have a family member who has died of HIV and AIDS, so I became a caregiver in order to help families to deal with denial and stigma associated with the disease.”

DISCUSSION

The overall results showed that participants experienced high to moderate compassion satisfaction and moderate to low burnout and secondary traumatic stress. According to Hudnall Stamm (2010), this result is the most positive combination obtainable by the ProQOL scale and indicates that participants did not suffer significant adverse fears as a result of their work. Considering that most participants had worked at the hospice for an average of 10 years, this factor could account for the low secondary traumatic stress levels experienced by the participants. Caregivers may become desensitized as a result of witnessing people die on a daily basis or may develop coping strategies in order to deal with the intensity of a patient’s illness and death. Although defences such as depersonalization are necessary when working in a hospice environment, one cannot discount the fact that patient care can be compromised. Authors such as Bride (2007) and Figley (2002) caution that despite the development of defences, the cumulative nature of trauma exposure can be considered a risk factor for secondary traumatic stress.

Additional factors such as gender and educational level may also influence how an individual experiences and copes with trauma (Friedman, 2006). In order to be a caregiver a tertiary qualification is not a requirement and as education about secondary trauma is not part of the caregiving course, many participants may not have the necessary knowledge or understanding of the effects of secondary trauma. It is therefore imperative that workshops addressing secondary trauma and effective coping are conducted with caregivers in order to equip them with the necessary knowledge and skills to ameliorate the effects of secondary trauma.

Some of the caregivers did identify symptoms of emotional exhaustion and burnout. Ross (2011) cautions that when one feels overwhelmed and unable to meet constant demands, this might result in emotional exhaustion and feelings of reduced personal accomplishment. As stress escalates one tends to lose motivation and enthusiasm for work that may have been initially inspiring. Constantly watching patients die and knowing that one cannot

change the inevitable outcome of death for these patients could result in caregivers having a low sense of professional accomplishment. One also needs to consider that some of the caregivers may themselves be living with HIV and therefore it may be extremely difficult for them to watch a patient die from AIDS-related illnesses. The constant exposure to death may raise questions about their own sense of health and mortality. (As there is still so much discrimination around HIV, many people who are living with HIV do not wish to disclose their status to others and so it was deemed appropriate not to explore participants' HIV status in a study of this nature.)

Mullins (2009) emphasizes how important it is for health-care workers and caregivers to have a sense of satisfaction with the work they do, as they are more likely to provide better care services to patients who are terminally ill when they are satisfied in their roles. Furthermore, over the past few decades there has been extensive research on the spillover effect of stress on both work and family (Laursen, Shulman, & Dickson, 2014). Work stress can easily contribute to home stress, as stressed employees may often be exhausted and/or irritable and not as attentive to the needs of their families. Participants spoke about how they felt that their work negatively affected their personal lives, as they always felt tired after the demands of a long shift worked at the hospice.

Many of the participants spoke about their frustrations with the hospice organization and their working conditions. Participants often felt unappreciated and that there were no opportunities for them to develop or advance within the organization. While theory on burnout (Maslach, 2001; Ross, 2011) does indicate that employees who are suffering from burnout may present with cynical and critical views of their employing organization, concerning an employee experiencing burnout may not only have negative views about work but these attitudes may also spill over into the employee's personal life. Participants did feel resentful that the hospice organization did not have any policies in place to assist them to cope with their work and indicated their willingness to make use of such initiatives if they were established by the organization.

Despite their work frustrations, participants did appear to derive high and average levels of compassion satisfaction from their work. In particular, caregivers appeared to derive a strong sense of fulfilment from their work as they felt that they were contributing to the fight against HIV and AIDS.

CONCLUSION AND RECOMMENDATIONS

Hospice caregivers encounter many stressors in their work, as they look after those who are terminally ill. Moreover, caregivers working at an AIDS hospice have additional challenges given that they need to ensure that they do not become infected with HIV or contract any opportunistic illnesses from their patients. As a result of being exposed to negative stressors over a prolonged period of time, caregivers may experience adverse effects. Caregivers need to be educated about secondary traumatic stress and burnout in order to help ameliorate the negative effects of helping. In addition, the positive side of helping should be emphasized, so that carers consciously monitor and enhance their compassion satisfaction. Caregivers acknowledged that despite the stressors, they derived much satisfaction from their work and this satisfaction helped them to continue to function.

Caregivers often need to feel a sense of accomplishment that will sustain them through any negative experiences and build their confidence and motivation to care for others (Radney & Figley, 2007).

It is apparent that the effects of burnout are far-reaching and can have severe consequences for the caregiver on a personal level, and can also be costly for the hospice organization as well as the patients who need quality assistance (Abdallah, 2009). In order to prevent burnout levels from escalating, the organization needs to ensure that carers have opportunities for engagement, continued education and growth opportunities (Hill et al., 2016; Hudnall Stamm, 2010; Ross & Deverell, 2010).

The conclusions that were drawn from this study need to be considered in terms of the limitations of the study.

First, none of the participants' first language was English, and both the research instruments were in English. However, as English is used as a medium of communication at the hospice to accommodate everyone, the interviews were conducted in English. The pilot study was conducted with English-as-second-language speakers and the feedback from the pilot study assisted the researcher to simplify the questions and make sure that the participants were given the same explanations to questions.

A second limitation is that participants may have provided socially desirable answers, given that some of the participants appeared to be uncomfortable talking about the organization. The researcher did try to assure participants about the confidential nature of the interview and that only pseudonyms would be presented when reporting on the study.

A further limitation is that, as the sample size only comprised 15 caregivers, the results cannot be generalized to any other population.

Furthermore, as only 15 caregivers were willing to participate in this study this may have introduced a bias; it is possible that only employees who felt dissatisfied with their work wanted to participate, viewing the research as an opportunity to express their views. None of the few male caregivers working at the organization wanted to participate in the research; had they agreed to participate, this could have yielded different results.

This study can make the recommendations outlined below.

Caregivers need to receive training about both the positive and the negative effects of looking after patients with AIDS during the final stages. Caregivers also need to monitor and be aware of the impact that their work might have on their personal and professional lives.

AIDS hospice organizations need to ensure that they develop and implement organizational strategies to help their employees cope with the emotional effects of their work. Regular debriefings, case discussion sessions and support meetings should be held to allow caregivers to share and talk about their challenges and the impact of working with dying patients and their families. Hill et al. (2016) advocate that organizations need to implement various psychosocial interventions in order to improve the well-being of staff who work in palliative care settings. Thompson and Bevan (2015) believe that leaders need to promote effective organizations and healthy workplace cultures in order to obtain the best results from employees. Activities to improve the psychological well-being of staff, enhance positive coping techniques and develop skills could all have a significant impact on reducing burnout levels. Positive acknowledgement from management and the implementation of organizational strategies can help carers to feel fulfilled in their work and enhance levels of compassion satisfaction.

Further research needs to be conducted in order to understand the effects of occupational stress on caregivers. For example, a comparative study could explore the challenges of caregivers employed at a general hospice organization as opposed to caregivers employed at a hospice caring for patients with AIDS. The similarities and differences that may be identified can help guide interventions for caregivers at each organization.

LESSONS LEARNT FROM THE STUDY: IMPLICATIONS FOR SOCIAL WORK

In keeping with the ecosystems approach of social work practice, social workers need to be mindful of all the systems and professions that contribute to addressing the HIV and AIDS epidemic. The findings emanating from this

study highlight the following implications for social work practice.

First, from the study it was apparent that caregivers are emotionally affected by their work with patients with AIDS. The social work response needs to move beyond assisting HIV-positive clients and their families and should incorporate interventions for those who care for individuals living with this disease. Education about the emotional and spiritual effects of working with terminally ill patients needs to be provided for the carers. Carers need to be aware that particular cases, such as those involving children, may be more emotionally difficult for them to handle. Social workers need to ensure that the necessary support and referral networks are established so that carers can receive counselling when it is necessary.

Second, self-care policies would appear to be applicable globally. Hence, social workers should advise organizations that assist patients with AIDS to develop self-care policies and programmes for their staff. Participants in this study complained that there were no self-care policies or strategies in place for emotional support or to deal with the effects of their work as caregivers. Group debriefings should be conducted on a regular basis to help normalize carers' responses when working with terminally ill patients. Organizational policies that address issues such as regular leave-taking and limiting the amount of overtime employees can work need to be implemented. A social worker's knowledge and expertise in drafting and implementing such policies and programmes can help to ameliorate burnout levels among staff and promote a healthy work environment.

Third, despite the advances that have been made in knowledge and the understanding of HIV, there is still significant stigma attached to the disease both in South Africa and elsewhere (Harber et al., 2011). Social workers have a role in advocacy and educating communities about HIV and AIDS. In so doing they can make a significant contribution to reducing stigma and discrimination and help attain the UNAIDS 2016–2021 Strategy of zero discrimination (UNAIDS, 2016b).

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Part 4: National and regional social work policy and professional development

**Miles to go before
we rest: Two decades
of social work
responses to HIV
stigma in India**

Melita M. Vaz and Vimla V. Nadkarni



ABSTRACTS

Despite the availability of free HIV testing and antiretroviral treatment in India, eligible people often avoid accessing services because of perceived stigma. These include women, sex workers, transgendered populations and men who have sex with men. They face discriminatory attitudes from families, peers, health-care workers and workplaces. From the 1990s, social work professionals undertook interventions at different levels of the system: individual and family counselling, sensitization of medical professionals, awareness campaigns and advocacy efforts with the government. Their efforts bore fruit through the expansion of HIV service jobs for social workers and the acceptance of counselling by policy-makers. However, in the context of persisting stigma, shrinking government budgets and medicalization of the response to HIV, social workers must renew advocacy efforts. They should also address internal challenges such as limited evaluation and documentation of social work responses, inconsistent quality of education and geographical incongruence in the availability of qualified social workers.

我们休息前需行进的里程：应对印度艾滋病歧视的社会工作二十年

尽管印度有免费的艾滋病毒检测和抗逆转录病毒治疗服务体系，但是，符合条件的人常常因为有耻辱感而不愿意接受此类服务。这些人员包括妇女、性工作者、变性群体和男男性接触者。他们要面对来自家庭、同辈、卫生保健工作者和工作场所的歧视。从20世纪90年代开始，社会工作专业人员在这个服务体系的不同层面上进行了一些干预：个人和家庭咨询、医疗专业人士的宣传、普及宣传活动和政府的大力宣传。通过加强社会工作者对艾滋病患者的服务工作和决策者接受相关的咨询，他们的努力结出硕果。然而，面对患者头脑中挥之不去耻辱感和政府缩减应对HIV病毒的预算的状况，社会工作者必须重新开展宣传工作。他们也应该解决内部的挑战，诸如有限的社会工作应对评价和文献记载、教育质量参差不齐、社会工作人才地理分布不均衡等。

Mucho camino por recorrer: Dos décadas de trabajo social con el estigma del VIH en la India

A pesar de la disponibilidad gratuita de la prueba del VIH y el tratamiento antirretroviral en la India, las personas con acceso a menudo evitan los servicios debido a la percepción del estigma. Mujeres, trabajadores sexuales, poblaciones transexuales y hombres que tienen sexo con hombres se enfrentan a actitudes discriminatorias de las familias, los compañeros, los trabajadores sanitarios y sus lugares de trabajo. Desde la década de 1990, los profesionales de trabajo social realizaron intervenciones en diferentes niveles del sistema: orientación individual y familiar, sensibilización de los profesionales de la medicina, campañas de sensibilización y actividades de promoción con el gobierno. Sus esfuerzos dieron sus frutos a través de la expansión de los empleos de servicios de VIH para los trabajadores sociales y la aceptación de asesoramiento por parte de los responsables de las políticas. Sin embargo, en el contexto de la persistencia del estigma, la reducción de los presupuestos gubernamentales y la medicalización de la respuesta al VIH, los trabajadores sociales deben renovar los esfuerzos de promoción. También deberían abordar los retos internos tales como la evaluación y documentación limitada de las respuestas del trabajo social, la calidad desigual de la educación y la incongruencia geográfica en la disponibilidad de trabajadores sociales calificados.

休む前に進まねばならない長い距離: インドでのHIV汚名への20年間の社会福祉対応

インドでは、無料のHIV検査が利用でき、抗レトロウイルス治療が受けられるにもかかわらず、該当する人は、広く認知された汚名のため、サービスの利用を避けることがよくあります。これらには、女性、売春労働者、性転換者と男性とセックスする男性などが含まれます。彼らは、家族、仲間、医療従事者からや、職場での差別的な態度に直面します。1990年代から、社会福祉の専門家は、制度の異なるレベルで、次の様な介入を行いました。個人と家族のカウンセリング、医療専門家の感作、認知キャンペーン、そして政府との擁護努力などです。彼らの努力は、ソーシャル・ワーカーへのHIVサービスの仕事の拡大と、政策担当者によるカウンセリングの承認を通して実を結びました。しかし、持続的な汚名、縮小する政府予算とHIVへの対応の医療化の背景で、ソーシャル・ワーカーは主張する努力を再開しなければなりません。ソーシャル・ワーカーは、社会福祉対応の限られた評価と文書化のような内部の課題、教育の品質が一貫していないこと、資格のあるソーシャル・ワーカーを利用できるのが地理的に不均衡となっていることも申し立てなければなりません。

Distance à parcourir avant le repos : Deux décennies de ripostes de travail social à la stigmatisation liée au VIH en Inde

Malgré la disponibilité des tests gratuits du VIH et du traitement antirétroviral en Inde, les personnes éligibles évitent souvent d'accéder aux services à cause de la stigmatisation perçue. Parmi ces personnes figurent les femmes, les travailleurs du sexe, les populations transsexuelles et les hommes ayant des rapports sexuels avec des hommes. Elles font souvent face aux attitudes discriminatoires des familles, des pairs, des professionnels de soins de santé et dans les milieux de travail. À partir des années 1990, les travailleurs sociaux ont mené des interventions à différents niveaux du système, notamment l'offre de conseils aux individus et aux familles, la sensibilisation des professionnels médicaux, les campagnes d'éducation et les initiatives de plaidoyer auprès du gouvernement. Leurs efforts ont porté des fruits se traduisant par la création d'emplois plus nombreux dans les services relatifs au VIH pour les assistants sociaux et l'acceptation des conseils par les décideurs. Cependant, dans le contexte de la stigmatisation persistante, la réduction des budgets de l'État et la médicalisation de la riposte au VIH, les travailleurs sociaux doivent renouveler les initiatives de plaidoyer. Ils doivent également résoudre les problèmes internes tels que l'évaluation limitée et la documentation des ripostes des travailleurs sociaux, la qualité peu consistante de l'éducation et l'incongruité géographique dans la disponibilité des travailleurs sociaux qualifiés.

INTRODUCTION

HIV was first observed in India in 1986. In the first decade it established itself firmly in three states: Maharashtra (west coast), whose capital city Mumbai is also India's commercial capital, Tamil Nadu (south India) and Manipur (north-east). Across the next two decades it spread to all 29 states and seven union territories. However, the prevalence of HIV differs across, and within, states (Government of India [GOI], 2015, p. 26). Manipur currently has the highest estimated adult prevalence, 1.15%, compared with the national average of 0.26% (GOI, 2016a). Tamil Nadu and Maharashtra also exceed the national prevalence. But there are other states that outpace them, such as Mizoram (0.8%) and Nagaland (0.78%) in the north-east, Andhra Pradesh and Telengana (0.66%) in the south, and Gujarat (0.42%) in the west. New Delhi, Rajasthan and West Bengal currently demonstrate prevalence rates below the national average. The HIV epidemic in India has changed to a great extent over the past 30 years. Given the overall prevalence rates across the

states, there are an estimated 2.1 million people living with HIV in India (GOI, 2016a).

The National AIDS Control Programme (NACP) was established in 1992 with the goals of creating awareness through Information Education and Communication, especially among people at higher risk of infection. Currently the NACP is in its fourth phase, and part of what it offers is also prevention services as well as care and treatment services (GOI, 2016a).

- Prevention services include targeted interventions for members from key populations and include a needle-syringe exchange programme, services for sexually transmitted infections, prevention of parent-to-child transmission and HIV testing services. Key populations are “groups of people who are more likely to be exposed to HIV or to transmit it and whose engagement is critical to a successful HIV response” such as “men who have sex with men, transgender people, people who inject drugs and sex workers” (UNAIDS, 2010, p. 62).
- Treatment includes antiretroviral treatment using standardized regimens, the treatment of opportunistic infections and coordination with the national tuberculosis programme.

Each service involves suitable counselling by trained personnel. Across successive phases of the NACP, testing facilities for HIV and sexually transmitted infections have been established in every district across the country and at present number some 18 000. Treatment facilities in the form of 519 antiretroviral treatment centres (ART centres) and 1073 link antiretroviral centres have been established in every state according to district-specific prevalence rates of those requiring treatment. This scale-up of services has had a demonstrated impact on the declining overall national prevalence (0.38% in 2001 to 2003; 0.34% in 2007; 0.26% in 2015; GOI, 2016b).

However, gaps persist. According to government figures, only 900 000 adults and 77 729 children of the total estimated 2.1 million people living with HIV receive antiretroviral treatment at government ART centres (GOI, 2016a). While this is partly due to the fact that the national eligibility criterion for the initiation of treatment is currently set at a CD4 count of 350 as of September 2015 (GOI, 2016a), the overall number of people living with HIV registered at ART centres (which includes people not yet receiving treatment) was a mere 1 080 058. The World Health Organization (WHO) 2016 consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection at present recommend immediate initiation of ART to people living with HIV upon diagnosis, regardless of the CD4 or viral load count (WHO, 2016). Thus, according to the government’s own estimates, only about half

the number of people living with HIV are enrolled in the government sector for treatment.

While it is true that some people may prefer to receive services through the private sector using self-financing, there is much evidence to show that the low numbers are due to the prevalence of barriers in the form of HIV stigma and discrimination. The Government of India is at present engaged in operationalizing a higher CD4 cut-off for service delivery in line with recommendations from the World Health Organization (GOI, 2016b). However, if stigma and discrimination persist, then treatment services will remain underutilized by people living with HIV.

This chapter outlines findings on HIV stigma and discrimination in India, especially in relation to the barriers they pose. It then discusses findings related to interventions on stigma reduction in India, and concludes by examining the contribution of social workers towards such efforts, especially in the context of treatment. All works cited in this chapter pertain specifically to India.

HIV STIGMA AND DISCRIMINATION IN INDIA

Stigma related to HIV has been defined as “negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV and other key populations at higher risk of HIV infection” (UNAIDS, 2014 p. 2). Discrimination refers to acting on these beliefs and attitudes. It consists of actual acts of differential treatment towards people living with HIV—both acts of omission and commission. This extends to behaviours towards groups of people who are vulnerable to HIV such as men who have sex with men and people who inject drugs. Working to eliminate HIV stigma and discrimination is one of the stated goals for the international community as well as for India.

In India, stigma and discrimination have been documented in many contexts and in many forms (UNAIDS, 2001), as outlined below.

- In hospital settings:
 - Testing without informed consent before surgery or delivery.
 - Refusal to provide treatment for HIV and related conditions or discontinuing existing treatment.
 - Refusal to touch people living with HIV or unnecessary use of protective gear only in the case of people living with HIV.
 - Refusal of admission to hospital care.
 - If admitted, discharging the person before completion of treatment.

- Restricting movement in the ward.
- Limiting access to the toilet and to common items used for eating and drinking.
- Not providing transportation for the bodies of people who were HIV-positive and have died.

- In the workplace:
 - Social avoidance.
 - Labelling and name-calling.
 - Denial of health benefits or insurance.
 - Removal from job.
 - Forced resignation.

- By family and in the community:
 - Labelling and name-calling.
 - Separate sleeping areas and physical accommodation.
 - Blocking of access to common areas, such as toilets.
 - Abandonment and breaking-off of relationships.
 - Not performing religious rituals in the event of death due to AIDS.
 - Denial of share of family resources, such as property.

The forms of stigma described above are both overt and covert. Some forms of denial of care, such as repeated testing for HIV, shunting a patient between doctors or delaying admission for weak reasons, are very subtle and difficult to pinpoint. Health facility workers report being likely to stigmatize or discriminate even in instances where there is a low possibility of coming into contact with infective body fluids, such as when taking blood pressure (Ekstrand, Ramakrishna, Bharat, & Heylen, 2013).

Stigmatization is reported in rural areas (Nyamathi, Ekstrand, Zolt-Gilburne et al., 2013) as well as in urban areas (Ekstrand et al., 2013; Mahendra et al., 2007). Although research is scarce, there is evidence of HIV stigma in indigenous communities in India also (Vlassoff, Weiss, Rao, Ali, & Prentice, 2012).

Moreover, irrespective of geography, women appear to face a disproportionately larger burden (UNAIDS, 2016). Often, women are more likely to provide care to infected spouses but are less likely to receive such care themselves. They face blame and suspicion as a result of being infected, especially if their status becomes known soon after marriage (UNAIDS, 2001). Further, they could also face accusations of not being womanly enough to

prevent their husband from straying to another woman (Weiss, 2008). This is a classical instance of victim-blaming.

Key populations such as men who have sex with men, sex workers and people who inject drugs, face a double burden of HIV stigma as well as “intersecting stigma” pertaining to their behaviours or professions (International Center for Research on Women [ICRW], 2013). For instance, men who have sex with men and who are also infected with HIV face stigma and discrimination from health facility workers and family, as well as from police and from other men who have sex with men (Chakrapani, Newman, Shanmugam, McLuckie, & Melwin, 2007). Sometimes physical violence is involved.

There is a rich body of research on the manifestations and effects of stigma in India that is based on a theoretical framework proposed by Steward et al. (2008). The strength of this framework is that it extends beyond acts of stigmatization by other people towards people living with HIV by acknowledging how people living with HIV also denigrate themselves for their own status, and the impact of such self-denigration.

- Enacted stigma refers to actual acts of discrimination or differential treatment because of one’s devalued or stigmatized status. This is an interpersonal form of stigma.
- Felt normative stigma is the perception of enacted stigma against other people who share one’s devalued status as well as a sense of how common it is.
- Internalised stigma is also called self-stigma and refers to the acceptance of one’s devalued status as being valid and deserved, the internalization of society’s blaming and shaming attitudes. This, along with felt normative stigma, is an intrapersonal form of stigma.

Early literature such as UNAIDS (2001) often captured enacted stigma in all its stark forms. However, the other forms of stigma are just as harmful and need to be eliminated because they violate human rights and affect mental health (Das & Leibowitz, 2011; Steward et al., 2008), in addition to the reactive depression caused by learning one’s HIV status. Further, anticipation of stigma or felt normative stigma causes people to avoid sharing their HIV status with others. This is termed disclosure avoidance (Steward, Bharat, Ramakrishna, Heylen, & Ekstrand, 2013). People living with HIV might make up elaborate reasons other than HIV for visiting the doctor (e.g. seeking tuberculosis treatment) or might go out of their geographical community to access care. But in its extreme form, disclosure avoidance could mean avoiding treatment

facilities altogether for fear of being seen by acquaintances and thus being outed, or for fear of being treated poorly by health workers. Delays due to disclosure avoidance have been observed in the so-called general population (Steward et al., 2013) as well as among various key populations in India such as sex workers (Chakrapani, Newman, Shanmugam, Kurian, & Dubrow, 2009), men who have sex with men, and transgender people (Chakrapani, Newman, Shanmugam, & Dubrow, 2011). Delays in treatment harm people living with HIV as well as their sexual partners.

Interventions to address HIV stigma in India

There are few documented interventions in India that directly seek to address HIV stigma. However, reviewing them elicits some understanding of areas that require greater attention.

Interventions with health-care providers

The literature on stigma interventions largely focuses on health-facility workers. These personnel consistently demonstrate intentions to stigmatize and discriminate even in instances where there is a low likelihood of coming into contact with infective body fluids (Ekstrand et al., 2013; Pulerwitz, Michaels, Weiss, Brown, & Mahendra, 2010). This is true of even those who report having received some training in HIV and whose HIV knowledge is reasonably accurate (Ekstrand et al., 2013). It has been seen that providing health administrators with data to make a plan to address stigma at the institutional level and encouraging them to make adequate provisions for materials for universal protection can assuage the fears of health-care workers (Pulerwitz et al., 2010). However, interventions with health-care providers in both government and private settings appear to have the greatest impact at the knowledge level (namely transmission misconceptions) or for low-risk activities such as taking blood pressure (Shah, Heylen, Srinivasan, Perumpil, & Ekstrand, 2014). They have a lower impact on improving closer clinical interactions with people living with HIV. It has been suggested by researchers studying stigma in India that a key driver for reducing stigma might be to increase actual contact with people living with HIV so as to normalize the experience (Ekstrand et al., 2013; ICRW, 2013).

Interventions with people living with HIV and marginalized populations

These interventions have thus far involved two components: providing accurate information about HIV and providing interpersonal counselling. With regard to the former, Nyamathi, Ekstrand, Salem et al. (2013) demonstrated

an improvement in stigmatizing attitudes in rural women living with HIV who were provided with information over multiple sessions, especially women who were depressed. Others have demonstrated the positive benefits of engaging with people living with HIV through interpersonal counselling to overcome the deleterious effects of stigmatization. For instance, ICRW (2013) reported on such efforts with sex workers. That these studies report large effect sizes in terms of intervention success is possibly reflective of poor implementation of government protocols regarding knowledge provision and counselling at government-funded counselling centres.

Public awareness campaigns

There is little publicly available data on the effect of public awareness campaigns in India despite these having been numerous, such as the Red Ribbon Express (GOI, 2016a). However, consistent anecdotal reports of enacted stigma from people living with HIV would indicate a limited effect on the general public.

It would appear that while there is a good deal of documentation on forms of stigma, as well as on their effects, there is very little systematic effort to document interventions related to stigma reduction, either for research purposes or as part of implementation reports. The Government of India dedicates considerable funds to annual in-service training of its personnel (GOI, 2016a). However, data on the impact of such training are limited. It is possible that training on HIV stigma is marginal in such programmes and produces only skin-deep changes; even workers in health-care settings intended for people living with HIV can be insensitive to their needs and feelings (Ekstrand et al., 2013). For instance, Chakrapani et al. (2011) reported that transgender people who self-identify as female perceive ART centres as gender insensitive; they dislike being asked to wait in the line for male patients.

Stigma research in India consistently describes drivers of stigma including lack of awareness among health professionals of the harm of stigma, social judgement by professionals and by the general public, and fear of infection through casual contact due to transmission misconceptions (Ekstrand et al., 2013; ICRW, 2013; Pulerwitz et al., 2010). This would suggest a continued need for awareness building.

Yet interventions for stigma cannot stop there. Mahendra et al. (2007) produced the only study to report on system-altering measures, such as developing a checklist for detecting stigma in the hospital and for improving the access of health-care personnel to items such as gloves. These are as critical as knowledge provision. One subtle means of discriminating against

people living with HIV is to refer them to other health facilities, citing lack of resources such as equipment (UNAIDS, 2001). Interventions with health-facility workers may succeed in reducing transmission misconceptions but could still be derailed by lack of resources. By the government's own admission there are bottlenecks in the release of funds to health systems (GOI, 2016b), and essential materials, such as protective gear, are often in short supply.

Contact strategies have also been promoted as necessary (ICRW, 2013). Indeed, Ekstrand et al. (2013) found the least stigmatizing attitudes in health-care providers with the most contact with people living with HIV. Yet contact strategies become inadequate when other intersecting stigmas, such as those operating against men who have sex with men and sex workers, become salient (Chakrapani et al., 2011). There is some evidence that when people living with HIV engage in service delivery themselves, they are able to influence public perceptions of their value and productivity (Pulerwitz et al., 2010). Indeed, people living with HIV have been involved in different positions under the NACP—as outreach workers in the Prevention of Parent to Child Transmission Programme, as care coordinators at ART centres, and as community workers in Community Support Centres. This is a kind of contact strategy that provides a livelihood to people living with HIV.

Parker and Aggleton (2003) critique approaches that treat stigma as a cognitive or psychological phenomenon; that is, approaches that address stigma as something within the individual that can be repaired or addressed through filling a knowledge gap. This sums up the approach of the interventions described above. Instead, they argue for a sociological perspective, which situates stigma within the belief framework of communities and thus makes it more deep-rooted and difficult to eradicate. HIV stigma is a newer manifestation of existing stigmas within society against already marginalized and vulnerable groups, such as men who have sex with men, transgender people, people who inject drugs and sex workers. The only way, then, to address stigma is through a multilevel effort involving the individual, families, the institutions of health care and the general public.

Such a multilevel effort would involve all of the components of sensitive counselling, provision of accurate information, attitudinal training and contact strategies. To make these efforts effective, however, it is also important to challenge structures that permit the persistence of stigma and discrimination. Some structural changes would involve consciously tailoring quality health services towards the needs of key populations in a form that respects their privacy and dignity. For instance, if sex workers awake late after their nightly work, the earliest they may be able to access care services

is in the afternoon. Traditional hospital outpatient departments conclude business at the lunch hour. A structural change would be to alter the hours of the outpatient department to accommodate everyone for whom the mornings are not convenient. Other structural changes include involving people living with HIV in committees that make such decisions and within structures that address grievance processes. At present, government health systems have a grievance process on paper. This needs to be strengthened through regular meetings of grievance committees.

Social workers could play a key role in addressing stigma, and we explore this in the next section.

SOCIAL WORKERS AND HIV STIGMA IN INDIA

The social work response to the challenge of HIV in India began in the early 1990s. Given the paucity of written documentation in the public sphere, this section of the chapter is, to a large extent, written anecdotally from memories of the two authors who, between them, have 50 years of collective experience with HIV at both nongovernmental and governmental levels. In particular we explore the impact of social work on the Government of India's health-care settings.

We were unable to identify a large number of professional reports or papers written by social workers as we prepared this chapter. However, it is our experience that social workers have been instrumental in challenging the discriminatory behaviours faced by people living with HIV. For instance, social workers have assisted people to establish their rights in family inheritance. They would talk to employers and try to get people living with HIV reinstated in cases where they were fired. They showed people living with HIV how to access available insurance schemes without getting outed for being infected with HIV. Even today, social workers stationed at police stations encounter women who have been thrown out of their marital homes because they are living with HIV, and help them in the restitution of their rights.

One of the earliest strategies adopted by social workers was to offer and demonstrate sensitive counselling for people living with HIV. Pioneer institutions like Tata Institute of Social Sciences (the home institution of the two authors) in Mumbai and Christian Medical College in Tamil Nadu (south India) undertook such counselling for people living with HIV from the early 1990s. They also provided cascade training for social workers and doctors using grants from the government and from foundations. They provided training across the country to social workers who worked in the health sphere

(for instance government hospitals) as well as other settings such as faith-based organisations like the Christian Medical Association and the Indian Railways. A key component of training involved training medical personnel on the ethics of informed consent, even though this was observed more in the breach.

During the early years of the social work response, antiretroviral treatment was largely unavailable, so counselling focused on building resilience in people living with HIV, developing healthy lifestyles and on suicide prevention. People living with HIV were often relegated to social workers, as their so-called territory.

Before the national scale-up of government services described at the beginning of the chapter, services such as treatment of opportunistic infections and sexually transmitted infections, outreach to sex workers, counselling and family support were provided by nongovernmental organizations (NGOs). Social workers across NGOs and educational institutions joined hands to create fora of likeminded individuals in cities like Mumbai, New Delhi and Pune in order to have dialogue with government officials to improve service delivery and other issues. They created awareness with policy-makers about issues pertaining to stigma, such as denial of treatment at public hospitals. These collaborative efforts of civil society remain strong even today, and social workers remain committed to them.

Social workers in various settings became models of how to undertake sensitive counselling and run group sessions. Some schools of social work began training students in the classroom and through field placements to work with people living with HIV. Classroom training involved sensitivity towards sex workers, men who have sex with men, people who use drugs and transgender people. Supervised field placements represented a form of contact strategy, which built sensitivity to the needs of people living with HIV and served to reduce stigma within social work students. However, such efforts have not been documented for the public domain; contrast this with articles dedicated to social work education in other countries (for example, Schwartz, 2003) or evaluation studies within India itself of courses for medical students and nursing students (Shah et al., 2014).

Recognising that international guidelines on HIV counselling were not automatically applicable to India, given its particular level of technology and its cultural context, social workers undertook efforts to adapt such materials or to develop indigenous materials. For instance, social workers at the Tata Institute of Social Sciences developed an indigenous module titled *Telephone counselling for HIV/AIDS: A counsellor's handbook* (Chitale, Vaz, Dua, & Nimla, 2000) in English and in local languages such as Hindi using

funds from the government as well as UNAIDS. This package examined how to deliver sensitive counselling services and training within the existing telephone services available, and was benefitted by advice from officials of the government telephone service, who was the sole service provider at that time. However, this documentation was an isolated effort and was not taken to scale. While released into the public domain, the absence of a clear marketing strategy meant that such publications did not reach even other schools of social work.

However, the consistent strength of these early efforts was recognized by the Government of India which, along with UNAIDS, established the first Technical Resource Group on Counselling within the Tata Institute of Social Sciences (Nadkarni & Rego, 2016). This technical body comprised experts in counselling—social workers and others—from different parts of the country. One of their key contributions was to establish minimum standards for counselling, including informed consent for HIV testing. This body helped to establish a clear expectation that all health-care facilities established by the government should include trained social workers in the delivery of HIV counselling. Thus, as the NACP was scaled up, 6 500 positions for social workers were created in governmental facilities alone (this number is derived from the NACP service centres established by the government; GOI, 2016a).

However, the establishment of service positions has been limited by an inability to match the demand for social workers. We reported that HIV is prevalent in all states. However, despite an anecdotally reported abundance of schools of social work in the country (some 500-plus, apparently), there are states that face a lack of personnel because of an absence of schools of social work. When the first author, Melita Vaz, was working within the national government she encountered states with no schools of social work at all, and which, therefore, requested an exception to the norms requiring social work personnel. Schools of social work must combat these geographical incongruities through outreach strategies that encourage eligible people in these states to enrol in social work education. One suggestion is to examine the development of social work educational programmes in a faster delivery mode than the traditional two-year Master of Social Work programme that is the norm in India, or through distance learning.

To rectify the mismatch between the scaled-up demand for personnel under the NACP and the need for quality training in counselling, the Tata Institute of Social Sciences and other schools of social work entered into a collaborative venture with the Government of India to build counselling capacity in the country (Maitra, Srivastava, & Bharat, 2013). With funds from the Global Fund for AIDS, Tuberculosis and Malaria (Global Fund), different

schools of social work from almost all states were capacitated to undertake HIV counsellor training and supportive supervision of counsellors across the country over a six-year period (2008 to 2013). In states with no schools of social work, the project operated through colleges of psychology.

However, to date this project also has failed to produce documentation of its impact in the public domain. An external study underlined the need for consistent collaborative work in developing the competencies of the various institutions involved in delivering quality training that meets the needs of the NACP (Vaz, Kadyan, Chalil, Prasad, & Singh, 2016). Especially in the early phases of the project, there appeared to be an unevenness of capacity to deliver counsellor training among the selected educational institutions.

One possible reason for the uneven quality could be that some social work institutions are located in areas of low HIV prevalence and trainers could not relate to material created largely in the context of states with high prevalence. For instance, in her administrative capacities, the first author had to relocate a planned training programme under this project from a district of low prevalence when it became apparent that the district did not have a local ART centre and thus could not demonstrate some of the processes mentioned in the standard training package. In another instance, a rurally located school of social work struggled to find a suitable trainer to handle the topic of HIV and mental health in that region. Thus, even within a single country, there is the need to ensure that standard training packages are adapted to each local region. This clearly outlines the need to “know your epidemic” (UNAIDS, 2010, p. 16)

Another reason for the uneven quality pertains to the overall scenario in education in India today. Many professional fields are facing a situation where education courses line up very poorly against the demands in the field. For instance, only 7% of applicants could pass a test of teacher eligibility from a pool of 785 227 (Gohain, 2012) and final-year medical students at a well-established medical college were found to be unable to identify different types of medical equipment (Mishra, 2012). This has led to questions about the impact of such lacunae on the national economy (Limaye, 2013). In our opinion, social work, for the most part, is no exception to this trend of decline in education.

The Global Fund project reached every counsellor in government service across a two-year period of supportive supervision and across six years of training. It is important for such projects to publicly document their outcomes. Training curricula for social workers in government positions include a session on stigma, however, these sessions are often cosmetic. Despite annual training and several years of supportive supervision,

complaints about quality of service remain (GOI, 2016b). Part of this can be explained by the statement made by one social worker, “I know it is wrong to test everyone for HIV before surgery. But I cannot do anything to counter a doctor’s orders.” Social workers remain part of the system and are unable to effectively overturn existing unethical practices. Without even a basic understanding of how social workers in these key settings perform with regard to service delivery, it is impossible to assess their professional response to stigma. For instance, do social workers actually implement key practices of informed consent in a consistent manner? Thus, while social work employment received a fillip from the creation of new jobs, this was not matched with a clear, measurable standard of quality.

The establishment of such standards would force schools of social work to reexamine their existing curricula. For instance, one-to-one counselling of people living with HIV may assuage the hurts caused by enacted stigma and self-stigma. But social workers may need to develop other skills, such as advocacy for patients, to ensure that they do not get turned away from health-care services or get treated disrespectfully. Social workers should also use their contextual knowledge to effectively refer people living with HIV to access social service benefits.

With the advent of antiretroviral treatment and the national scale-up of treatment, services for people living with HIV at ART centres have become medicalized. In such a context, it is easy for hospital-based social workers to slip into the role of directing people living with HIV from testing facility to treatment facility or to be relegated to the position of enforcing adherence. This forces social workers to categorize people living with HIV who present for treatment as good if they are treatment compliant and bad if they fail to take medicine as prescribed. They face a real challenge of stigmatizing people living with HIV who do not take their medicine in the prescribed manner. Pleading the burden of large numbers of patients, it appears that few take the time to probe the reasons why people living with HIV fail to take medicines as prescribed. Other needs of people seeking services are liable to be ignored. Without adequate documentation, it is difficult to prove otherwise: far from being able to discuss the role of social workers in addressing stigma, social workers face difficulty in demonstrating that they meet a minimum service standard. However, the challenges of stigma and discrimination continue to affect people living with HIV, including those seeking treatment at ART centres.

Facing the challenge of shrinking government budgets (GOI, 2016b), social workers in ART centres and at testing facilities are often reduced to paper-pushing. It is important to resist this trend. If social work professionals

fail to demonstrate their relevance and added values, they risk seeing their own positions being task-shifted to other personnel—a very real possibility given the medicalization of HIV treatment. If social workers stay true to their professional training, they would be in a position to interpret the non-medical needs and condition of people living with HIV for other medical professionals. They would be able to use their knowledge of social sciences and of human behaviour to facilitate the well-being of people living with HIV. For instance, a state government administrator reported reading in the newspaper of the suicides of a married couple who were under treatment at two different ART centres. The administrator, a public health specialist, was struck by how neither ART centre picked up on the fact that the couple were individually seen at different health-care facilities, and no attempt was made to bring the family together under a single treatment roof. Such details could be picked up through routine history-taking; the inability to view the couple as a family unit with special needs reflects a lost opportunity for the social workers at both ART centres.

Social workers need not be limited by resource-constrained environments where protective gear, such as gloves and syringes, are scarce given that these are not the tools of their trade. Given India's status as a developing country, such resource challenges are unlikely to end soon. Social workers need to accept that they have to find a way around these situational hurdles.

Our chapter focuses on social workers in established HIV care settings because these are the most visible points at which social work professionals interact with people living with HIV. However, social workers in other spheres also face the challenges posed by HIV stigma. For instance, family social workers in counselling centres at police stations routinely encounter women facing domestic violence due to HIV, as do social workers based within family courts. It is important for social work education to also cover these situations.

Unfortunately, the paucity of social documentation makes it likely to overlook the contribution of social workers.

LESSONS LEARNED

Social workers in India have firmly placed counselling and informed consent on the government agenda. Today the Government of India has established facilities where, in theory, a person living with HIV should be able to encounter trained staff to discuss their issues. Social workers in these locations have an opportunity to create an enabling environment for people

living with HIV as well as for key populations, which will counter their experience and expectation of stigmatization.

However, with the national scale-up it has been challenging to ensure the availability of trained professionals and consistent quality of counselling in all states. Schools of social work face the challenge of producing well-trained professionals. This situation is complicated by the geographical incongruence in the availability of schools of social work and regional differences in HIV prevalence.

Social workers in India have been poor at documenting the impact of their work. It has been very difficult to demonstrate even the simplest impact in terms of stigma reduction because social workers have sometimes failed to write up basic assessments and evaluations for public consumption, despite doing good work. This may provide the erroneous picture that social workers have done nothing to combat stigma when their personal day-to-day experiences say otherwise. Even when documentation efforts have been undertaken, they have failed to reach the larger social work community. If we want to ensure a standard of quality that is consistent across states then we need to put into the public domain honest assessments of the quality of social work care, including strategies for how to improve it, and evaluations of how social workers are meeting the needs of people living with HIV. Without such efforts it is difficult to combat the trend of medicalization, and we face the prospect of reducing the person living with HIV to a mere receptacle of antiretroviral medicine—it is easy to develop tunnel vision. Without such basic documentation, it is difficult to make an advocacy case for the needs of people living with HIV, including key populations. The profession is unable to engage in a necessary self-reflection that folds back into curriculum-building. Further, without solid evidence of effectiveness, social workers run the risk of falling victim to task-shifting.

Besides documenting for the public domain, social workers must examine effective ways to disseminate. Often good adaptations of interventions or even indigenously developed interventions do not reach the larger community of social work educators. Thus social workers who are keen to engage in good practice do not have access to quality materials for self-learning and improvement.

India does not have a licensing system for social work practice, and thus there has been inconsistency in the quality of education. This is not limited to social work education alone, but there is a professional obligation to ensure that graduating professionals are competent to handle the job requirements and are able to create an enabling environment for people living with HIV. As the framework of Steward et al. (2008) demonstrates, stigma is not

necessarily just overt words or deeds of denigration: even the anticipation of being treated unfairly or poorly may cause a person living with HIV to avoid accessing services. If government documentation focuses almost exclusively on medicine adherence, it is important for social work educators to establish alternative standards that contextualize the well-being of the individual against the backdrop of her/his own life.

CONCLUSION

Social workers' early efforts to respond to HIV involved advocating for the rights of people living with HIV with employers, spouses and family members. They offered assistance for HIV in hospitals, community support centres and legal aid centres. Social workers established the importance of counselling for people living with HIV. The value demonstrated by these early efforts resulted in an increase in the jobs available to social workers. The national scale-up of HIV services means that every district could have at least two social workers as the focal points for HIV services, which in turn provides an opportunity to demonstrate caring, responsive and respectful social work attitudes.

Today, as the trend towards medicalization of the HIV response grows stronger, it becomes even more critical for social workers to challenge this trend through a constant focus on addressing people as people. When medical adherence becomes the focus of treatment it is easy for even health-care professionals to stigmatise those who do not consume medicine as so-called bad patients rather than examine the challenges they face in adjusting to a complex medical regimen. Social workers have the training and the skills to assess these challenges, present these challenges to other professionals and jointly explore ways to address these challenges. Further, as the government seeks to apply the most recent recommendations (WHO, 2016) to offer antiretroviral therapy to all, irrespective of viral load, and more people are included in the treatment net, people with lower viral loads (that is, relatively more healthy people) now face the challenge of adjusting to antiretroviral medicines. Social workers have the training to provide tailored assistance to these people.

However, the regional differences in the country with regard to the prevalence of HIV also mean that some states are less equipped to address HIV-related issues. Schools of social work, therefore, face the challenge of preparing their graduates for professional work in all contexts. Thus the social work profession in India faces new challenges and has more miles to cross.

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Challenges and lessons in three decades of the HIV epidemic and neoliberalism: An analysis of Brazil, Mozambique and South Africa

Evandro Alves Barbosa Filho, Ana Cristina Vieira and Solange Rocha



ABSTRACTS

This chapter analyses the relationships arising from more than three decades of the HIV epidemic and neoliberal supremacy in Brazil, Mozambique and South Africa. It also proposes to support social workers with theory about class, race and gender relationships that hamper the fulfilment of the target of Getting to Zero and the 90-90-90 goals. The study is qualitative and arises from bibliographical and document analysis and field research in the three countries. The data were analysed through a critical social work perspective, based on the materialist theory of the state and its intersectional approach. It was identified that the permanence of neoliberal policies and the rise of conservative discourse, which strengthen social vulnerabilities and gender asymmetries, are the principal determinants delaying the implementation of the Getting to Zero Strategy. Some of the lessons learned include the need to politicize the determinants of the HIV epidemic, increase social protection programmes and empower the most vulnerable groups.

Desafios e lições em três décadas de Epidemia de HIV e de neoliberalismo: Uma análise da África do Sul, do Brasil e de Moçambique

Este capítulo analisa as relações entre mais de três décadas de epidemia de HIV e de supremacia neoliberal no Brasil, Moçambique e África do Sul, e propõe fundamentar teoricamente assistentes sociais sobre as relações de classe, raça e gênero que obstaculizam a realização das metas “Chegando a Zero” e “90-90-90”. O estudo é qualitativo e resultado de pesquisa bibliográfica, documental e de campo realizada nos três países. Os dados foram analisados a partir da perspectiva do Serviço Social Crítico, fundamentado na teoria materialista do Estado e sua abordagem interseccional. Foi identificado que a permanência das diretrizes neoliberais e a ascensão de discursos neoconservadores, que reforçam vulnerabilidades sociais e as assimetrias de

gênero são os principais determinantes para retardar a implementação do “Chegando a Zero”. Algumas lições para o Serviço Social são a necessidade de politizar as determinações da epidemia, de ampliar os programas de proteção social e de empoderar os grupos mais vulneráveis.

三十年的艾滋病疫情和新自由主义的挑战和教训：从批判社会工作理论成果角度，对巴西、莫桑比克和南非的分析

本章分析了巴西、莫桑比克和南非过去三十多年的艾滋病疫情与新自由主义霸权之间的关系。它还提出要用关于阶级、种族和性别的关系的理论来支持社会工作者关，这些关系阻碍了零艾滋和90-90-90-目标的实现。本研究是基于上述三个国家的文献、资料及现场数据进行分析的定性研究。这些数据是基于辩证唯物主义的社会工作观，以交叉学科的方法，从批判性社会工作的角度进行分析的。经鉴定，新自由主义政策的持久性和保守话语的提出，加强了社会的脆弱性和性别之间的不对称，这些是阻碍向零艾滋战略目标迈进的决定性因素。从这些社会工作所得到的教训是：将艾滋病毒流行病的决定因素政治化，增加社会保护方案和赋予最弱势群体权力。

Desafíos y experiencias de tres décadas de la epidemia del SIDA y el neoliberalismo: Un análisis de Brasil, Mozambique y Sudáfrica

En el presente capítulo se analizan las relaciones de más de tres décadas de epidemia del VIH y la supremacía neoliberal en Sudáfrica, Brasil y Mozambique. Asimismo, se propone apoyar a los trabajadores sociales con teoría sobre las relaciones de clase, raza y género que dificultan el cumplimiento de los objetivos de llegar al cero y las metas de 90-90-90. El estudio es cualitativo y surge de la investigación bibliográfica y documental, y de investigación de campo en los tres países. Se analizaron los datos a través de la perspectiva crítica del trabajo social, basado en la teoría materialista del estado y su enfoque interseccional. Se identificó que la permanencia de las políticas neoliberales y el aumento del discurso conservador, que refuerza las vulnerabilidades sociales y las asimetrías de género, son los principales determinantes que retrasan la aplicación de la estrategia Llegar a Cero. Algunas lecciones aprendidas incluyen la necesidad de politizar las determinantes de la epidemia del VIH, para aumentar los programas de protección social y para potenciar a los grupos más vulnerables.

30年間のAIDSの感染拡大と新自由主義の課題と教訓：ブラジル、モザンビークと南アフリカの分析

現在の章では、南アフリカ、ブラジル と モザンビークでの30年以上のAIDSの

感染拡大と新自由主義の覇権から関係を分析します。また、ゼロと90-90-90の目標の達成を妨げる、階層、人種と性別間関係の理論を用いて、ソーシャル・ワーカーを支援することを提案します。この研究は定性的なもので、3カ国の文献、書類、フィールドスタディから成り立っています。これらのデータは、クリティカルソーシャルワークの視点を通して、状態の唯物論とその交差的アプローチに基づいて分析されました。社会の脆弱さと性差を強化する新自由主義的政策の持続性と保守的な論調の高まりが、ゼロにする戦略の開始の実現を延ばす主要な決定要素であることが確認されました。社会福祉が学んだいくつかの教訓は、AIDSの流行の決定要素を政治化し、社会的保護プログラムを拡大して、一番の社会的弱者に力を与える必要性でした。

Défis et enseignements tirés en trois décennies d'épidémie de Sida et de néolibéralisme : Une analyse du Brésil, du Mozambique et de l'Afrique du Sud

Le présent chapitre analyse les relations entre plus de trois décennies d'épidémie de VIH et la suprématie néolibérale au Brésil, au Mozambique et en Afrique du Sud. Il propose également de soutenir les travailleurs sociaux au moyen d'informations théoriques sur les classes, la race et les relations de genre qui empêchent d'atteindre les trois zéros et 90-90-90. L'étude est de nature qualitative et le fruit d'une recherche bibliographique et documentaire, et expérimentale menée dans les trois pays. Les données ont été analysées sous une perspective d'assistance sociale essentielle, sur la base de la théorie matérialiste de l'Etat et son approche intersectionnelle. Il a été déterminé que la permanence des politiques néolibérales et l'apparition du discours conservateur qui aggravent les vulnérabilités sociales et les asymétries de genre sont des principaux facteurs déterminants du retard dans la mise en oeuvre de la stratégie Objectif : Zéro. Certaines des leçons apprises se concentrent sur la nécessité de politiser les déterminants de l'épidémie de VIH, d'augmenter les programmes pour la protection sociale et d'autonomiser les groupes les plus vulnérables.

INTRODUCTION

The aims of this chapter are to analyse the relationships between more than three decades of the HIV epidemic and the predominance of neoliberalism in South Africa, Brazil and Mozambique, and to provide a theoretical and methodological groundwork for social workers on class, race and gender relationships that pose an obstacle to meeting the Getting to Zero Strategy (UNAIDS, 2010) and 90-90-90 goals (UNAIDS, 2014).

The study starts out from the theoretical presupposition that neoliberal policies and ideology have, since the 1980s, created a context of structural social and economic vulnerability on a global scale. This, in conjunction with inequalities relating to social class, race/ethnicity and gender, has fostered and exacerbated the dynamics of the HIV epidemic, especially in peripheral capitalist countries. Furthermore, the reduction and commodification of social welfare policies and systems have restricted the response of governments to the global HIV epidemic.

In the past three decades, social workers have been challenged by the social demands generated by the dynamics of morbidity and mortality of the HIV epidemic in a context of growing impoverishment and the rolling back of social rights occasioned by neoliberal structural adjustment programmes. Hickel (2012, p. 513) has called the close relationship between neoliberal experiments in social and economic policy and expansion of the epidemic the “neoliberal plague”. This is also occurring in a context of increasingly complex gender inequality generated by a patriarchal conservatism that restricts speech regarding the body, pleasure and sexuality.

Despite its critical approach to these limitations, the present study acknowledges the progress made in access to treatment in Brazil, South Africa and Mozambique, with a view to meeting the 90-90-90 treatment target, with significant increases in life expectancy, principally in South Africa, the country most heavily affected by the epidemic. According to the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR, 2016), South Africa has already reached peak incidence and aims to reduce new adult infections by 500 000 and achieve zero discrimination by 2020. The cost of new and existing infections is expected to be met by an increase in the annual public budget of US\$ 8 billion by 2020.

According to UNAIDS (2014), ending the AIDS epidemic requires uninterrupted access to treatment with health and community systems that ensure the protection and promotion of human rights and funding for treatment. In addition to the provision of antiretrovirals and the adoption of more readily tolerated formulas, attention should also be paid to medication for opportunistic diseases, which are often neglected by health providers. The emergence of new technologies that simplify diagnosis, making it more accessible, has given rise to a need to reorganize health services and community networks to ensure respect for the rights of people living with HIV.

This study was designed to understand the political and economic obstacles and limitations in the light of two of the main strategies for controlling the epidemic: Getting to Zero (UNAIDS, 2010) and 90-90-90

(UNAIDS, 2014). It may help social workers and other professionals involved in drawing up, introducing and evaluating measures to control the epidemic and protect the rights of people living with HIV and their families.

Even though the study focuses on three countries from the economic periphery, it provides theoretical, conceptual and methodological elements for analysis of two worldwide social processes: the concentration of the epidemic among certain key populations and the dismantling of public social-welfare and health systems, which are so important for ending the epidemic and improving the quality of life of people infected. Such elements help to analyse the limitations that beset the achievement of 90-90-90 and recognition of its relation to the Sustainable Development Goals.

THE DYNAMICS OF SEXIST AND RACIST NEOLIBERALISM AND ITS EFFECT ON THE HIV EPIDEMIC

Neoliberalism is, first and foremost, a theory of political and economic practice that proposes that human well-being can be maximized by expanding the freedoms and entrepreneurial capacities of individuals in the context of market-oriented (political, judicial and administrative) institutional structures. It is characterized by defending the right to private property, which is the principal function of the state, understood here as the bourgeois political strategy for ensuring the best conditions for development of the needs of capital (Harvey, 2008, 2011; Hirsch, 2010; Barbosa Filho, 2013).

According to Hirsch (2010), the neoliberal state cannot be reduced to the expression “minimal state”, since this would entail an absence/withdrawal of the state from the process of social reproduction. For this author, since the crisis of capitalism of 1973, which grew deeper in the following three decades, there has been a redirecting of state action towards the needs of capitalist accumulation, to the detriment of collective social needs. It can be assumed, then, that the HIV epidemic originated at a point in history when the responsibilities of the state for the promotion and provision of health services as citizenship rights were coming under question. The direction that states have predominately taken has been to privatize health policy and systems or provide only basic health-services coverage.

The common ground between neoliberal adjustment programmes and the spread of the epidemic has expressed itself in terms of the obstruction of social and economic conditions that could curb the proliferation of HIV in

developing countries, by way of privatization or elimination of infrastructure and local economies. In the three countries under study here, there is evidence that neoliberalism involves more than removing political and institutional barriers to the accumulation of capital. Neoliberalism also represents an epistemological commitment that is promulgated in political, social, cultural and economic circles, presenting itself as common sense, as the best system for humanity, since there is no social alternative to that offered by late capitalism: privatization of all spheres of social life, including social rights (Sastry & Dutta, 2013, p. 22). Neoliberal thinking is not restricted to economic and government circles but produces profound changes and inequalities in time and space, in the concept of the individual, culture, community and social class. For example, the language about health and the HIV epidemic propagated by governments and the agents of neoliberalism generally demands that a liberal view of health care prevail (Mirowski & Plehwe, 2009). It thus depoliticizes strategies for confronting the epidemic, naturalizes the biologization of bodies and the commercialization of treatment, ignoring or marginalizing the critique of the economic, political and gender factors that mostly determine who gets ill, dies or becomes poorer and more oppressed as a result of the epidemic.

Given the global nature of the epidemic, it is essential to adopt a gender-based focus founded on feminist concepts of power relations, in the context of intersecting inequalities of class and race, as a way of questioning a heteronormative approach and the control of sexuality in all cultural settings. Conservative bias can be found in situations of gender-based violence, low economic and decision-making power, poor access to resources and control of material wealth and early pregnancy, with religious and state interference and reification of cultural habits, local customs, taboos, disinformation, oppression and submissiveness—especially in African countries—all of which restricts the success of strategies to counter the epidemic among women and black and indigenous populations (Rocha et al., 2016).

According to the principles of empowerment of women for gender equality of the United Nations Entity for Gender Equality and the Empowerment of Women (UN Women, 2010), gender refers to a variety of socially constructed roles and relationships, personality traits, attitudes, behaviours, values, and relative power and influence that society attributes to the sexes in a differentiated manner. While biological sex is determined by genetic and anatomical features, gender is an acquired identity that is learnt, changes over time and varies within and between cultures. Gender refers not only to men or women but also to the relationships between people.

As universal knowledge has historically been founded on male experience

and thinking, feminist theory avers that women are socialized in a patriarchal culture that represents a system of power with norms and values that position women in the world in such a way as to make it difficult for people to pursue their own interests. Patriarchy, with its racist and neoliberal roots, socially and economically structures social inequalities and operates by way of force and control, dissociating mind and body, in such a way that both the labouring and the sexual body are exploited. People who are not educated to think critically are both alienated from their own productive capacity and freed of responsibility for their bodies and sexuality (Rocha, 2011).

The connections between neoliberal ideology, patriarchy, racism and the rise of the HIV epidemic have created a global rationale for responses to the syndrome, an order of discourse around the HIV epidemic and responsibility for it that tends to be closer to the neoliberal view of health care based on individual behaviour and responsibility, rather than the broader perspective of the relationships between society, health and disease, as envisioned in the Alma-Ata Declaration (World Health Organization [WHO] & United Nations Children's Fund, 1978) and the Ottawa Charter (WHO, 1986). These stress the impact of social factors on health and disease and the way unequal distribution of power within capitalist societies conditions the ability of individuals to maintain their health.

METHODS

The present study is guided by a view of society as a whole and uses the materialist theory of the state to analyse reality, with awareness that the HIV epidemic intersects with relationships of production and the whole political, cultural and social system, structured dialectically around the contradiction between the collective production of wealth and its private expropriation.

The materialist theory of the state does not reduce social relationships to a mechanical relationship of cause and effect between economics and society. Its total perspective considers the complex intersection between class relationships and social relationships of power and submission, such as sexism, racism, homophobia and xenophobia, to be elements fundamental to the social reproduction of capitalism in the contemporary world. Analysis of the socialization of capital thus also requires that these other forms of exploitation/oppression be considered (Hirsch, 2010).

The approach is primarily qualitative but does not neglect the importance of quantitative data regarding the epidemic. The study uses bibliographical research and document analysis focused on items relating to health policy for

people living with HIV in the countries under study. The data thus comprise a number of publications, books, research reports, monographs and articles in social and human sciences and medical and health-care journals, and official, administrative and technical documents in English and Portuguese that address the responses of the Brazilian, Mozambican and South African state to the HIV epidemic. The bibliographical research and document analysis were carried in stages: identification, location and registering of the literature analysed.

The study also uses secondary data on care for people living with HIV obtained from articles and field studies reports developed in the three countries between 2010 and 2015, as a result of international cooperation projects addressing the question of access to health services and social welfare (Barbosa Filho, 2013; Barbosa Filho & Rocha, in press; Rocha, Vieira, Casimiro & Lyra, in press; Rocha, Vieira, & Soares, 2013; Soares et al., in press). These studies followed international ethical principles and guidelines for research involving human beings.

THE HIV EPIDEMIC: ECONOMIC, POLITICAL AND SOCIAL OBSTACLES TO ACHIEVING THE GETTING TO ZERO STRATEGY AND 90-90-90 GOALS

Brazil in the late 1980s differed from the rest of Latin America, where the trend was towards reducing the responsibilities of the state. The Federal Constitution of 1988, drawn up after the end of the dictatorship, approved a system of social security and universal health care. But the neoliberal orientation of national governments over more than three decades of democracy created a state more committed to the maintenance of capitalist profit than to progressive social reforms for the working class. Brazil, which has been successful in countering the HIV epidemic, is faced with great challenges to the 90-90-90 goals for 2020—challenges caused by neoliberalism, which promotes dismantling and privatization of health services by the rise of conservative political discourses. These conservative discourses also reinforce HIV stigma and discrimination, violence against the LGBTI community and sex workers and several restrictions over women's sexual and reproductive rights.

In South Africa, when the African National Congress (ANC) finally came to power in 1994, putting an end to apartheid, the progressive health proposals of the party were soon replaced by neoliberal ideology, extending the role

of private health insurance and reducing the responsibilities of the state for health service provision as a social right (Dennill, 2014). The commitment of the ANC, which has been in power for 21 years of democracy with a neoliberal agenda, was made clear by the 1996 launch of the national social and economic reform plan Growth, Employment and Redistribution (GEAR), which reflects the most orthodox strains of neoliberalism, and its economic and political guidelines have essentially been followed by existing policy (Barbosa Filho, Vieira, & Rodrigues, in press). The prevalence of HIV among prenatal women grew from 7.6% in 1994 to 24.5% in 2000, constituting a generalized epidemic but one distributed unequally among the nine provinces of democratic South Africa and among the races, with a concentration in the poorest black populations and especially among black women (Dennill, 2014; Heunis, Wouters, & Kigozi, 2012).

In South Africa, the goal of all people living with HIV being covered by all national social welfare strategies and having access to care and support services, as outlined in the zero AIDS-related deaths vision, is still far from being achieved. Nutritional support services and income redistribution have been expanded but still fall short of what is needed to reduce mortality to zero, since, consistent with neoliberal ideology, they are focused only on minimal provision for the very poorest.

In Mozambique in 1989, the FRELIMO party switched its ideology and political practices from a Marxist-Leninist orientation and effected a constitutional reform clearly guided by the neoliberal ideology of opening up the economy, mass privatization and reduction of the social responsibilities of the state.

Since the 1980s the Mozambique Government has created a neoliberal state, leading to exploitation of natural and mineral resources, without assuming responsibility for ensuring minimal conditions for the reproduction of the Mozambican labour force. In this country, the fledgling welfare system makes it impossible to meet practically any of the 90-90-90 goals, at least by way of state policy.

Although some intellectuals (Bremmer, 2011) have noted a return to developmentalism in the 2000s, with the state taking a leading role in fostering economic development and the provision of minimal social conditions, the real situation in Brazil, Mozambique and South Africa is quite different; although South Africa has invested massively in ensuring broad provision of ART, which is the second 90-90-90 goal. Mozambique faces challenges in meeting the goals because of its dependence on international aid. Brazil has been successful in countering the HIV epidemic but the *Gap Report* (UNAIDS, 2014) highlighted that the epidemic increased 11% from

2005 to 2013, especially among young men who have sex with men. Nonetheless, Parker—director of ABIA (Brazilian Interdisciplinary AIDS Association), a nongovernmental agency—says, “there is a consensus among researchers and activists that the great achievement of the Brazilian response to the epidemic was the boldness and success of its social and political response” (2015, p. 1), pointing out that the ideological virus is as important as the biological one.

The bringing to fruition of the neoliberal project has entailed, in the case of the AIDS epidemic, the denial or restriction of social and health services that ensure the achievement of the 90-90-90 goals, and zero new HIV infections, zero discrimination and zero AIDS-related deaths. Thus, even though infection in general has declined, it continues to grow in all three countries in the social groups, social classes and regions that fare worst in the capitalist economic and moral order. These include young people, sex workers, men who have sex with men, heterosexual women, black people from the most exploited sectors of the working class, Mozambique and South Africa’s less-developed regions, and the Northeast region of Brazil, where most new cases occur.

What epidemic are we dealing with?

In all three countries, in different proportions, HIV infection has grown among women. Although in the early stages in Brazil it mostly affected men who have sex with men, over the years women have been infected by heterosexual relations. Considering the whole country, since 2003 infection has been decreasing among women. However, if we look at different regions, as shown in the surveillance report of 2014 (Brasil, Ministério de Saúde, Departamento de DST.AIDS, 2014, p. 32), the cases of AIDS among women are increasing in the North (from 800 cases in 2005 to 1561 in 2014), Northeast (from 2286 cases in 2005 to 3150 in 2014) and Center-West (863 cases in 2005 to 951 in 2014) regions. In South Africa and Mozambique, HIV infection has been devastating from the outset, and the epidemic has mostly affected heterosexuals (Rocha et al., 2013).

In Brazil, 798 366 cases of AIDS have already been registered. Although the data indicate that Brazil’s detection rates have stabilized, the North, Northeast and Center-West regions have seen significant growth. In the past year, the rates were 25.7% (North region), 15.2% (Northeast region) and 18.4% (Center-West region), representing increases of 79.7% (North), 30% (Northeast) and 6.4% (Center-West). The sex ratio varies significantly from region to region: in the Southeast and Center-West the rate is increasing among men, while

in the North, Northeast and South the rate is increasing among women. The detection rate for pregnant women with HIV in Brazil has increased 25% in the past 10 years (Brasil, Ministério de Saúde, Departamento de DST.AIDS, 2014).

There has been a drop in mortality in Brazil in these past 10 years, although not in the North and Northeast regions, which are the least developed socially. In the Northeast, which has the largest black population in the country, it increased 34.3%, from 3.2 to 4.3 deaths per 100 000 inhabitants. Nationally, there is a significant difference among the black population, with the proportion of deaths among black women higher than that of men. In 2014, 14% of deaths occurred among black men, while the proportion was 15.7% for black women. This confirms that although Brazil has one of the best HIV prevention and treatment programmes in the world, as Werneck (2010) reports, this level of excellence has not been sufficient to halt the growth of the HIV epidemic among women, especially among black women.

Despite these challenges, the Boletim Epidemiológico do Brasil (Brasil, Ministério de Saúde, Departamento de DST.AIDS, 2015) points out that cascading continuous care, one of the most important tools for monitoring the response to the epidemic worldwide, has seen an increase in the population testing positive, the inclusion of more people in treatment and an increase in adherence to treatment, with a suppression of the viral load close to the goal that countries worldwide set for 2020.

In South Africa, according to data for 2015, around 7 million people live with HIV, a prevalence of 19.2%, with 48% of adults in antiretroviral (ART) treatment. It is the country with the largest number of cases in the world and there is a great programmatic and financial effort underway to expand treatment coverage. For every three women infected with HIV, there are two infected men (UNAIDS, 2015). Twenty-five per cent of cases fall in the 15 to 24 years age bracket and the difference between men and women is increasing: for every four young women infected, there is one man. This has facilitated vertical transmission, which is considered one of the most dramatic consequences of the involvement of women in the epidemic (Human Sciences Research Council, 2013).

Although South Africa is the only country in sub-Saharan Africa that has formal rights for the LGBTI community, social stigma, discrimination and violence against the homosexual population are still rife and lesbians are especially hard hit, with murders and homophobic rapes. This drives homosexuality underground and makes it difficult to develop more progressive attitudes and ensure freedom of access to health services for people living with HIV (UNAIDS, 2010).

In Mozambique, the infection rate is 8.3% for young women compared with 2.8% for young men. Among adolescents aged between 12 and 14 years the prevalence is estimated to be 1.8%, without great differences between girls and boys. The prevalence among young women aged 15 to 24 years is 11.1%, three times higher than that among young men of the same age bracket (3.7%). In the Gaza province, in the south of the country, six young women are infected for every one young man; while in Sofala, in the central region, five women are infected for every one young man (Ministério da Saúde, Instituto Nacional de Saúde, & Instituto Nacional de Estatística, República de Moçambique, 2009). Studies reveal that at 18 years of age, three out of five of these young women are already married, 40% of them to much older men, which may expose these women to HIV and sexually transmitted diseases (Conselho Nacional de Combate ao HIV e SIDA, República de Moçambique, 2014). It is worth noting that Mozambique has revoked the law prohibiting same-sex sexual relations, in keeping with South Africa's more progressive LGBTI rights legislation.

In terms of gender relationships, the three countries are similar. The epidemic is growing among women and they tend to be young, black and poor. Most of these women are users of health facilities but there is a resistance on the part of their partners to acknowledge their health status, accompany them during consults or support pregnant women on the vertical transmission programme—these women have to follow certain breastfeeding guidelines.

90-90-90 and the challenges of prevention and treatment

Spurred by recognition of the important progress towards meeting the 90-90-90 goals, UN agencies, governments, companies, civil society organizations and activists have renewed efforts for 2020, and by 2030 countries will have come close to zero new HIV infections, zero discrimination and zero AIDS-related deaths.

It is worth noting numerous advances in public policy and health services in the three countries. Coverage of provision of antiretroviral medicines (ART) has improved: Brazil has universal access, the other two countries have substantially extended coverage. South Africa, given the scale of the epidemic, is the country with the largest provision of ART worldwide and health policies for the workplace have been expanded, along with laws and regulations to combat prejudice and discrimination. In Mozambique, abortion and homosexuality were decriminalized in 2014, and care for people subject to gender-based violence and other health services have been expanded, especially access to ART. However, above all, there is growing

recognition that it is possible to live a dignified and healthy life with HIV.

In the case of the goal of 90% of people living with HIV knowing their status, the strategy is to provide innovative, safe tests with rapid results. Brazil has made progress in this direction and has already approved the self-test; South Africa is on the way to providing it for the population. Mozambique, owing to its specific social and economic conditions, has not made progress in this regard. In South Africa, it is estimated that fewer than one in three adolescents living with HIV are aware of their status and adolescents also experience less favourable outcomes than adults at all subsequent phases of treatment. Stigma still discourages people from taking the HIV test and seeking out other health services.

However, education and information technology are not emphasized in this goal, which may explain the limitations of prevention in the light of the moral order created or entrenched by neoliberalism and the dismantling of health services geared towards health promotion, thereby frustrating expectations regarding the Getting to Zero proposal of revolutionizing prevention.

Women, especially people of oppressed classes and ethnic groups in South Africa, Brazil and Mozambique, have difficulty accessing protection measures that they themselves control (Barbosa Filho & Rocha, in press; Rocha, 2011). Anti-HIV microbicide is still not a reality. The female condom is expensive and thus not very accessible for the population, and public distribution is not available for all women—only people considered key populations, such as sex workers, people who inject drugs or their partners, women with HIV or sexually transmitted infections or the female partners of men with HIV (Rocha, 2011).

According to Rocha (2011), prevention remains focused on men's bodies, which leaves women at a disadvantage in using condoms, since it is difficult to negotiate prevention in situations of inequality generated by sexism, racism and generational and class differences. Taken together, such situations may generate violence and make negotiation impossible. In Brazil, one example of this is the emergence of conservative political discourse at all levels; one HIV-prevention campaign among sex workers was censored after political pressure from dogmatic evangelical Christian groups (Corrêa, 2016).

In South Africa, the combination of unprotected sex, poor access to education and information, a low perception of the risk of acquiring HIV, and the resistance of men to using male condoms has meant that black women have 4.5% more chances to become infected than men (Human Sciences Research Council, 2013). In South Africa in March 2015, Oxfam lodged a formal complaint with the Gender Equality Commission on behalf of a group of women living with HIV who were coerced into being sterilized. They are

currently seeking reparation for this and demanding that the law be altered to prevent such discrimination (Serrao, 2015).

In both African countries, the defence of traditional cultures is used as a powerful argument against aspects of gender equality that lead to changes in the features of those cultures that oppress or abuse women. In all three countries, especially Mozambique and South Africa, sex and sexuality are still taboo subjects in most families, schools and communities. The ability to talk about such subjects and enjoy full reproductive and sexual rights is still not a reality for all people. The expression “this is our culture” provides a seemingly incontestable argument for maintaining the subordination of women, not using condoms or denying the existence of homosexuality.

The second 90-90-90 treatment target is 90% of people who know their HIV-positive status accessing treatment. This goal is directly linked to access, which, in turn, is determined by the political will to provide services and the ability of the individuals to seek out services. This requires material, human and financial resources and greater decentralization and reorganization. Given the scarcity of medical doctors, services are handing over treatment to the nursing team. UNAIDS (2014) envisions encouraging the lay community of workers to participate in broadening access to ART. Expanding awareness of, access to and adherence to antiretrovirals entails encouraging the community to get involved in care. On the one hand, this may lead to increased solidarity and mutual aid in the sense of *Ubuntu* (showing humanity towards others), but may also be a neoliberal reification. With absent decentralized universal public health services, the responsibility for care is passed on to the community, in most cases women (UNAIDS, 2010). Despite progress in all three countries, universal access to antiretroviral therapy for people living with HIV has still not been achieved. Even Brazil, which is an international point of reference for access to antiretrovirals and the only one of the three countries that has introduced a free universal health system, has not achieved universal access.

However, as a result of this policy, Brazil has seen a sharp drop in mortality associated with HIV. It currently has one of the best antiretroviral coverage rates among medium- and low-income nations, with approximately half of people living with HIV, 48%, receiving ART, while the global average in 2014 was 41% (UNAIDS, 2015). However, Brazil’s current track record, in terms of not only access to antiretrovirals but also the national HIV policy itself, is at risk because of underfunding of public health and a preference for public-private partnerships in health. Although investments in HIV responses are not decreasing, as evidenced by its antiretroviral coverage rate, there are other needs of people living with HIV that are not getting answers

from the Brazilian health system as a result of insufficient resources at its implementation by the Federal Constitution of 1988 (as cited in Marques, Piola, & Ocké-Reis, 2016).

Underfunding of public health services, combined with a continuous process of downsizing and privatizing services, leads to increasingly more inadequate provision of care for people living with HIV, long waiting lists and difficulty accessing medicines and medical examinations, despite progress in recent decades (Soares et al., in press). Health expenditure in Brazil is low. While countries with similar universal health and public systems spend on average 8% of their gross domestic product (GDP), in 2014 the Brazilian health system spent only 3.9% (Marques, Piola, & Ocké-Reis, 2016, p. 248)—a very low per capita expenditure. Marques et al. further comment that “recent proposals still pending in the National Congress involving an adjustment in the public accounts can bring more damages to public health funding” (2016, pp. 255–256).

The third 90-90-90 goal is that 90% of people on treatment have suppressed viral loads. As late diagnosis seems to be the main reason for nonadherence and failure of treatment, discontinuous care also contributes to unsuccessful outcomes, especially among children (PEPFAR, 2016). The strategies for this goal are also focused on the community, including increasing the number of community health workers and encouraging the use of lay HIV counsellors. In contrast to Brazil, in South Africa and Mozambique, civil society organizations also distribute antiretrovirals.

The barriers to achieving this goal is deeply entrenched in social factors and the limitations imposed by patriarchal conservatism, since family and the social norms of the community reproduce gender inequalities, fear and stigma. PEPFAR (2016) acknowledges the importance of removing social and structural barriers to treatment. Stigma discourages people from seeking treatment and health services owing to fear of discrimination.

The 90-90-90 goals cannot be effectively achieved by 2020 with the available material, human and financial resources and community partners. A review of the literature shows that only Brazil is close to the planned implementation. The other two countries face serious challenges in halting the advance of the epidemic. Social and economic limitations will require that countries develop strategies for addressing the vulnerability of women, especially young and black women.

The programmes and projects need to provide real impact on gender relationships that strengthen women’s defences against patriarchal oppression. Most women living with HIV find it difficult to access health services, follow treatment and control their own lives. Implementation of

public policy has involved much language disconnected from reality. The three countries have strategies for confronting the epidemic and have made legal progress on women's rights, but implementation faces serious barriers and challenges.

90-90-90-based plans for confronting the epidemic have similar perspectives and all focus on testing and treating. But, despite acknowledged successes in increased testing, more people in treatment and with a suppressed viral load and a consequent reduction in morbidity and mortality, the epidemiological data show that women in poor regions, young and black people are key populations in ways that cannot be overcome merely by medication and technology.

In Brazil, despite progress in introducing a policy to counter vertical transmission, some women have become pregnant in the past five years without knowing their HIV status, despite prenatal care and childbirth being conducted in a medical institution. In relation to mother-to-child transmission, there has been a downward trend for Brazil—33.3% in the past 10 years. However, there are important differences among regions in this trend. The Southeast, South and Center-West regions have a downward trend, with percentages of 58.3%, 40.1% and 26.1%, respectively, in the period 2005 to 2014. The Northeast region showed a slight decrease of 12.1% (from 3.3 cases to 2.9 cases per 100 000 inhabitants from 2005 to 2014). However, in the North there was a 69.2% increase in the rate in the same period (2.6 cases to 4.4 cases per 100 000 inhabitants; Brasil, Ministério da Saúde, Departamento de DST/AIDS, 2015, p. 14). In Mozambique and South Africa, maternal mortality is high. Maternity health services have limited national coverage, and prenatal coverage and HIV testing still pose great challenges.

In all three countries, and especially the African ones, breaches of confidentiality regarding HIV status undermine patient trust. Data presented by Rocha et al. (2013) show that in maternity hospitals and childbirth centres, some nurses openly reveal the HIV status of patients and express prejudice while caring for women in labour or during breastfeeding.

The spread of the HIV epidemic to poorer populations in Mozambique reveals the dramatic failure of health services, especially in provinces far from the political and economic centre of Maputo. In South Africa, despite a national health policy with a structured network of services, the health system has failed to provide coverage for all.

Antiretroviral medicine is not enough; care needs to be seen within a context of access to health and social services, education, employment, personal improvement and political engagement. Care must be integrated into an intra- and inter-sector network of social welfare but must also respect the limitations

the HIV epidemic involves, such as the need for specific medication. Support actions are needed that involve the right to quality of life and participation of these individuals in social-policy decision-making (Rocha et al., in press).

Why do international guidelines on HIV recommend universal distribution of antiretrovirals as soon as HIV is detected? Understanding social policy as a field of contradictions sheds light on this: it opens up the possibility of reducing the health problems and mortality of people with HIV, reducing complications and transmission of HIV and hence incidence, while pharmaceutical companies and doctors, who are the only professionals able to prescribe medication, stand to gain. In other words, the HIV epidemic is set in a field of supercapitalization, open to the profit of pharmaceutical companies in various parts of the world. Treatment, especially in sub-Saharan Africa, is too expensive for individuals; only governments can ensure the provision of antiretrovirals. Countries that cannot meet the cost of HIV treatment obtain international aid to help provide this medication. The administration of these medicines requires national and local governments to be structured to meet the needs of sick individuals.

Preventive action is certainly limited by privileging health care using antiretroviral medicines. As UNAIDS states, “HIV treatment is a critical tool towards ending the AIDS epidemic, but it is not the only one. While taking action to enhance the prevention effects of HIV treatment, urgent efforts are similarly needed to scale-up other core prevention strategies, including the end of mother-to-child transmission, condom programming, preexposure antiretroviral prophylaxis, voluntary medical male circumcision in priority countries, harm-reduction services for people who inject drugs, and focused prevention programming for other key populations. To put in place a comprehensive response to end the epidemic, concerted efforts will be needed to eliminate stigma, discrimination and social exclusion” (UNAIDS, 2014, p. 2).

LESSONS LEARNED

Three main lessons can be learned from this study. First, confronting the HIV epidemic requires the defence, expansion and strengthening of health policy and systems as the responsibility of the state and of civil rights, as a way of providing patient access to antiretrovirals and other health and social services needed to maintain and promote health. Social workers and other health professionals are generally involved in the implementation of health services but should also help to draw up policies and programmes and evaluate and monitor actions. In all these fields they should analyse

the connections between neoliberalism, the HIV epidemic and the process of capitalist reproduction. The materialist theory of the state provides a fundamental theoretical and methodological framework for this critical assessment of the dynamics of the epidemic.

This analysis of the social totality in which the epidemic is processed may help to confront the downscaling of resources for social policy as broadly advocated by neoliberal discourse and, in particular, encourage the participation of progressive sectors of organized civil society in social-policy decision-making in health and other fields to ensure that individuals have access not only to medication and health care but also to all other elements necessary for a dignified life with human and social rights, questioning the restrictions that neoliberal ideology and policy seek to impose on these. Understanding the economic, political and social dimensions of the epidemic is indispensable if the 90-90-90 goals are to be met. One big challenge is ensuring universal access to ART, including due support in dealing with side-effects, given the need for systematic and permanent use of this medication.

The second lesson is that actions to uphold human rights are fundamental in countering stigma and prejudice surrounding HIV and these should be encouraged. Preventive and empowerment actions should not therefore be minimized because of the importance that the distribution of antiretrovirals has assumed. These actions in the fields of politics, education, health, culture and everyday life should be stepped up, institutionalized and accorded a central role in the public policy agenda and in the nongovernment organizations that work with prevention and care for people living with HIV; principally those policies and organizations that deal with the populations currently most affected, such as young men who have sex with men, women, sex workers and working-class men and women.

In prevention and individual and collective empowerment, power relationships reveal gender, race and class inequalities, and strategies for countering these can be drawn up by the subjects themselves. It is widely accepted that social workers have an educational role and, thus, actions to break down stigma, discrimination and a culture that pathologizes the HIV epidemic should be as important for these and other professionals as social welfare and the provision of health services.

Finally, women should be a target group for health policy and services. They need to know more about HIV to strengthen their affective ties and to have access to and control of resources and support in countering the economic and social inequalities and gender discrimination to which they are subjected. When the state is subordinated to the capitalist, racist, sexist, patriarchal system, social problems become more complex, exacerbating

issues such as violence, malnutrition, unemployment, unequal power relationships between men and women, and avoidable sickness and death (Rocha et al., in press).

Women account for most of the world's poor and this has been aggravated by neoliberalism on a global scale. Dealing with the HIV epidemic among women is thus a highly complex challenge. Strategies are needed that address economic, social and class inequalities, sexism, homophobia and racism, beyond the field of health. Sexual and reproductive rights should be guaranteed both legally and in the everyday working of public services. Condoms should be widely distributed throughout each country. Gender-based violence should be countered and denaturalized in all institutions and social groups. Taboos and cultural habits should be discussed and questioned by men and women. There is a need to strengthen connections between the actions and collective strategies of civil society organizations and networks with human rights, HIV strategies, and women's and LGBTI movements to create a synergy that will confront the epidemic and foster empowerment and activism among women.

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HIV and AIDS in the English-speaking Caribbean: Social work responses

Letnie F. Rock



ABSTRACTS

The Caribbean is considered the second-most affected region in the world, after sub-Saharan Africa, with regard to the spread of HIV and AIDS in the population. In 2013 there were 250 000 adults and children living with HIV in the Caribbean. This chapter discusses the response of social work in the English-speaking Caribbean to HIV and AIDS in the areas of prevention, treatment and support. At the micro- and meso-levels, social workers provide psychosocial support to people living with and affected by HIV and to at-risk groups. They directly support individual behaviour change and the empowerment and capacity-building people affected by HIV. At the macro-level, they engage in HIV and AIDS education and advocacy for clients, as they seek to redress legal and human rights issues, particularly around stigma and discrimination. They also work towards establishing enabling policy environments and promote the development of new policies and approaches to the problem.

操英语的加勒比地区艾滋病毒和艾滋病：社会工作响应措施

关于艾滋病毒和艾滋病在人群中传播的情况，加勒比地区被认为是排在撒哈拉以南的非洲地区之后的、世界上第二个受影响最严重的地区。截至2013年，加勒比地区有25万名成人和儿童为艾滋病毒携带者。本章讨论了在操英语的加勒比地区社会工作对艾滋病毒/艾滋病的预防、治疗和支持所做出的反应。在微观和中观层面上，社会工作者为感染者、受影响者和高危人群提供社会心理支持。他们直接支持个人行为的改变并赋予受艾滋病毒/艾滋病影响的人们力量和能力。在宏观层面上，他们为客户提供艾滋病毒/艾滋病宣传教育，同时他们也尝试解决一些法律和人权问题，特别是围绕“被侮辱和受歧视”的问题。另外，他们还努力创造一些有利的政策环境，以促进一些新政策的制定，找到一些解决问题的方法。

VIH y SIDA en el Caribe de habla inglesa: Las respuestas del trabajo social

El Caribe está considerada la segunda región del mundo, después de África subsahariana, más afectada por el VIH y el SIDA. En 2013 había 250.000 adultos y niños que vivían con VIH en el Caribe. En este capítulo se analiza la respuesta del trabajo social en el Caribe de habla inglesa al VIH/SIDA en las áreas de prevención, tratamiento y apoyo. A niveles micro y meso trabajadores sociales proporcionan apoyo psicosocial a las personas infectadas y afectadas y los grupos de riesgo. Ellos apoyan directamente el cambio de comportamiento individual y el fortalecimiento y desarrollo de la capacidad de las personas afectadas por el VIH/SIDA. A nivel macro, se involucran en la educación del VIH/ADS, y la promoción para los clientes, ya que pretenden solventar los problemas legales y de derechos humanos, en particular en torno “al estigma y la discriminación”. También trabajan en el establecimiento de marcos de políticas favorables y promueven el desarrollo de nuevas políticas y enfoques para el problema.

英語圏のカリブ海でのHIVとAIDS：社会福祉の対応

カリブ海は、HIVとAIDSの感染の広がりや患者数に関して、サブサハラ・アフリカに次いで世界で2番目に影響を受けた地域と考えられます。2013年には、カリブ海でHIVに感染した大人と子供は250,000人いました。この章では、予防、治療と支援の分野で、英語圏のカリブ海でのHIV/AIDSに対する社会福祉の対応について論じます。ミクロおよびメゾレベルで、ソーシャル・ワーカーは感染して影響を受けた人とリスクのあるグループに心理社会的支援を提供します。ソーシャル・ワーカーはHIV/AIDSによって影響を受けた人の個人の行動の変容と権利拡大と能力養成を直接支援します。マクロ・レベルでは、ソーシャル・ワーカーは、HIV/ADS教育、そして、法的な救済や人権問題に努めながら、特に『汚名と差別』に関わる面でクライアントの支援に従事します。また、支援的政策環境の確立に向けて努力し、問題への新しい政策とアプローチの展開をも促進します。

VIH/Sida dans les Caraïbes anglophones : Ripostes dans le cadre du travail social

Les Caraïbes sont considérées comme la deuxième région la plus affectée dans le monde, après l'Afrique subsaharienne, en ce qui concerne la propagation du VIH/Sida au sein de la population. En 2013, 250 000 adultes et enfants vivaient avec le VIH dans les Caraïbes. Le présent chapitre analyse les ripostes de travail social au VIH/Sida dans les Caraïbes anglophones dans les secteurs de la prévention, du traitement et de la prise en charge.

Au niveau micro et méso, les assistants sociaux fournissent les services de prise en charge psychosociale aux personnes affectées et infectées ainsi qu'aux groupes exposés. Ils encouragent directement le changement de comportement individuel, l'autonomisation et le renforcement des capacités des personnes affectées par le VIH/Sida. Au niveau macro, ils interviennent dans l'éducation sur le VIH/Sida et plaident pour les clients, tout en cherchant à résoudre les problèmes de droits juridiques et humains, notamment la stigmatisation et la discrimination. Ils s'efforcent également de créer des cadres stratégiques favorables et de promouvoir l'élaboration de nouvelles politiques et approches au problème.

INTRODUCTION

The Caribbean has the second highest HIV prevalence in the world, surpassed only by sub-Saharan Africa (Averting HIV and AIDS [AVERT], 2016; USAID, 2011). UNAIDS (2016e) reports that in 2015 there were 2 000 000 [1 700 000–2 300 000] adults and children living with HIV in Latin America and the Caribbean. The HIV epidemic surfaced in the Caribbean in the 1980s (Kelly & Bain, 2003), and in the early days sexually active adolescents, young adults, sex workers and their clients were considered at risk of exposure to HIV, and men who have sex with men at greatest risk. It was soon discovered that heterosexual sex was a primary mode of transmission (United Nations Children's Fund [UNICEF], 2007) and the epidemic was generalized in the population. When the number of people living with HIV kept climbing, particularly among people aged 25 to 44 years, Caribbean countries recognized that the epidemic was threatening their socioeconomic development and if left unchecked would overwhelm their health-care systems and decimate the workforce. Individual countries began to put strategies in place to combat HIV. They placed the fight against HIV on their political agendas (Haynes, 2005).

Eventually, countries realized that a coordinated regional response was required to fight the epidemic. In 2001, the Pan Caribbean Partnership Against HIV and AIDS (PANCAP) was formed as a “partnership of regional governments, regional civil society organizations, regional institutions and organizations, bilateral and multilateral agencies and contributing donor partners” (Caribbean Community and Common Market [CARICOM,] 2016b, para. 16). PANCAP supports regional HIV policy development and implementation and “coordinates the regional response through the Caribbean Regional Strategic Framework on HIV and AIDS” (CARICOM,

2016b, para. 16). PANCAP was named a global “best practice” by CARICOM and UNAIDS (CARICOM, 2013; 2016b). All Caribbean countries have national strategic plans on HIV to guide them in their interventions. These plans “embrace a comprehensive approach which includes prevention, care, treatment and institutional development, management, and coordination, including monitoring and evaluation” (USAID, 2011, para. 20).

CARICOM, which has 15 Caribbean member states, has placed the fight against the HIV epidemic high on its political agenda and together with PANCAP has pledged commitment to fast-tracking the regional response to prevention, care and treatment of all people living with HIV and at risk for HIV (CARICOM, 2016a; UNAIDS, 2016b). With CARICOM’s commitment to fast-track the end of the epidemic under the UNAIDS 2016–2021 Strategy (UNAIDS, 2016b), to implement the 2016 *United Nations Political Declaration on HIV and AIDS: On the Fast-Track to Accelerate the Fight against HIV and to End the AIDS Epidemic by 2030* (UNAIDS, 2016c), and to achieve the United Nations’ 2030 Sustainable Development Goals, CARICOM has embraced the UNAIDS vision of ending the AIDS epidemic by 2030 (CARICOM, 2016a; UNAIDS, 2016b). In following the strategic directions of UNAIDS, the region therefore aims to: 1) revolutionize HIV prevention; 2) catalyse the next generation of treatment, care and support; and 3) advance human rights and gender equality for the HIV response (UNAIDS, 2016b).

Social workers in the English-speaking Caribbean (hereafter referred to as the Caribbean, or region) have played significant roles in addressing HIV from the onset of the epidemic by working alongside medical and health professionals (Nathaniel-DeCaires, 2009) in several aspects of prevention, treatment, care and support. They work with people living with and affected by HIV, and key populations at risk of exposure to HIV. In the Caribbean, these include men who have sex with men, transgender people, sex workers, young men and women. Social workers have also played critical roles in the development of agency and public policies, the management of programmes and education on HIV.

This discussion is informed by selected literature on HIV that addresses the Caribbean situation and the author’s experiences of teaching and working in the field of social work in the Caribbean. It discusses the response of social work to the HIV epidemic in the region over the past three decades in the areas of prevention, treatment, care and support. It is noted that in less developed countries of the region there are just a few social workers, and most of them are untrained.

THE CONTEXT

This chapter will make specific reference to some of the independent nation states of the English-speaking Caribbean that are members of CARICOM. The English-speaking member states include Antigua and Barbuda, Bahamas, Barbados, Belize in Central America, Dominica, Grenada, Guyana in South America, Jamaica, Trinidad and Tobago, Saint Lucia, Saint Kitts and Nevis, and Saint Vincent and the Grenadines. Many of these countries are small developing states and share commonalities of a linguistic, socioeconomic and cultural nature. The characteristics of the HIV epidemic are similar in these countries.

The number of people living with HIV in the Caribbean varies from country to country; for example, in Guyana in 2015 there were 7800 [7200–8700] adults and children living with HIV and in Jamaica there were 29 000 [25 000–34 000] (UNAIDS, 2016a). AIDS-related deaths also vary by country, from as low as less than 100 [<100 – <100] in Barbados in 2015 to as high as 1200 [<1000 –1600] in Jamaica (UNAIDS, 2016a). In 2009, AIDS was the leading cause of death in the region among people aged 15 to 44 (CARICOM, 2010). The statistics for 2015 show that the epidemic is much more concentrated in Bahamas, Guyana, Jamaica and Trinidad and Tobago than in other countries of the region (UNAIDS, 2016a). In their response to the HIV epidemic, Barbados, Bahamas and Jamaica implemented comprehensive HIV-related programmes, with the Barbados model considered best practice for the region.

The response to the HIV epidemic by Caribbean governments constitutes internally driven initiatives or initiatives driven by external partnerships. Over the past three decades, governments have built strong strategic partnerships with local, regional and international development partners/organizations from which they receive support. At the local and regional levels, these include nongovernmental organizations (NGOs), National Commissions for HIV/AIDS, regional organizations such as PANCAP, the Caribbean Epidemiological Centre, CARICOM, the Organisation of Eastern Caribbean States and the University of the West Indies (UWI). At the international level, the region partnered with many organizations/development partners. These include the Department for International Development in the United Kingdom, UNAIDS, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the United Nations Development Programme, the International Labour Organization, the Pan-American Health Organization (PAHO), the World Health Organization (WHO), the World Bank and USAID. The funding and assistance has been critical in contributing to measures

aimed at halting the spread of the epidemic and reaching the targets of zero discrimination, zero new infections and zero AIDS-related deaths. Initiatives to achieve these targets include treatment and prevention programmes and universal access to antiretroviral medicines by people infected with HIV. The support has led to the reduction in the overall number of new HIV infections in countries of the region; for example, Bahamas had 329 new infections in 2006 (Government of the Commonwealth of the Bahamas, 2010) and approximately 220 new infections in 2016 (Pinder, 2016), and Trinidad and Tobago had 1453 new infections in 2005 (Government of Trinidad and Tobago, 2010) and there were fewer than 500 [<500 – <500] in 2015 (UNAIDS, 2016a). There was also a significant decline in AIDS-related deaths in Latin America and the Caribbean over the past five years, from 568 400 in 2010 to 50 000 [41 000–59 000] in 2015 (UNAIDS, 2016a).

The programmes developed at the national and regional levels to expand treatment, care and support aim to intensify preventive strategies, reduce HIV infection rates, reduce stigma and discrimination in the population, address social and behavioural norms that affect gender inequalities and homophobia, provide sex education to adolescents and young people and accelerate policy and programme development. However, Caribbean countries still face several challenges, which include insufficient funding for HIV prevention and treatment, ending stigma and discrimination against key populations and ensuring their human rights, the abolition of discriminatory punitive laws and policies, and ending gender-based violence (UNAIDS, 2016b, 2016d).

HIV TREATMENT, CARE AND SUPPORT: THE CARIBBEAN SOCIAL WORK RESPONSE

Across the region health-care professionals are playing leading roles in HIV diagnosis, treatment and clinical management of the disease, and social workers are playing leading roles in treatment, prevention, care and support. Social workers are employed in areas that require an integrated response to the epidemic and multilevel programming with key populations and people living with HIV. Social work practice in the area of HIV and AIDS is developing as a specialization in the discipline (Nathaniel deCarries, 2009).

People infected with HIV require treatment immediately on diagnosis to reduce the risk of virus transmission and improve their chances of living with HIV. In the Caribbean the use of antiretroviral therapy (ART) by people diagnosed with HIV has helped to prolong their lives. Their use

by pregnant women has helped to significantly reduce mother-to-child transmission, with lower rates of HIV among children (UNAIDS, 2016d). In 2015 in Barbados, for example, there were reportedly 2600 people living with HIV and 1139 of these were using ART (UNAIDS, 2016b). The treatment gains are so profound that HIV is no longer considered an imminent death sentence. These achievements have been brought about by a multisectoral response to the epidemic and through financial assistance from regional and international donors, such as UNAIDS, which facilitated the procurement of costly antiretroviral medicines by governments.

Social workers in the Caribbean deliver direct and indirect services to people living with or affected by HIV. These include community-based care, psychosocial support and HIV testing and counselling. They work with individuals, families, groups, communities and organizations and function as practitioners, advocates, policy-makers, educators, researchers and members of multidisciplinary teams in the response to HIV. They provide a holistic approach to care, treatment and support for people living with HIV as they strive to meet psychosocial and basic human needs. The following section discusses the Caribbean social work experience with treatment, care and support for people living with and affected by HIV in the areas of counselling and testing, services to orphans and other children made vulnerable by AIDS, and social support.

HIV testing and counselling

Social workers employed in primary health-care facilities across the Caribbean perform voluntary counselling and testing (VCT) services (pretest, posttest and follow-up counselling). In Barbados, VCT counsellors are trained social workers. Generally when a person has a positive diagnosis for HIV the VCT counsellor links the person (client) to treatment and care services. The client benefits from a comprehensive psychosocial assessment and is provided with a holistic approach to treatment and care. The counsellor assists the client with adherence to treatment and medication and performs a case management role. The client who is non-adherent is referred for social work services, and the VCT counsellor in collaboration with a social worker manages the treatment and care of the client in the community. Individual counselling is essential to people living with HIV to help them deal with the biopsychosocial issues around the disease. The social work counselling relationship provides a safe space for people living with HIV to discuss issues of treatment, care and everyday life.

In terms of family planning, social workers provide counselling around

family planning services, sexual and reproductive health issues and the importance of VCT. They engage in school and community outreach programmes and educate primary and secondary school students about the consequences of unprotected sex, sexually transmitted infections (STIs), including HIV, and healthy lifestyles. In Barbados, undergraduate social work students include VCT services in their community-based activities.

In some countries, VCT services are being extended to communities via mobile units and outreach activities in an effort to reach all segments of the population. However, in others where health and social service programmes suffer from untrained personnel and the lack of funding and other resources, the expansion of VCT programmes is limited. Muturi (2009) states that in Jamaica, the lack of affordable medical care for people diagnosed with HIV coupled with prevailing HIV-related stigma and discrimination “defeats the purpose of getting tested for many Jamaican people” (p. 105). Advocacy by social workers for the expansion of VCT services is imperative since people living with HIV must be identified and referred for treatment and care if the region is to reach the 90-90-90 treatment targets.

Orphans and other children made vulnerable by AIDS

It is important that treatment, care and support target the population of children who are orphaned or made vulnerable by AIDS. Current data for the region show that the number of children infected with HIV has declined (UNAIDS, 2016d). Fewer children are being orphaned because ART is helping to improve the quality of life of their parents who are living with HIV, while also keeping them alive. The lives of children orphaned and made vulnerable as a result of the death of their parents generally fall apart. If they live in poor households they may have to help take care of a dying parent, and if abandoned after the death of the parent they may be placed in residential care or turn to the streets for survival (UNICEF, 2008), facing the risk of abuse and HIV exposure.

In some cases, older children assume care for younger siblings and head their households (Jones, 2009a). Extended relatives do not always provide support and take these children into their care, due to HIV-related stigma and discrimination. However, when they are referred to social service agencies, guardianship and permanency planning is undertaken by social workers. Unfortunately, not all children in need of help are reached due to the inadequacy of the services in some countries. Jamaica and Trinidad and Tobago have high numbers of children orphaned due to AIDS. In 2015 the number of orphans in Jamaica aged 0 to 17 years was 13 000 [10 000–15 000]

and in Trinidad and Tobago it was 1700 [1400–1800] (UNAIDS, 2016a). These countries also have well-organized child welfare systems through which orphans and vulnerable children can receive care and protection. Social work research on the experiences of orphans and other children made vulnerable by AIDS in Caribbean society is almost nonexistent.

Therapy and support groups

Psychosocial support to people living with HIV and their families is a priority area for HIV care in the region. Social workers and mental-health professionals provide much of this support. They engage people living with HIV or affected by HIV and members of key populations in support and therapy groups as a way of helping them deal with issues around HIV. Groups provide mutual aid and enhance the social functioning of members through providing a safe environment in which to vent feelings and share experiences (Ison, 2009). Group work is also a medium for empowering people living with HIV to deal with relationship issues, grief, diagnosis disclosure, stigma and discrimination and adherence to treatment.

The aim is to empower individuals and build their competence and capacity to cope with the adversities resulting from the disease. Social workers use essential knowledge regarding HIV and its treatments, and a body of theory, to gain insight into the issues faced by group members in order to make strategic interventions. In the Caribbean, social workers intervening with people living with or affected by HIV generally employ theoretical approaches that are western in orientation. However, they are being urged to develop indigenous models since the socioeconomic and cultural nuances demand interventions that are unique and fitting to the context (Jones, 2009b; Sogren, Jones, Nathaniel, & Cameron-Padmore, 2012).

Social support

Social support networks (formal and informal) play a prominent role in the lives of people living with HIV (Ison, 2009). In the Caribbean, formal social support is mainly provided under the auspices of government and may be delivered in an uneven way across countries. In well-resourced countries such as Barbados, people living with HIV have greater access to social welfare services, such as welfare grants, housing, food support, home and community-based care and counselling, than in poorly resourced countries, like Dominica. Joseph (2009) notes that “among Caribbean countries there is a dearth of welfare programmes that take into account the financial and

socioeconomic needs of people affected by HIV-AIDS” (p. 209).

In providing access to formal sources of support, social workers perform casework and case management functions, and link clients living with HIV and their families to essential resources and services while “empowering them to function as independently as possible in securing the resources themselves” (Ison, 2009, p. 128). In the management of clients’ situations, social workers follow up with clients to ensure that they are accessing medical care and other essential services. They help clients cope with issues such as grief, loss, stigma and discrimination, feelings of isolation, guilt, partner notification, and physical and financial challenges. However, social workers must be unflinching in helping clients to advocate on their own behalf for services to which they are entitled but cannot gain access to due to structural barriers such as stigma and discrimination.

Informal social supports, family and friends, faith-based organizations and other social groups also play a vital role in the lives of people living with HIV. It is the duty of the social worker to help people connect to or maintain sources of social support. A person living with HIV “having the support of family members would more readily adhere to the complex regimen of medication and other requirements necessary to ensure an improved quality of life” (Ison, 2009, p. 134). In a case study of a man living with HIV in Trinidad and Tobago who was cared for by his family, the researcher found that “family members derived the most satisfaction from the informal support that they provided to each other [...] The main caregiver [...] found that her siblings, parents and friends were very supportive, while teachers and friends provided positive support to the children” (Ison, 2009, pp. 135–136).

Joseph (2009) reported on a study conducted in 2005 that investigated informal social support among 16 women living with HIV in Trinidad and Tobago. The study found that most of the women who received support “got a large part of their affective support from their informal system, as opposed to instrumental or concrete support [...] The gaps of low social support found in the informal system were among friends, religious leaders and church members” (p. 206). Husbands and partners provided strong support, including affective and instrumental support (Joseph, 2009). Evidence shows (Lifson et al., 2015) that social support is critical to the person who is living with HIV and the family. However, research on the effects of social support on individuals and families affected by HIV in the region remains an unexplored area for social work (Ison, 2009; Joseph, 2009).

HIV PREVENTION: THE CARIBBEAN SOCIAL WORK RESPONSE

HIV-prevention programmes need a well-coordinated strategy that involves all sectors of society. Many of the HIV-prevention programmes in the Caribbean currently focus on reducing sexual behaviours that create risk among seropositive people and key populations, reducing stigma and discrimination in the population through public sensitization campaigns, expansion of VCT services, providing support for people living with HIV and their families, expanded access to antiretroviral medicines, and prevention of mother-to-child transmission services. These strategic programmatic initiatives focus on issues such as behaviour change among groups at risk of HIV infection, life skills education, eliminating gender inequalities, public education around HIV, advocacy and human rights, educating professionals who work with key populations and providing antiretroviral therapy to pregnant women diagnosed with HIV. Prevention is better than cure is the focus of initiatives to end the HIV epidemic in the Caribbean. Information sharing, education, communication, legislation, policies, advocacy, capacity-building and the promotion of behaviour change are areas that support prevention and are among priority areas for Caribbean governments. Social workers play a central role in these areas and in HIV prevention. The following section discusses social work's response to sexual behaviour change, gender inequality, stigma and discrimination, education and research.

Sexual behaviour change for HIV

Behaviour change for HIV is a multilevel strategy aimed at reducing risky sexual behaviours among sero positive people, people at risk of exposure to HIV and the general population. In the Caribbean, behaviour change communication specialists creatively use Caribbean culture (music, theatrical drama and dance) in preparing materials to convey behaviour change messages. Activities such as sporting events, public celebrations and events on World AIDS Day are used to spread behaviour change messages via various communication channels (PANCAP, 2014).

The programmes aim to teach safer sex, how to negotiate condom use, the importance of engaging in monogamous relationships, practising abstinence and faithfulness to partners. They address knowledge, attitudes and practices in relation to sexual health. These interventions are critical. Research has shown that there is misconception among adolescents and young adults in the Caribbean about condom use (UNICEF 2010, 2011; UNICEF & CARICOM,

2008). In a study on the “response of Caribbean youth to HIV/AIDS prevention messages and campaigns” (UNICEF, 2008, p. 1) that surveyed a sample of over 200 respondents between the ages of 14 and 18, almost half of the respondents did not see themselves as at risk for contracting HIV and STIs even when they engaged in unprotected sex. Female respondents indicated that they had sex without condoms “because of their partner’s wishes” (p. 60). Respondents generally indicated that media campaigns did not cause them to change their behaviour.

Adult men, women and adolescents in the Caribbean place themselves at risk for STIs, including HIV, by having multiple partners (UNICEF, 2008, 2011; UNAIDS 2016d). The risk is indeed greater for sex workers and their clients, men who have sex with men and other people who engage in risky sexual behaviours. In a study conducted in Belize, “young men demonstrated positive attitudes about multiple sex partners (as evidence of power, virility) and in some regions [...] there was a cultural pattern of introducing young men to sex through commercial sex workers” (UNICEF, 2011, p. 57). In Jamaica and Trinidad and Tobago, HIV is concentrated among sexually active adolescents and young women between the ages of 15 and 24. The prevalence rate is 0.6% in both countries (UNAIDS, 2016a). With the spread of the epidemic into the heterosexual population and with unprotected sex being the main transmission route, behaviour change programmes are targeting everyone.

Social workers are the main social care providers who promote behaviour change. They visit schools and educate students about sexual behaviour, including condom use, abstinence and delaying the onset of sexual activity. They partner with teachers and enable the integration of HIV information into the school curriculum. This is an important strategy. A 2008 study by UNICEF found that “school and media campaigns were the main sources of information for young people” (p. 60). Behaviour change programmes are grounded in theory and research (Muturi, 2009; UNAIDS, 1999) and therefore social workers must use research findings to understand the root causes of the so-called problem behaviours, develop policy and modify behaviour change approaches. These programmes must tackle gender inequalities and the HIV-specific needs of women and girls as they empower them to take charge of their lives and protect themselves from sexual violence (Muturi, 2009).

Advocacy for gender equality

Caribbean societies are traditionally patriarchal and women and girls are seen as not having equal power with men (United Nations Development Fund for Women, 2005). The “traditional gender roles in many Caribbean countries

imply that women should be submissive, allowing men to make decisions about engaging in sex. This limits women's ability to negotiate condom use and makes them vulnerable to sexual assault" (USAID, 2011, para. 7). Research shows that child abuse and gender-based violence are widespread in the Caribbean (United Nations Women, 2016), that women and girls are the main victims of sexual violence, and that the main perpetrators are men (UNICEF, 2010). The result is that they are often coerced into unprotected sex by men and this sexual violence provides a gateway for STI and HIV exposure (Muturi, 2009).

Research also shows that females in the Caribbean have early sexual experiences (PAHO & WHO, 2013; UNAIDS 2016e) and that "subcultural norms and values" (Barrow, 2006, p. 69) place adolescent girls at risk. Additionally, for some girls their "lived socioeconomic environments are neither safe nor secure" (Barrow, 2006, p. 69). In a study on child sexual abuse in the eastern Caribbean (UNICEF, 2010), it was found that teenage girls entered transactions with men in which sex was exchanged for favours, goods and money, and that mothers encouraged these transactional sexual relationships. The data also show that "men were three times as likely as women to state that this [practice] was acceptable (9.6% of men [...] compared to 2.9% of women)" (p. 17). The power imbalances that exist among men and women in Caribbean societies afford men not only more power but also more material benefit (Antoine, 2009; UNICEF, 2010). In poor households, women and their children often depend on men for their socioeconomic survival.

The gender inequality issue is also displayed in the risk-taking behaviour of adolescent males and young men who engage in at-risk sexual behaviour due to societal pressure "to prove their masculinity by engaging in sex at an early age, having multiple partners and using physical force against women" (USAID, 2011, para. 7).

Efforts to address gender inequality and violence against women and girls through public education and legislative reform have not been very successful. Social workers help to develop policies around gender-based violence. They advocate for and provide care and protection to victims of child abuse and domestic violence, and empower women and girls to take charge of their lives. However, empirical knowledge about the dynamics of gender-based violence in the region is essential "to inform intervention and prevention protocols and policies that are culturally and contextually specific and effective" (Hadeed, 2006, p. 107). The protection of children and women from abuse is a critical area of HIV prevention for social work as countries work towards implementation of the UNAIDS Agenda for Accelerated Action for Women, Girls, Gender Equality and HIV.

Addressing stigma and discrimination

Stigma and discrimination are a major barrier to halting the spread of HIV in the region and therefore the key problem being addressed in programme planning. People living with and affected by HIV, such as men who have sex with men, transgender people and sex workers, have reported experiencing stigma and discrimination from personnel in the service delivery system, colleagues in the workplace and members of the general public. In a study conducted by Andrewin and Chien (2008), people living with HIV in Belize reported experiencing discrimination from doctors and other health-care personnel (UNICEF, 2011).

Stigma and discrimination against men who have sex with men are entrenched in Caribbean society, where homosexuality is taboo and remains illegal in most countries because of existing legislation against ‘sodomy’ (AVERT, 2016; UNAIDS, 2016e). Additionally, some people who are members of faith-based organizations view homosexuality as a sin. The result is that men who have sex with men are ostracized (Kang Dufour et al., 2013). During the early days of the epidemic, HIV was “identified with homosexual men” (Antoine, 2009, p. 57), which led to increased stigma and discrimination against this group. The discriminatory behaviour perpetrated against gay men, other men who have sex with men and members of other key populations has been helping to drive the HIV epidemic among the MSM group underground, thereby making it problematic to provide this group with prevention and treatment services. In the closely-knit societies of the region, people are afraid to disclose their HIV status or seek treatment for fear of ostracism.

Caribbean countries have ratified international human rights treaties, such as the Universal Declaration of Human Rights (UN General Assembly, 1948) that require Member States to protect the human rights of all citizens and promote equality. Social workers in the region support human rights initiatives through their involvement in public awareness campaigns, education, and recommendations for humane policies and legislation reform. Over the past three decades, they have proposed changes in policies to protect children, women and other vulnerable groups from gender-based violence, a problem made more visible by the HIV epidemic and that helps to fuel the epidemic. In some countries antidiscriminatory workplace policies have been adopted and legislation proposed to protect the workplace rights of people living with HIV. The goal of CARICOM is to help establish enabling and transformative policy environments that protect all people and provide them with access to the services to which they are entitled.

Social workers must lead the fight to abolish discriminatory laws and

support antidiscrimination legislation that would protect the rights of key populations. To be effective in this advocacy role, many social workers will need to examine their own moral, cultural and religious attitudes to these groups. If HIV-related stigma and discrimination remain unresolved and if antidiscriminatory legislation to protect these groups remains a moot issue, the fight against HIV in the region will be difficult. Social workers are in a key position to advocate for change in the current legislative environment that is tardy in abolishing stigmatizing policies and punitive laws that negatively affect vulnerable groups and inadvertently legitimize discrimination. Regardless of age, sexual orientation or socioeconomic status, people living with HIV are entitled to treatment, care and support. Their dignity and worth is paramount. In pursuing their HIV-prevention agendas, social workers must commit to the regional and international targets aimed at ending the AIDS epidemic by 2030.

Education and research

Education is a fundamental strategy in HIV prevention and “the education sector in almost all countries has developed programmes to address HIV/AIDS” (CARICOM 2010, p. 262). Countries have instituted information and communication programmes on HIV. These programmes have helped to disseminate information on HIV transmission, dispel myths around HIV, build capacity among professionals and build community awareness of HIV, while supporting the regional response to the epidemic. Social workers engage in formal and informal education on HIV.

Caribbean tertiary-level social work programmes seek to educate students about HIV and build their skills in working with people living with HIV and their families. Many Caribbean social work educators infuse content on HIV into the social work curricula, develop and teach courses on HIV, and share information and research at conferences, seminars and workshops. By using these media, they extend critical information on HIV to students, community members and other social workers who need to continuously update their knowledge about HIV.

Among the tertiary institutions in the region, the University of the West Indies (UWI) has provided the most concerted response to the HIV epidemic. It developed a policy on HIV and AIDS and in 2001 established the UWI HIV-AIDS Regional Response Programme with the goal of using the expertise of UWI in working with committed partners to provide a collaborative response to the epidemic. HIV information is delivered to students in the four undergraduate social work programmes offered by UWI, through curriculum

infusion, stand-alone courses on HIV and special projects. A graduate course and a concentration on HIV are offered by the UWI Saint Augustine Campus in the Master of Social Work programme (Sogren et al., 2012). In 2016, social work faculty members and students of the UWI Cave Hill campus in Barbados collaborated with students and faculty members from the College of the Bahamas and the United States of America's Howard University to deliver an international social work pilot course entitled "Addressing the Complexities of HIV-AIDS in the Caribbean and United States". This project, funded through a grant from the International Association of Schools of Social Work (IASSW), was delivered in blended mode (online and face-to-face). It exposed students to the impact of HIV in the two regions. Social work students, both graduate and undergraduate, engage in internships and often gain opportunities to work with people living with and affected by HIV and other vulnerable groups. This special preparation is part of their education because "irrespective of their fields of specialization, many [...] are very likely to encounter people infected or affected by HIV-AIDS" (Sogren et al., 2012, p. 883).

Social work professionals and students also try to enable marginalized groups, such as men who have sex with men, to advocate on their own behalf and engage communities in activities geared towards ending stigma, discrimination and the HIV epidemic. In Barbados, social workers employed by the Community Development Department have established HIV committees in all parishes across the island. These committees are led by community members who plan educational and outreach programmes on HIV for their communities. These macro-level interventions reach key populations and build community leadership. Social work educators have also been constructing culturally relevant theoretical approaches that can be used by social workers in the Caribbean in their HIV interventions, for example a "social action model for social work practice in developing countries" (Jones, 2009b, p. 35).

After three decades of the HIV epidemic, the body of published social work research and literature on HIV in the Caribbean is still scant. However, the existing research has proven insightful in the planning of HIV-prevention programmes, policy development and the refining of social work practice techniques.

LESSONS LEARNED

Social work in the Caribbean faces several challenges in helping to end the AIDS epidemic. What lessons has the profession learned that can be used

to inform its response and regional initiatives geared to achieving zero new infections, zero discrimination and zero AIDS-related deaths? Social work has learned that:

- HIV remains a problem for the Caribbean, and ending the epidemic will require an effective systemic, multisectoral and multidisciplinary response. To enable a holistic and accelerated approach to the treatment and care of people living with or affected by HIV, social workers must be included in all programmes targeting prevention, treatment care and support.
- The inability of social work to respond effectively to the epidemic in all countries of the region is hampered by insufficient resources, few trained social workers and a dearth of research. The biopsychosocial issues arising from HIV demand adequate resources and specially trained practitioners to effectively deliver services to people living with HIV, people affected by HIV and other key populations. Social work research on HIV in the Caribbean is needed to provide data to inform interventions around behaviour change, education, theory development and policy and prevention programmes.
- Gender inequality is endemic in Caribbean societies. It violates the human rights of women and girls and is helping to fuel the HIV epidemic. Social work needs to support national and regional policies to protect women and girls, and initiatives geared towards zero tolerance for gender-based violence.
- Stigma and discrimination against people infected with HIV, men who have sex with men, transgender people and marginalized groups is systemic and a barrier to accessing services. It is incumbent on the social work community to support initiatives to abolish stigmatizing policies and punitive laws. These laws, and stigma and discrimination, are inadvertently driving the HIV epidemic underground (Sutherland, 2014), thereby thwarting prevention efforts. Advocacy by social workers and people living with or affected by HIV is essential for the creation of transformative policies, grounded in human rights principles that will enable all people to gain access to HIV services.

CONCLUSION

“There are a number of environmental and social influences that shape the epidemic in the Caribbean” (USAID, 2011, para 6), and therefore HIV-related

interventions require a holistic, integrated and sustained multisectoral response. Advances are being made in HIV prevention, treatment, care and support, with social workers playing critical roles. However, there must be “locally tailored responses within a framework that fosters regional leadership and accountability frameworks” (UNAIDS, 2016b, p. 15). These efforts also need to be sustained by comprehensive services to meet the holistic needs of key populations (UNAIDS, 2016b). The existence of stigma and discrimination in health-care settings and communities remains a major barrier to treatment. Social workers as advocates, human rights professionals and change agents must challenge the institutionalization of HIV-related prejudice (Maharaj, 2009), and lead efforts towards zero discrimination.

If the social work profession is to truly play its role in ending the AIDS epidemic in the Caribbean by 2030, social work educators, practitioners, researchers and policy-makers must be current in their knowledge of the epidemic’s trends and collaborate with other disciplines and sectors to address the issues that are barriers to achieving this goal. Without question, the profession in the Caribbean has a key role in accelerating and scaling up the fight (UNAIDS, 2016c) to end the AIDS epidemic as a public health threat.

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**The social work
response in the
United States of
America to the
AIDS epidemic:
1989 to 2016**

Vincent J. Lynch



ABSTRACTS

In this chapter, I will discuss the social work contributions in the United States of America (USA) to the AIDS epidemic through systematic analysis of the titles of all 3008 presentations given at the USA-based Annual National Conference on Social Work and HIV/AIDS from 1989 through 2016. These titles show how the response of USA social work has changed markedly over time, largely due to the wildly unpredictable nature of the complicated medical and person-in-environment challenges of the epidemic. Lessons learned include that outcomes, such as those proposed in Getting to Zero, will remain unattainable unless complex person-in-environment issues are more fully appreciated by all health-care professionals and policy-makers, not only in the USA but also globally.

美国社会工作对艾滋病疫情的响应：1989年 – 2016年

通过对1989年-2016年期间美国社会工作暨艾滋病病毒/艾滋病防治年度会议上所宣读的3008份报告标题的系统分析，本章我们将讨论美国社会工作对防治艾滋病疫情所作的贡献。这些标题显示了随着时间的推移，社会工作应对如何发生了明显的变化，这些变化在很大程度上是由于医学方面的极端不可预测性以及因所处的环境的影响而带来的挑战所引起的。经验教训：我们所期望的结果，就如很多人所提出的“向零艾滋病迈进”这样的结果一样，将是可望而不可及的，除非美国的还有全球的医疗保健专业人士和决策者都能更充分地正确理解这些复杂的因所处的环境而受到的影响问题。

La respuesta de trabajo social de los Estados Unidos de América a la epidemia de SIDA: 1989-2016

En este capítulo se discuten las contribuciones de trabajo social de los Estados Unidos de América (EEUU) en la epidemia del SIDA a través de un análisis

sistemático de los títulos de todas las 3.008 ponencias presentadas en Estados Unidos en la Conferencia Nacional Anual de Trabajo Social y HIV/AIDS durante 1989-2016. Estos títulos muestran cómo la respuesta del trabajo social ha cambiado notablemente con el tiempo, en gran parte debido a la naturaleza impredecible de los desafíos médicos y de contexto humano/persona en el entorno de la epidemia. Los datos muestran cómo los trabajadores sociales han tenido que permanecer ágiles en la adaptación de sus actividades a los extremadamente complejos desafíos de contexto humano/persona en el entorno de esta epidemia. Lecciones aprendidas: Los resultados como los propuestos en Llegar a cero seguirán siendo inalcanzables, a menos que los complejos problemas de contexto humano/persona en el entorno sean completamente apreciados por todos los profesionales y los responsables de políticas sanitarias, no sólo en los EEUU., sino a nivel mundial.

AIDSの流行に対する米国での社会福祉の対応：1989年 - 2016年

この章では、1989年から2016年の間、米国に本拠を置く年次全国会議で行われた、社会福祉とHIV/AIDSに関する3,008のプレゼンテーション全てのタイトルを組織分析し、AIDSの感染拡大に対する米国の社会福祉の貢献を検討します。これらのタイトルは、主にこの感染症の複雑な医学的および「環境の中の人」の課題が、非常に予測不可能な性質であるために、米国社会福祉の対応が時間とともに、いかに著しく変化してきたかを示しています。

学んだ教訓として、「ゼロにする」で提案されているような結果は、複雑な「環境の中の人」問題を、すべてのヘルスケア専門家と政策担当者がより完全に認識しない限り、米国だけでなく全世界でも引き続き到達不能です。

La riposte de travail social aux Etats-Unis d'Amérique à l'épidémie de SIDA : 1989-2016

Dans le présent chapitre, nous examinons les contributions de travail social aux Etats-Unis d'Amérique (EUA) relatives à l'épidémie de Sida à travers une analyse systématique de tous les titres des 3008 présentations données lors de la Conférence nationale américaine sur le travail social et le VIH/Sida au cours des années 1989-2016. Ces titres montrent comment la riposte de travail social a remarquablement évolué au fil du temps, évolution due en grande partie à la nature très imprévisible des difficultés médicales et dites de personnes dans leur contexte propres à l'épidémie. Les enseignements tirés incluent le fait que les résultats tels que ceux proposés dans la stratégie pour atteindre l'Objectif : Zéro resteront non réalisables à moins que les problèmes

complexes dits de personnes dans leur contexte ne soient entièrement évalués par les professionnels de santé et les décideurs, non seulement aux États-Unis, mais aussi dans le monde.

INTRODUCTION

Social work is practised differently throughout the world, in diverse cultural contexts and within varied approaches to education, training and professional regulation. What unifies all social work efforts, however, is the focus on core values and principles that we share in common. These are clearly stated in the global definition of social work approved in July 2014 by the International Federation of Social Workers (IFSW) and the International Association of Schools of Social Work (IASSW):

Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion and the empowerment of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance well-being.

The above definition may be amplified at national and regional levels.

(IASSW & IFSW, 2014, para. 1).

WHAT THIS CHAPTER IS—AND ISN'T

This chapter will tell a simple story about the important activities of professional HIV social workers in the United States of America (USA). To accomplish this, I explored the titles/subject areas of all 3008 presentations delivered at the Annual National Conference on Social Work and HIV/AIDS during the years 1989 through 2016. I came up with the initial idea for this conference in 1988, and served as its chair for 28 consecutive years. During those years, 12 114 registrants have attended these conferences. The conference is a four-day yearly forum where HIV social workers have the opportunity to deliver presentations about their work to their peers. The presentations each

year reflect the areas in which HIV social workers are most engaged. I want to emphasize that the study of these presentation titles represents a very basic effort. I am fully aware that there are many serious limitations to this project if one looks at it through the eyes of a researcher. A more rigorous analysis might reveal very different findings. Nonetheless, I think that these presentation titles collectively shed an interesting light on the activities of social work over many years, how these activities have changed over time and perhaps the reasons why these changes have taken place.

This is not a research article that has used methodologies such as meta-analysis to organize large volumes of qualitative and quantitative data (Borenstein, Hodges, Higgins, & Rothstein, 2009). I would certainly advocate for a future study on this topic that would implement a more rigorous methodology than that I have employed here. This project did not stem from a scholarly research conceptualization but rather from my own personal interest in understanding more fully the work that I have been a part of for nearly 30 years. I felt the need to engage in such an activity to help me make meaning of my life's work as I approached retirement age. I set about doing that by simply reading and then organizing the titles of all presentations that have been offered at this conference to see how our work has evolved over time. Rather serendipitously, I found that some themes and trends emerged as I studied these titles. I will discuss these later in the chapter.

METHODS

I first obtained all of the 28 conference programme books for the years 1989 through 2016. Each book contained a listing of every presentation title offered for that year, about 110 to 115 presentations per year. I then organized seven time intervals. Each interval represented a distinct four-year period in the history of the conference and of the HIV epidemic (1989–1992; 1993–1996; 1997–2000; 2001–2004; 2005–2008; 2009–2012; and 2013–2016). I then placed each programme book into the four-year time interval in which it occurred.

I studied the titles of the presentations in each time interval, noting those titles/subject areas that recurred with regular frequency. For a title/subject area to be considered as occurring with regular frequency, I felt it needed to occur at least 15 times in the interval. With that information in hand, I then collectively blended all the recurring titles/subjects in each interval and created a single explanatory organizing concept for each interval. Each organizing concept describes, in a highly condensed way, the major

challenges/foci of USA HIV social work practice activities during each four-year interval.

SOME BACKGROUND ON HIV SOCIAL WORK AND THIS CONFERENCE

For more than 35 years, HIV has brought devastation and death to millions across the globe. During the entire epidemic here in the USA, social workers with a Master's of Social Work have arguably been the largest group of health-care professionals addressing the complex and evolving psychosocial needs of those living with and affected by HIV. For more than three decades in this country, social workers have taken the lead in developing and implementing HIV-specific psychosocial service programmes in areas as varied as case management, client advocacy/empowerment, mental health, housing, treatment adherence, risk reduction and end-of-life care.

The idea for a national HIV social work conference emerged after a group of 10 Boston-based HIV social workers met with me during the summer of 1988 in my role as Director of Continuing Education at Boston College School of Social Work. They requested this meeting to discuss their frustration at not being able to find any continuing education resources that addressed psychosocial aspects of the disease. While there were dozens of conferences available that focused on medical issues, none addressed psychosocial ones. I proposed to this group that if they could provide expertise around HIV social work content, I could offer my skills and the resources of Boston College to host, for the first time ever, a multi-day HIV conference on social work issues.

We decided that the best way to proceed was to issue a call for presentation proposals inviting HIV social workers to submit on topics that reflected their expertise. We directed this call for proposals to our local Boston area, but soon word spread to other parts of the country, as well as internationally. We received 143 presentation proposals from colleagues representing 37 states and territories in the USA and from social workers living and working in 16 other nations across five continents. The registration fee was kept low (US\$ 100), and we hosted the meeting on the Boston College campus and provided affordable lodging in student dormitory rooms. The meeting took place over 12 to 15 June 1989. There were 431 attendees, and we offered 112 presentations. The only compensation that presenters received was a 50% discount on their conference registration fee.

I served as chair for the 1989 conference and obtained a variety of Boston College in-kind contributions to defray some planning expenses. The

postconference evaluations were consistently positive in nature. Attendees strongly requested that we hold this meeting on a yearly basis, not unlike the then-annual conference of the International AIDS Society, a more medically focused event. After careful consideration, Boston College School of Social Work permitted me to organize this four-day conference yearly provided it could be self-sustaining.

Each year, the conference draws between 450 and 550 attendees and offers more than 100 different presentations. It also draws a loyal audience. Four books have been published that primarily contain presentations given at many past conferences (Gant, Stewart, & Lynch, 1998; Lynch, Lloyd & Fimbres, 1993; Lynch, 2000; Lynch & Wilson, 1996). Although the conference's administrative structure has remained at Boston College for the 28 years covered in this chapter, each year many social workers from across the country assist in marketing the conference to new social work audiences, reviewing presentation proposals, suggesting new conference presenters and helping in a variety of other roles in the conference planning process.

We have given priority to presentation proposals from HIV social workers, although we have also considered proposals from people living with HIV and colleagues from other health-care provider groups. More than 80% of presenters have been social workers holding a Master's of Social Work degree. The most recent conference took place over 26 to 29 May 2016. As I approach retirement later this year, the conference leadership for 2017 and beyond will pass to a new planning group chaired by Russell Bennett, chief executive officer of Collaborative Solutions, Inc., a social work organization in Birmingham, Alabama, USA. These colleagues have been extensively involved in the conference for many years.

CAN SOCIAL WORKERS IN OTHER NATIONS DEVELOP THIS TYPE OF CONFERENCE?

HIV has revolutionized the professional development needs of social workers and, indeed, of all health-care workers. We cannot expect colleagues in medicine, nursing, public health or other disciplines to provide the very specific person-in-environment HIV trainings that we as social workers require. We need to look to ourselves to provide that kind of education to our colleagues through conferences, workshops and similar professional development programmes. The principal lesson learned from studying how this conference has developed is that the power of social work is real, and we can mobilize it through sustained grass-roots efforts. For example, as

noted earlier, the conference was founded *by* frontline HIV social workers and *for* frontline HIV social workers with minimal external funding. We still structure our conference in this same grass-roots manner some 28 years after its founding. While the facts associated with this conference may be of interest primarily to a North American audience, it is possible for any nation or region to develop successful grass-roots efforts that incorporate the power of social work as this conference has done.

Much good can result from sustained grass-roots efforts like ours to harness the collective power of social work. Our social work professional training involves the skills and values of advocacy, brokering, negotiation, collaboration, dignity of the individual person and social justice. These skills and values are immensely valuable when we are assisting our clients. We can also harness them in a collective fashion among ourselves to advance our own professional status, educational needs and other aspects of professional development. Many think it desirable to have our professional associations as partners in developing ventures such as ours. However, our experience has been that these large organizations have many levels of bureaucracy and are typically unable to be as nimble as individual social workers and smaller nongovernmental organizations can often be. We should not view the inability for our social work associations to partner with us as a rebuff, but rather as a manifestation of the organizational complexities that exist within those associations.

Some readers may think we have been able to establish this conference solely because we live in a developed country with more financial resources than most. While that may be partly true, I would like to emphasize that this conference was launched not due to the presence of generous funding sources but instead due to the commitment of a nationwide network of HIV social workers pooling their personal and professional talents to a venture that they desired to make a reality.

A recent Internet search for ongoing HIV social work professional development conferences or programmes such as ours in other nations did not reveal a single reference. This tells me that there exists an unmet need in most nations for such an educational resource for their HIV social workers. How can colleagues in other nations take first steps in advancing HIV social work education through the development of a similar conference? I would recommend that they keep in mind the wise principle of start small, think big. Reach out to colleagues who have similar interests to explore how they can start small by launching a single HIV social-work educational event in their nation. If it succeeds, perhaps they will develop more visionary ideas about future directions for the project. It is that principle that we kept in

mind as we began our efforts. Slowly, over many years, that small idea took on bigger dimensions.

I must emphasize that one major advantage that exists now and that was not available to us in the early years of the conference is the range of new and emerging technologies that can be creatively employed at little or no cost to communicate messages about conference announcements, calls for presentation proposals and the like. Today's social workers can utilize social media platforms as a way to offer support, provide learning opportunities and disseminate relevant educational information to HIV social workers. Additionally, they can use technologies such as webinars and other distance-learning strategies to deliver HIV social work trainings over vast areas at minimal cost. Our experience has been that HIV social workers greatly welcome formal and informal opportunities to learn about HIV with other social workers. These experiences increase skill-building and decrease burnout among our colleagues. In short, I think this is an area ripe for exploration by HIV social work colleagues across the globe.

WHAT DO OUR CONFERENCE PRESENTATION TITLES AND TOPICS TELL US?

What can we learn from organizing this glimpse of HIV social work contributions in the USA? It became clear that the successes and disappointments of social workers during the time intervals mirrored, in many ways, the frustrating up-and-down progression of the epidemic during the years studied. The organizing concepts help us understand more fully how HIV social work has changed over time, largely in response to the unpredictable ways in which the virus has morphed over the years. As I will describe below, social workers needed to be extremely nimble in their ability to tailor activities in response to the changing realities of HIV disease over time. Let us now look at our findings in some detail.

TIME INTERVAL: 1989 TO 1992

Organizing concept: Uncharted territory

During the first interval studied, this disease remained extremely mysterious, impacting almost exclusively white, gay male communities in the USA. It was a virtual death sentence, with most people living an average of only six months after initially becoming ill. Grief, fear, uncertainty and multiple

losses gripped all gay communities nationwide. Though azidothymidine (AZT) was a drug that was slowly becoming more available, the US\$ 10 000 annual cost for this drug was prohibitive for most people. Some examples of the presentation subjects appearing with great regularity in this interval included those on bereavement support services, hospice care, AIDS stigma, burnout, multiple losses, AIDS-related suicide and the right to die.

Putting it together

In our first time interval, 1989 to 1992, HIV social workers were fighting a never-ending uphill battle, trying to serve a client population decimated by a mysterious and deadly disease, the likes of which had never been seen in modern times. Colleagues from that era remember well the exhaustion, hopelessness and terror that defined their work and, indeed, touched every part of their lives. They also remember the vicarious trauma and burnout they experienced from continued exposure to such devastation. I marvel to this day at the level of resilience, strength and commitment shown by these early HIV social work warriors as I came to know them, their work and their stories.

TIME INTERVAL: 1993 TO 1996

Organizing concept: a clearer path emerges

New discoveries during this period helped us better understand the nature of the virus (for example, modes of transmission, the infection process and so on). Many new medication options also became available. Case management, a service to clients often provided by social workers that dealt with disseminating education and information, referrals, locating client resources and treatment monitoring, became widely recognized as an important aspect of HIV care. Social work also began to recognize the importance of caring for caregivers. A stronger HIV care infrastructure emerged within the federal government, providing important new resources for care and treatment. A large number of presentations in this interval dealt with topics such as medical updates on new medications, various models of case management, understanding the new federal grants guidelines, methods of HIV transmission, mother-to-child HIV transmission, treatment adherence and caring for the caregiver.

Putting it together

The old adage that knowledge is power certainly holds true as we reflect on this interval, 1993 to 1996. During this period, we came to know more about this virus. This knowledge also contributed to the development of medications that could slow down (but not cure) the progression of this wily viral infection. The new drugs that became available during this period offered promise and new hope to those living with this disease. Some of the outcomes from these medications were very encouraging but, sadly, many of these results were short-lived. Social workers during this period played a crucial role in helping many people faithfully adhere to their rather complex medication regimens. This offered the greater likelihood of successful treatment outcomes, aimed at reducing viral load to undetectable levels. Additionally, during this period, we saw a growth in new federal sources of funding. This made it possible for more people to engage in treatment. These resources also made it possible to recruit many new social workers into the field.

TIME INTERVAL: 1997 TO 2000

Organizing concept: the epidemic morphs

Here we began to see increasing numbers of new infections emerging in communities of colour, among both men and women. We also saw the epidemic begin to stabilize among gay men in terms of new infections. The newly available class of drugs known as protease inhibitors gave real hope to many close to death (a phenomenon known as the Lazarus effect), although as time went on, those drugs proved less promising than at first hoped. Some recurring title subjects in this period included presentations on Hispanic women and HIV, Black men and HIV, capacity-building in organizations serving minority clients, HIV and African American families, the use of protease inhibitors and social determinants of health in communities of colour.

Putting it together

In this interval of 1997 to 2000, there was a dramatic shift in the epicentre of the epidemic and the rise of new challenges that were previously unpredicted. Largely because of new and increasingly effective treatment options, as well as improved prevention efforts, urban, gay, predominantly white communities were slowly seeing significant gains in fighting HIV. At the same time, however, HIV was beginning to devastate communities of colour. Although people of colour (primarily Blacks and Latinos) accounted

for about one third of the population in this country during this period, they accounted for over 60% of new AIDS diagnoses (The Body.com, 2002). As with many other diseases, HIV found an easy entry into many urban communities of colour largely because of pockets of poverty, lack of access to acceptable care, distrust of mainstream health-care resources, systemic racism and other realities associated with marginalization. During this period, many social workers of colour became involved in HIV care and began to make many substantial contributions both to direct service delivery and to research activities. These important contributions continue today.

TIME INTERVAL: 2001 TO 2004

Organizing concept: diversity/global issues

The enormous prevalence of HIV throughout the African continent was a major focus of attention in the USA at this time. We saw the establishment of the President's Emergency Programme for AIDS Relief (PEPFAR), which provided vast amounts of HIV drugs to nations throughout Africa, especially in the hardest hit sub-Saharan region. Efforts in the USA to better understand and serve communities of colour also increased as rates of new infections in Black and Hispanic communities continued to soar. Frequent presentations included end-of-life care in Africa, women and AIDS in Africa, the Minority AIDS Initiative in the USA, HIV in sub-Saharan Africa, ethical issues in AIDS care, reaching Hispanics who were not receiving care, building HIV service capacity in communities of colour and cultural competency issues.

Putting it together

The crushing reality of devastation in communities of colour continued into this interval, 2001 to 2004. During those years, we also saw increased attention given to the ways in which HIV disease is truly a global epidemic, devastating all corners of the world, especially sub-Saharan Africa. Horrific reports of thousands of African children orphaned by HIV emerged. Other stories reported the loss of nearly an entire generation of young people to this disease in some African countries. The PEPFAR programme sparked a complex debate in the USA. This debate centred around the belief of some that our government was excessively spending resources to fight HIV in Africa while failing to meet the existing needs of communities of colour in the USA that were similarly suffering from the disease. Important issues of race, class, privilege, ethics and cultural competencies were widely discussed

in our conference during this period. Conference attendees discussed and debated many complicated points of view surrounding these issues during those years.

TIME INTERVAL: 2005 TO 2008

Organizing concept: new tools

A major development for our colleagues during this period was the widespread availability of a range of new measurement tools from two federal agencies, the Health Resources and Services Administration and the Centers for Disease Control and Prevention. These tools greatly assisted health-care providers in their ability to measure the success of their work and to implement quality improvement initiatives using evidence-based findings. Frequent conference presentation titles during this interval included achieving meaningful client outcomes, structured behavioural interventions in HIV care, software packages to assist in treatment monitoring, treatment adherence issues, collecting treatment outcome data and strategies for programme evaluation.

Putting it together

This interval, 2005 to 2008, ushered in new information that many social workers integrated into their work. The idea of measuring outcomes and using them as a way to work towards best practices became a new emphasis in our conferences at that time. During this period, our colleagues from the federal agency HIV/AIDS Bureau of the Health Resources and Services Administration partnered with us to offer within our conference a series of workshops that exposed social workers to ways in which they could use technology to achieve more-effective practice. They also helped social workers become more familiar with newly developed measurement tools that clients and social workers could utilize together to better monitor and achieve treatment goals and outcomes. These workshops contributed greatly to social workers acquiring new sets of skills that they could add to their array of professional competencies.

TIME INTERVAL: 2009 TO 2012

Organizing concept: a growing confidence

Social workers experienced greater confidence in the work they were doing at this time, as many expanded the use of measures of care-related outcomes. Case management continued to evolve as an important technique in which social work skills were valued and utilized in HIV care. In addition, Congress passed the Affordable Care Act (ACA) in 2010, and the White House rolled out the National HIV/AIDS Strategy (NHAS) in the same year. Recurring presentation topics/titles included health-care reform issues, various psychosocial case management models, strategies for quality improvement, medical case management issues, developing programme-planning skills and improving access to care for the uninsured.

Putting it together

A growing confidence in our work marked the interval from 2009 to 2012. Many social workers were engaged in a variety of approaches to traditional psychosocial case management, as well as service delivery of medical case management (a strategy that incorporates both medical and psychosocial issues into the case management function). Large numbers of presentations focused on these areas. There also was great hope that the newly introduced ACA and NHAS were two policy developments grounded in social justice that would lead to the development of access to health care for the millions ineligible for care for a variety of reasons. Although both initiatives are still works in progress, there have been significant obstacles to implementing them as broadly as many initially hoped.

TIME INTERVAL: 2013 TO 2016

Organizing concept: a complex future

During this period, both the ACA and the NHAS made slow progress, due, in large measure, to political infighting in Congress. Financial resources for HIV care have been reduced in many sectors. Medicalization of HIV treatment expanded during this time. Deaths continued to decrease in the USA, but the number of new infections remained fairly constant, leaving us puzzled as to why prevention strategies were not more effective. Frequent topics/titles included HIV care in a period of transformation, medical case management competencies, financial sustainability in HIV organizations,

roles of activism/advocacy, new HIV prevention challenges, compassion fatigue and staying relevant in a time of great change.

Putting it together

Our final interval, 2013 to 2016, reveals some uncertain prospects for the future. The Ryan White Program, though still an important funding resource in HIV care, has greater restrictions and limitations than in previous years. Also, hoped-for progress related to ACA and NHAS has stalled in many ways, largely due to rancour between the two major political parties. Also, new medical developments, such as the availability of preexposure prophylaxis treatment, have shown great promise in reducing the likelihood of infection for those most at risk. However, this development is one more breakthrough in the medicalization of HIV and may result in more future employment opportunities for the medically trained nurse (rather than the social worker) as the professional of choice when organizations hire additional medical case management professionals in the future.

CONCLUSION: SOCIAL JUSTICE/HUMAN DIGNITY ARE CENTRAL TO HIV CARE EFFORTS

Our profession's central value of social justice guides the activities of all social workers, including HIV social workers. This value honours the dignity of the individual person. The website of the National Association of Social Workers (NASW) defines social justice as:

[...] the view that everyone deserves equal economic, political and social rights and opportunities. Social workers aim to open the doors of access and opportunity for everyone, particularly those in greatest need. A brief glance at the many roles of social workers shows how this value system underscores everything they do. (NASW, n.d., para. 2)

As social workers, we have been trained to carry out this critical social-justice-informed approach to practice on a daily basis by keeping it front and centre in our minds as we respectfully assess and address the very complex realities in the lives of our clients. This important person-in-environment perspective, grounded in social justice that is uniquely social work in nature, is often lacking in many of our medical colleagues. Indeed, no medical

treatment will be effective unless the critical underlying psychosocial realities of a person's life are fully understood and addressed, including poverty, lack of education, mental health, inadequate housing and unemployment, just to name a few. These realities of life contribute to a person's ability or inability to carry out the very real demands of complex HIV treatment regimens. Quite often, the HIV social worker can not only assist clients in seeking HIV services but can also act as a broader agent of change to bring about improvements in the complex myriad psychosocial challenges in a client's life that adversely affect general well-being.

Similar to our profession's value commitments noted above, Getting to Zero also places social justice and human dignity as central to all our HIV care efforts. Michel Sidibé, UNAIDS Executive Director, clearly states at the end of his foreword in *Getting to Zero: 2011–2015 UNAIDS Strategy*, "In pursuit of social justice and human dignity we must move decisively from slogan to action. Let us unite our efforts to ensure success" (UNAIDS, 2011, p. 5).

The third vision in Getting to Zero, zero discrimination, and its related global goals (reducing HIV-related stigma, reducing restrictions on entry and stay within countries, increasing efforts to meet HIV-specific needs of women and girls, and zero tolerance for gender-based violence), are all grounded in the recognition that social justice is a necessary preexisting condition for the delivery of effective HIV medical care. Further, this vision and its four accompanying goals are also grounded in the important value of honouring the dignity of every person. Both social work and UNAIDS' Getting to Zero Strategy emphasize that many essential social conditions/policies need to exist at the micro level to support social justice and the dignity of the person for effective care and treatment of disease to take place. On the macro-level, countries that support social policies of HIV stigma and inadequate health care, policies that demean women, girls and gay men, and social policies of gender-based violence, among others, blatantly reject human dignity and social justice. They also force many struggling with HIV issues to go deeper into social isolation. This type of isolation makes it highly unlikely that such people will engage in treatment.

To reach the stated goals of Getting to Zero is indeed an unfinished and monumental task. Although we have passed the end date of 2015 for reaching all its critical goals, we must still seek to fully achieve these kinds of outcomes in many nations throughout the world. There are many significant links between Getting to Zero and HIV social work. Both value a fundamental commitment to social justice and to honouring the dignity of the individual person. Before any medical interventions can succeed, many nations across the globe still need to fully embrace these values. UNAIDS and social work,

together, will no doubt redouble their efforts in the years ahead to make these goals more achievable globally at both the micro- and macro-levels.

What does our joint future look like? The visions and accompanying goals of Getting to Zero still need to be the focus of global efforts designed to create a world in which we will one day eliminate HIV as a threat. We will probably not achieve these goals for many years to come. UNAIDS and the profession of social work (not only in the USA but indeed across the globe) think very much alike regarding the desire to infuse the values of social justice and human dignity into all HIV care and treatment carried out worldwide. Perhaps our organizations can together build new and creative global partnerships in the future that can establish a new synergy directed towards one day finally achieving the important and noble goals articulated in Getting to Zero.

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About the editors and authors

Diana Ball, MSW, CSW, has been a medical case manager at the Bluegrass Care Clinic in Lexington, KY, USA, for four years. She is completing coursework for a PhD at the University of Louisville. Her professional and research interests include HIV treatment engagement, trauma, mental illness and substance use disorders.

Evandro Alves Barbosa Filho, MSW, is a social worker and social work PhD student at Federal University of Pernambuco, and researcher at State University of Pernambuco, Brazil. His research fields are health policy analysis, critical discourse analysis, health systems and HIV/AIDS. Email: evealves85@yahoo.com.br

Zena Berhanu, PhD, is Assistant Professor of Social Work and Social Development at Addis Ababa University, School of Social Work, Ethiopia. He is the coordinator of the graduate programmes of the school. His interests include social policy issues and practices, HIV and AIDS issues, health care social work and spirituality. Email: zena.berhanu@aau.edu.et or zen_ed@yahoo.com

Nontembeko Bila is a lecturer in the Department of Social Work and Criminology at the University of Pretoria in South Africa. She teaches both undergraduate and postgraduate courses, focusing on the mental health and disability fields. Her research interests include mental health, child health, disability and developmental social work. Email: Nontembeko.Bila@up.ac.za

Melissa R. Carnay is Programme Manager for the Highly Vulnerable Children Research Center at Tulane University. She holds an MSW/MPH and has experience managing data collection in South Africa.

David Chipanta (editor and UNAIDS liaison), is Senior Advisor Social Protection, UNAIDS. He provides leadership at UNAIDS to develop and implement high-profile tools and guidance on HIV and social protection. He has 20 years' experience in health and development. He graduated from Harvard University with a Master's degree in Economics and International Development (MPA/ID). Email: chipantad@unaids.org

Daniel Deimel, PhD, MSc, is Professor for Clinical Social Work at the Catholic University for Applied Sciences in Aachen, Germany. He has 10 years' experience as a social worker working with drug-dependent people and people living with HIV. His key activities are in the fields of social psychiatry, dependence disorders and HIV/AIDS research. Email: d.deimel@katho-nrw.de

Mary Edinger, MSW, CSW, graduated Eastern Kentucky University with a Bachelor in Speech Communications (Dispute Resolution) and the University of Kentucky with a Master of Social Work. She has been a medical case manager at Bluegrass Care Clinic for nine years. Her professional interests include medical case management, substance misuse, corrections and infectious diseases.

Ngozi Enelamah is a PhD student at Boston College's School of Social Work. Her background is in reproductive health programmes and institutional capacity-building to provide interventions to pressing health and education problems. Her research interests include social determinants of health and models for building resilience in families.

Theresa Fox is Quality Manager at Rutgers University in New Jersey. She has been providing programme support and quality management services to the Ryan White community for the last 16 years. She has a Master's degree in social work with focus on administration, policy and planning. Email: fox@ssw.rutgers.edu

Lindsay B. Gezinski, PhD, is Assistant Professor at the University of Utah's College of Social Work. Her research focuses on the commodification of women's bodies, specifically pertaining to sex work and transnational reproductive assistance. To date, her sex work research has explored gender-based violence, health and the history of trafficking. Email: Lindsay.Gezinski@socwk.utah.edu

Michael Hager is Manager of Technical Assistance at the National Quality

Center. He has been actively involved in planning, implementation and evaluation for 12 years. He earned his Master of Arts degree concentrating in Health Policy, and his Master of Public Health degree concentrating in epidemiology at Boston University. Email: michael.hager@health.ny.gov

Mark Henrickson, PhD, RSW (Editor in Chief), is Associate Professor at the School of Social Work, Massey University, New Zealand. He worked in many aspects of HIV prevention, care, programme development and evaluation for two decades before moving into the academy. He continues HIV-related research and publications, and has been involved with IASSW since 2010. Email: m.henrickson@massey.ac.nz

Susann Hößelbarth, PhD, is Professor at the Faculty of Health and Social Work at the University of Applied Sciences in Coburg, Germany. Her main fields of expertise are social work theory, gender issues and research into risk-taking behaviour. She has longstanding experience as a social worker working with people who use drugs. Email: susann.hoesselbarth@hs-coburg.de

Sharvari Karandikar, PhD, is Associate Professor at the College of Social Work, Ohio State University. She began her career practising as a social worker for sex workers in Mumbai, India. Her current research relates to sex trafficking in Asia, egg donation, international surrogacy, and medical tourism and its impact on women. Email: karandikar.7@osu.edu

Florin Lazar, PhD, is Professor at the Faculty of Sociology and Social Work, University of Bucharest. He has studied extensively and written on HIV and vulnerable populations, and worked for 10 years as a social worker with people living with HIV in Romania. His latest research focuses on HIV stigma in Romania. Email: florin.lazar@sas.unibuc.ro

Nathan L. Linsk, PhD, ACSW, is Professor in Family Medicine and Jane Addams College of Social Work (Emeritus) at the University of Illinois, Chicago. He established Midwest AIDS Training and Education Center (1988 to present), developed educational and service programmes internationally, including para-social work, and served on the National Association of Social Workers' HIV task force and spectrum advisory committee. Email: nathanlinsk@yahoo.com

Margaret Lombe, PhD, is an Associate Professor at Boston College. Her area of expertise is international social development, focusing on social inclusion/

exclusion. She specializes in food security and nutrition assessment along with programme evaluation. Her current research portfolio includes understanding food security, livelihood mechanism and empowerment of children classified as OVC. Email: Margaret.lombe@bc.edu

Brian G. Luckett, MS, MSPH, PhD, is a Research Scientist with the Highly Vulnerable Children Research Center at Tulane University's School of Social Work. He is a quantitative analyst with a background in economics and biostatistics, and has 25 years of experience in international and domestic research; visit www.hvc-tulane.org. Email: bluckett@tulane.edu

Vincent J. Lynch, MSW, PhD (author and regional editor), is Director of Continuing Education at Boston College's School of Social Work. In 1988 he founded (and still chairs) the United States of America-based annual National Conference on Social Work and HIV/AIDS. He has edited/co-edited four books dealing with HIV, AIDS and social work topics. Email: lynchv@bc.edu

Harriet Mabikke, MSW, holds a Bachelor of Social Sciences from Uganda's Makerere University and a Master of Social Work from Boston College. She has worked as an OVC Coordinator for Habitat for Humanity in Zambia and as a Senior Researcher with the Museum of Science in Boston.

Adelaide Mangena graduated in 2003 with a Bachelor in Social Work from the University of the Witwatersrand. She completed her Master of Occupational Social Work in 2015. She worked at a counselling centre as a coordinator for lay counsellors. Her interests and areas of specialization include HIV and AIDS.

Francine Masson, PhD, is a lecturer in the Department of Social Work at the University of the Witwatersrand. Her doctoral and master's research were in the area of secondary trauma. She currently coordinates the Master of Occupational Social Work Programme, and lectures and supervises at both postgraduate and undergraduate levels.

Abel Blessing Matsika is a registered social work practitioner currently lecturing at the University of Zimbabwe's School of Social Work. He has a keen interest in child protection and gender. He has published and consulted for international agencies on issues of child protection and gender-based violence. Email: ablessingmatsika@gmail.com

Munyaradzi Muchacha is a social worker from Zimbabwe. He has experience and expertise in child protection, gender and livelihoods and HIV and AIDs programming, and has also published in these domains. Email: munyaradzimuchacha@gmail.com

Babbot Muchanyerei currently works as a social worker in Johannesburg, South Africa. He holds a Bachelor of Social Work (Honours) from the University of Zimbabwe and a Master of Social Work (Health Care) from the University of Pretoria. His research interests include child welfare and HIV issues. Email: babbotm@webmail.co.za

Hernando Muñoz Sanchez, PhD (regional editor) is a Professor at the University of Antioquia, Medellín, Colombia, and Dean of the Faculty of Social Sciences and Humanities. He is a social worker, researcher and activist in gender, family and the rights of LGBTI people. He is also a political leader in the city of Medellín. Email: hernandomunozsanchez@gmail.com

Vimla V. Nadkarni, PhD (author and regional editor), is a social work educator with more than three decades of experience. She has been involved in HIV and AIDS programming in India right from the initial days of the epidemic, and has served as an expert to the Government of India on several occasions. Email: vimla1912@gmail.com

Johanna K. Nice, MPH, is the Senior Programme Manager for the Highly Vulnerable Children Research Center. She is currently pursuing a PhD at the Tulane University School of Public Health and Tropical Medicine. Her research interests include the development and evaluation of interventions to address risk and resilience among HIV-affected families.

George Palattiyil, PhD, is a Lecturer in Social Work at the University of Edinburgh. With teaching and research experience spanning India and Scotland, his interests include international social work, social work with older people, HIV and AIDS, forced migration, health and human rights. Email: g.palattiyil@ed.ac.uk

Solange Guerra Rocha, PhD in Social Work, is a researcher at the University of Cape Town, South Africa. Her research fields include social movements, communication, feminism, public health, HIV and AIDS, public policies and human rights, and she participates in national and international nets of social movements. Email: msolgrocha@gmail.com

Letnie F. Rock, PhD, is a Senior Lecturer in Social Work, and former Head of the Department of Government, Sociology and Social Work at the University of the West Indies' Cave Hill campus. Her published work includes peer-reviewed articles and book chapters on child abuse and neglect, domestic violence and disaster management. Email: letnie.rock@cavehill.uwi.edu

Tetyana Semigina, MSW, PhD, Dr. Habil. (author and regional editor), is a Professor at the Academy of Labour, Social Relations and Tourism at the National University of Kyiv-Mohyla Academy in Ukraine, and works on international projects. She has authored more than 300 publications on social work, social and health policy, and HIV and AIDS issues. Email: semigina.tv@gmail.com

Vishanthie Sewpaul, PhD (regional editor), is a Professor at Zayed University, Dubai. Previously she was a Senior Professor at the University of KwaZulu Natal in South Africa, where she spent several years working in the area of HIV and AIDS, integrating therapeutic intervention, prevention, advocacy and lobbying. She remains committed to emancipatory education, human rights and global justice. Email: Vishanthie.Sewpaul@zu.ac.ae

Dina Sidhva PhD, is a Lecturer in Social Work at the University of the West of Scotland and an Associate of the University of Edinburgh's Global Health Academy. She has a passion for researching and giving voice to marginalized, vulnerable people in areas such as HIV, human rights, gender-based violence, asylum seekers and refugees. Email: Dina.Sidhva@uws.ac.uk

Rusty Souleymanov is a PhD student at the University of Toronto's Faculty of Social Work. He is actively involved in community-based HIV and AIDS research and HIV education with gay and bisexual men and people who use drugs. His work is supported by the Social Sciences and Humanities Research Council of Canada. Email: rusty.souleymanov@mail.utoronto.ca

Alexandra Spyrelis is a South African researcher at Tulane University's Highly Vulnerable Children Research Center, and holds a Master of Research Psychology. She has professional experience conducting research, programme implementation and evaluation focused on social and behavioural HIV-prevention among vulnerable populations in South Africa.

Heino Stöver, PhD, is Professor for Social Scientific Addiction Research at the Faculty of Health and Social Work at Frankfurt University of Applied

Sciences in Frankfurt, Germany. His main fields of research and project development expertise are health promotion for vulnerable groups, drug services, prison health care and related health issues (HIV/AIDS). Email: hstoever@fb4.fra-uas.de

Tory M. Taylor, MPH, is the Director for Capacity Building Initiatives in the Department of Global Community Health and Behavioral Sciences at Tulane University and is Technical Advisor to the Highly Vulnerable Children Research Center. She has 20 years of experience in monitoring and evaluation for health and nutrition programmes.

Adam Thompson is the South Jersey Regional Partner Director for the Northeast/Caribbean AIDS Education and Training Center. He has served on multiple advisory bodies and expert panels in the areas of patient involvement and engagement, performance measurement, and HIV care and prevention delivery systems. He is an advocate for quality. Email: athompson@g sida.org

Tonya R. Thurman, MPH, PhD, is an Associate Professor at Tulane University's School of Social Work and Director of the Highly Vulnerable Children Research Center. Residing in sub-Saharan Africa for 10-plus years, she has focused her expertise in programme design and evaluation on strengthening the evidence base for initiatives serving HIV-affected children. Email: tthurma@tulane.edu

Donna Van Alst holds Master's degrees in social work and business administration and a PhD in social administration and policy from Columbia University's School of Social Work. She has worked in applied research and programme evaluation for more than 10 years. Her projects focus on HIV consumer empowerment. Email: vanalst@ssw.rutgers.edu

Melita M. Vaz, PhD, is a social work practitioner with 23 years of experience. She has worked within grass-roots organizations as well as within the Government of India as a national-level programme officer in charge of social work functionaries. Email: melitavaz@gmail.com

Ana Cristina Vieira, PhD in Social Work, is Professor at Federal University of Pernambuco, Brazil. Her research fields include social policies, health policy and psychosocial aspects of HIV and AIDS. Email: anacvieira12@gmail.com



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