Committed to caring

Older Women and HIV & AIDS in Cambodia, Thailand and Vietnam

The Global Coalition on Women and AIDS

HelpAge International

Leading global action on ageing

www.helpage.org

HelpAge International has a vision of a world in which all older people fulfil their potential to lead dignified, healthy and secure lives. HelpAge International is a global network striving for the rights of disadvantaged older people to economic and physical security; healthcare and social services; and support in their caregiving role across the generations.

Author: David Orbach, HelpAge International

Design: Kornchai Thitasuta, Blueprint Graphic Design

Printing: Nopburee Press

Committed to Caring
Older Women and HIV & AIDS in Cambodia, Thailand and Vietnam

Acknowledgments

Numerous organisations have contributed to the development of this publication, in particular, the Vietnam Women's Union (VWU), Foundation for Older Person's Development, Health Promotion Group in Sansai, Mother and Child Concern Foundation, Thai Network for PLHA, and HelpAge International office in Cambodia. The efforts and patience of translators - Sombat Suwannasri and Boondee Pattalapusit in Thailand, Yun Bunchhay and Nath Boravuth in Cambodia, and Vu Thi Thu Ha in Vietnam - deserves specific acknowledgment.

Our sincere thanks also to all focus group participants, including people living with HIV, orphaned and vulnerable children, community representatives, and key informants from government and civil society who participated in interviews. We especially want to recognise the pivotal contribution of older women to the research, for their candour and strength in relating often very personal and sensitive details of their lives.

This document would not have been possible without the hard work of David Orbach, an Australian Youth Ambassadors for Development volunteer at the Asia Pacific Regional Development Centre. Sompong Chareonsuk from UNAIDS Thailand and Nguyen Thi Hoa Binh and Tran Bich Thuy from the VWU also provided us with valuable comments. Thanks to each of these people.

Finally, this publication was only made possible with the generous financial support of the Global Coalition on Women and AIDS & UNAIDS.

Godfred Paul
Regional Programme Manager
HelpAge International APRDC

Contents

Acronyms and Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral therapy
CoC	Continuum of Care
FHI	Family Health International
FOPDEV	Foundation for Older People's Development
HBC	Home-based care
HIV	Human Immunodeficiency Virus
IDUs	Injecting drug users
IEC	Information, education and communication
IGA	Income-generating activities
MIPAA	Madrid International Plan of Action on Ageing
NAPHA	National Access to Antiretroviral Program for People living with HIV/AIDS
NGO	Non-governmental organisation
OIs	Opportunistic infections
OPAs	Older People's Associations
OVC	Orphaned and vulnerable children
PEPFAR	President's Emergency Plan for AIDS Relief
PLHA	People living with HIV or AIDS
PTMCT	Prevention of Mother-to-Child Transmission
TAO	Tambon Administration Organisation
UN	United Nations
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session
VWU	Vietnam Women's Union

Summary

HIV and AIDS can prove devastating in undermining traditional support structures that sustain many families in Asia, reversing the expectation that parents will be looked after by their adult children as they become older. Instead, older people, primarily women, are confronted with the task of caring for a sick adult child, coping with their eventual death, and possibly looking after a surviving grandchild.

Interviews and focus group discussions with older women carers in three countries – Cambodia, Thailand and Vietnam - indicate that they assume multiple responsibilities in caring for people living with HIV and/or orphaned and vulnerable children. Looking after an adult child can involve a range of tasks, from obtaining food, water and medicine to assisting them to eat, bath, and dress. Caring for both affected and infected grandchildren requires them to take on important duties in areas such as health, nutrition, and education. In both cases, older women are key providers of emotional support.

The consequences of serving as the main carer in these circumstances are often severe, interconnected, and enduring. Their economic status can be weakened due to direct costs (medical, food, clothing, education) and indirect costs (loss of income support, lack of time to earn money), leading them to sell assets and borrow money. The ill-health and/or death of a family member and ongoing financial concerns results in immense trauma and stress, and the physical and emotional strain of providing care can have major consequences for their health. Social interaction may decrease due to stigma and discrimination and the considerable amount of time spent caring, accentuating feelings of isolation.

Despite their evident burden, older women carers remain neglected within the response to HIV and AIDS in Cambodia, Thailand and Vietnam. Numerous commitments relating to older carers have been made at international level, but national policies guiding the response contain few, if any, specific references to them. Thailand alone has achieved progress in this area. Lack of data about older carers and the impact of caring ensures that resources are rarely allocated towards their specific needs. Programmes or measures intended to support their role and alleviate its impact, from governments or civil society, are uncommon.

The impact is sometimes mitigated by initiatives or mechanisms that target vulnerable households generally. Interventions focused on the wellbeing of PLHA and/or OVC, such as formal home-based care, food support or educational assistance can indirectly reduce their burden and strengthen their ability to provide care. However, the coverage of these activities is often limited and carer's distinct needs are usually peripheral to their implementation. Relatives and friends are often the only direct source of material and emotional support. The recent scaling up of free antiretroviral treatment for PLHA has probably been most significant in reducing the financial, emotional and physical pressure on many carers, though their role may continue to be important.

Even in this changing environment, older women carers, particularly those looking after affected grandchildren, still need targeted assistance that invests in their ability to provide care and addresses the profound impact on their lives. Supporting and working with older women carers requires a multifaceted approach:

- Access to a regular, predictable income source
- Opportunities for income generation
- Ongoing psychosocial support
- Home-based care programmes that address and integrate their specific needs
- Information and training on HIV prevention and care
- Collection of sex and age-disaggregated data about older carers
- Involvement in programme design, implementation and monitoring
- Raising awareness about the impact of HIV and AIDS on older women

Introduction

HIV and AIDS can prove devastating in undermining traditional support structures that sustain many families in Asia. Multigenerational households remain common; an estimated 73% of older people live with children and/or grandchildren in Southeast Asia[1], and there is still an expectation that adult children will look after their parents as they become older. The situation is often reversed when HIV strikes a family, usually a young adult. Current or future assistance from the adult child is likely to disappear. In addition, older people are faced with the prospect of providing care as the child becomes sick, coping with their eventual death, and possibly becoming the primary carer to a young grandchild.

Where this occurs it is primarily, though not exclusively, an older woman undertaking the bulk of caring work, due to a combination of 'traditional' gender roles and demographic imbalances. Caring for people living with HIV or AIDS (PLHA) and/or orphaned and vulnerable children (OVC) brings with it multiple responsibilities that can have significant consequences for their economic status, health (emotional and physical), and social relationships. Poor older women in low and middle income countries, who are more likely to be widowed than men and have limited resources to expend in caring for a child or grandchild, are particularly vulnerable to these impacts.

Despite indications that they bear a significant proportion of the caring burden within families affected by HIV and AIDS, the contribution of older women remains distinctly undervalued. Substantive, coordinated action that focuses on their needs is absent in most countries. There is a clear disjuncture between the pivotal role performed by older women carers, and the amount of attention and resources allocated to them. It suggests their efforts are taken for granted and also reflects the wider marginalisation of older people within the HIV and AIDS field. Older people living with HIV are largely excluded from data collection, and prevention activities invariably focus on populations considered at higher risk of infection.

This report highlights the role of older women as carers, and the impact of that role, in the context of the HIV epidemic, with reference to three Asian countries: Cambodia, Thailand and Vietnam. While each country has made commendable progress in tackling different elements of their respective epidemics, the response to older women affected by HIV and AIDS, particularly as carers, has been inadequate. The extent to which governments and organisations working on HIV and AIDS in each country recognise and address their situation merits greater scrutiny. Approaches and recommendations to increase support for older women carers and strengthen their contribution in the future will also be presented.

Methodology

In preparing this publication, secondary literature relating to older carers and HIV and AIDS, and various country-specific documents were reviewed. Primary research was then conducted in Cambodia, Thailand and Vietnam. The author held in-depth interviews and focus group discussions with older women carers; focus group discussions with PLHA, OVC, and community representatives; and interviews with key informants. Owing to the limited, qualitative nature of the data collection, this report does not conclusively represent the current situation of older women carers in each country, but intends to provide an illustrative picture of the experience of many, mainly vulnerable or disadvantaged, older women. It is desirable that this topic be the subject of additional, rigorous and comprehensive study in the future.

International Commitments: Older Carers and HIV & AIDS

At international level, there is explicit acknowledgment that the situation of older carers, particularly women, requires specific attention as part of the response to HIV and AIDS. UN member states have committed themselves in a number of documents to understand and address the needs of older people caring for PLHA and OVC.

The 2002 *Madrid International Plan of Action on Ageing (MIPAA)*[2], a non-binding agreement, established three main objectives relating to older people and HIV and AIDS:

1) Improvement in the assessment of the impact of HIV/AIDS on the health of older persons, both for those who are infected and those who are caregivers for infected or surviving family members.

2) Provision of adequate information, training in caregiving skills, treatment, medical care and social support to older persons living with HIV/AIDS and their caregivers.

3) Enhancement and recognition of the contribution of older persons to development in their role as caregivers for children with chronic diseases, including HIV/AIDS, and as surrogate parents.

A separate objective was to support the caregiving role of older persons, particularly older women, which included recommendations to:

- identify how to assist older persons, in particular older women, in caregiving and address their specific social, economic and psychological needs.
- reinforce the positive role of grandparents in raising grandchildren.

In 2001, the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) produced the Declaration of Commitment on HIV/AIDS, including the following pledges:

"By 2003 … ensure the development and implementation of multisectoral national strategies and financing plans for combating HIV/AIDS that …… address gender and age-based dimensions of the epidemic …

and … review the social and economic impact of HIV/AIDS at all levels of society, especially on women and the elderly, particularly in their role as caregivers, and in families affected by HIV/AIDS, and address their special needs"[3]

More recently, the 2006 Political Declaration on HIV/AIDS adopted by the UN General Assembly committed member countries to:

"addressing as a priority the vulnerabilities faced by children affected by and living with HIV; providing support and rehabilitation to these children and their families, women and the elderly, particularly in their role as caregivers"[4]

In practice, it is evident that many countries are failing to address these commitments or report on any advances made in supporting older women as carers. Despite lobbying by HelpAge International, progress on meeting the 2001 commitments was not reviewed at the 2006 High-Level Meeting on AIDS.[5] The UN Secretary-General's five-year progress report last year did not include a section on 'Alleviating social and economic impact' - a key part of the original Declaration. UNGASS Country Progress reports contain no references to work with older people, and recently published MIPAA+5 country reviews did not explain what action had been taken to fulfil the main objectives relating to HIV and AIDS.

NGOs: good practice guidelines relating to carers

The non-governmental organisation (NGO) sector has established a *Code of Good Practice for NGOs Responding to HIV/AIDS* which sets forth guidelines for signatories to apply in their work.[6] Over 160 organisations worldwide signed up to the original document. Older people are recognised as a vulnerable population group in the Code, both as carers and as people who become infected, though it doesn't provide specific guidelines in working with older people, unlike OVC. In relation to carers, the Code indicates that good practice should include the following:

- ensure that the social, economic and psychosocial affects of HIV/AIDS on PLHA, their family and carers are addressed (p.69)
- provide training and resources to ensure carers have appropriate information about HIV/AIDS prevention and care and knowledge of available health services (p.69)
- ensure development programmes reach households where there are limited employment options, where food supplies are insecure and/or income-generating capacity is affected by HIV/AIDS-related illness or death, and where there is reduced productivity due to increased burden of care, and/or changes in family composition, including grandparent-, women- and child-headed households (p.76)
- strengthen the caring capacity of families and communities to protect and care for OVC by provision of economic, material and psychosocial support and development of life skills of children, parents and carers (p.82)

Caring Role

Responsibilities

Discussions with older women carers in the three countries, and a review of prior research, indicate that they take on multiple responsibilities in providing care to a PLHA and/or OVC. The extent of their role depends primarily on the age of the person under their care, presence and support of other relatives, and whether they receive formal assistance.

Many adult children are already living with parents or return to live with them once they become aware of their status, particularly at the terminal stage of the illness. Older parents living with an adult child during their illness are more likely to provide care, pay medical costs and take responsibility for orphaned grandchildren. One study found that 62% of parents in Cambodia and 70% in Thailand co-resided with a child prior to their death from an AIDS-related illness.[7]

"He is my son so I have a responsibility to take care of him … If I motivated him, maybe he would feel better"

Toem, 59, Cambodia

Caring for a PLHA requires that older women undertake a number of activities, with the stage of their child's illness determining the nature and volume of the work.

"At their age they should be enjoying leisure, but instead they use all their time and energy caring for their children and grandchildren"

Community leader
Focus group, Vietnam

Responsibilities may include:

- Food preparation, cleaning, and washing clothes
- Acquiring food, water and medicine
- Dispensing medicine, cleaning wounds, and relieving pain
- Accompanying them to and staying with them in hospital
- Watching over or checking on them throughout the night
- Assisting them to move, eat, dress, bath, and use the toilet

Furthermore, older women carers are a key provider of emotional support, usually encouraging their adult child to remain positive and look after their health, and serving as a calming influence when they become upset.

Older women effectively become a surrogate parent if circumstances require them to provide care to a grandchild or multiple grandchildren, before or after the death of an adult child. Caring for grandchildren that are below school age and/or HIV-positive consumes most of their day. Duties include bathing and dressing them, preparing food, getting them to sleep, and administering medicine when they are ill.

Similar tasks are performed in looking after school age grandchildren, though there may be increased time for other activities during the day. They often work to generate income for the household, if their health permits them and the opportunities exist. Additionally, they may be responsible for transporting grandchildren to and from school, obtaining an increased quantity of food, and paying education-related costs.

Older women carers are also an important source of advice and emotional support for grandchildren during, and beyond, the grieving process that follows their parent's death. They may motivate them to continue attending school and provide guidance on issues related to maturation. The intergenerational caring relationship often becomes mutual as both parties grow older, with grandmothers receiving assistance with domestic chores and being nursed when they fall ill.

Impact

A relatively small but significant body of research, mainly derived from two projects in Cambodia and Thailand (see Further Reading), has enhanced understanding about the impact of HIV and AIDS on older people, particularly as carers. It is evident that the consequences they experience are often severe, interconnected, and enduring. In-depth interviews and focus group discussions reinforced this message. Older carers, however, are not a homogenous group and the impact varies greatly, depending on their level of vulnerability and the context in which they live.

In analysing the impact of AIDS on older people in Cambodia and Thailand, one paper identified a number of factors influencing the extent of its economic impact, including: economic position of the parent/s and sick adult child prior to illness, living arrangements during illness, assistance provided by other family members, presence of orphaned grandchildren, and access to welfare or health insurance. Broader features of a country also underpin the potential experience of an older carer, such as levels of economic development, access to healthcare and formal social protection systems, community attitudes, and political will.[8] Further issues with relevance for older carers include their age and health status when caring begins, knowledge about HIV and AIDS, duration of the adult child's illness, social networks, and geographical setting (urban or rural).

Economic

A central issue for older women caring for a PLHA and/or OVC is the impact on their economic status, which also has multiplier effects that influences their emotional and physical health. Every older woman participating in the research had borne a financial burden, some greater than others, as a result of their role as carers. There are both direct and indirect costs associated with providing care.

Direct costs while looking after a PLHA can include paying for treatment (medical care, transport to services, drugs), food, and clothes. Bereavement is closely followed by the onerous expense of a funeral. For instance, in Vietnam, because of misunderstanding and fear about HIV infection, most people dying of AIDS-related illnesses are cremated, which is more expensive than burial. Looking after OVC can involve paying numerous additional expenses, such as education fees and materials, clothing, healthcare, small cash allowances, and food. These costs tend to increase as the OVC grows older.

"Few people knew about our situation because my son didn't talk about or reveal his status, so there was no support for me … I had to do all the work myself. Even though I knew he would die, I spent a lot of money on medicine and bought him whatever he wanted"

Lan, 60, Vietnam

Indirect costs are equally significant for older women carers and their families. In many cases, though not always, adult children were providing financial support to their older parent/s. This assistance usually disappears after they become sick. Stigma and discrimination can also force healthy PLHA to stop working. Research suggests parents with lower incomes are more likely to rely on economic support from a child.[9] Earnings from a family business or farm may decrease due to the loss of productive labour and skills previously contributed by an adult child. Older carers can experience the loss of their own income through relinquishing or reducing work due to the time-consuming demands of providing care.

"Every morning I wake up thinking about how I will have money for my grandchildren ... I can't sleep because I think about it so much"

OVC Carer,
Focus group, Cambodia

Those older women seeking to re-enter the workforce to earn extra income may be similarly impeded by a lack of time or find there are limited employment opportunities due to age discrimination. Poor physical health or general weakness, sometimes worsened by caring activities or stress, is another barrier. A number of older women carers did not feel strong enough to work, and many did not benefit from social protection schemes. Indeed, the majority of older people in the three countries lack access to any form of financial allowance or pension. The absence of a regular, predictable source of income in their situation can contribute to a series of responses with long-term consequences.

Rising household expenditure and/or a reduction or loss of income leads older women to employ a number of different coping strategies. These include:

- Utilising savings (if available).
- Borrowing money from relatives, friends and moneylenders, with high interest rates often attached by the latter.
- Selling assets, such as land, livestock, furniture, and even houses to raise money or repay accumulated debts.
- Reducing expenditure in certain areas, such as food or clothing, while decreasing their personal consumption to ensure the PLHA or OVC is not unduly affected.

Accruing large debts, relative to household income, was a frequently reported experience. While many older women emphasise the importance of their grandchildren remaining at school, severe financial pressures can eventually lead them to be withdrawn (especially noted in Cambodia). The sale of arable land also leads to higher food costs in households that relied on that asset as a key source of food.

There are also possible opportunity costs associated with caring. The time spent providing care could instead be used to earn income or produce food. Money that is used for direct costs or to repay debts could have been invested in resources for an existing business or income-generating activities that helped to increase household income. Additionally, the forced sale of assets such as land or livestock denies older women carers' access to an economically productive asset in the future.

Emotional

Older women suffer considerable emotional pain in caring for a sick adult child and/or coping with their death. The emotional impact is difficult to quantify compared with the obvious economic or physical effects that often occur. Being informed about their child's status and its implications shatters long-held assumptions and aspirations related to both their future and their child's future. Many older women are suddenly compelled to be a provider of care and support, rather than receive assistance. The loss of an only son or daughter can prove especially traumatic.

"I was so sorry at the time when I found out because he was my only son and usually according to our culture, the son is supposed to look after the parents when they grow old but in my case my son couldn't do that for me … Even now, when I see other boys or men, it makes me sad and reminds me of him"

Insuan, 72, Thailand

"When he told me about the situation I cried a lot because he was my only son … I could not bear the thought of losing him"

OVC Carer, 59
Vietnam

A number of interweaving issues contribute to their distress: the poor health of their child/grandchild, their often precarious financial situation, the difficulty of specific caring duties, and general uncertainty about the future of the household and family. Lack of information and poor knowledge about HIV prevention leads some older women to feel worried about how to provide care and fearful of exposing themselves to HIV. Witnessing or hearing about discrimination against their child or grandchild, and/or experiencing discrimination themselves, adds to their anxiety and unhappiness. A number of older women felt isolated and unsupported, and suggested there was nobody with whom they could discuss their emotions.

Following the death of a child, the grief and bereavement may not abate for some time – it can take months, if not years, to come to terms with their loss. In cases where they are responsible for grandchildren, they must deal with the grandchild's own trauma over losing a parent or parents, and sorrow is mixed with concern about the future.

"I worry that if I am sick, no one will take care of me and no one will take care of my grandson"

OVC Carer, 66, Vietnam

Many older women experience difficulties and stress in adapting to a new parenting role that sees their relationship with grandchildren become more authoritative.[10] This is especially true as grandchildren enter adolescence, with a lack of understanding between grandchild and grandparent potentially straining relations. Both older women and OVC made reference to the 'generation gap' issue. On a more positive note, a number of women emphasised that they gained solace and

fulfilment in caring for grandchildren.

"It's good to have my grandchild to care for – it has allowed me to move on with my life …It would be very lonely without her"

Pad, 73, Thailand (who lost three daughters to AIDS)

Physical

The physical impact of caring for a PLHA and/or OVC derives from two main issues: the strain caused by caring tasks, and the emotional stress experienced during the caring process and after the death of the child's death. Strenuous tasks such as moving adult children out of bed, giving them a bath and taking them to the toilet are very difficult for older women who lack assistance from other people. Caring for infant or young grandchildren can also prove demanding because they need to be carried and have most things done on their behalf. Undertaking labour-intensive chores previously performed by the adult child, such as chopping wood, adds to the physical strain on older women carers.

"Sometimes I would fall down myself when trying to pick my daughter up and move her"

OVC Carer, Focus group, Cambodia

Headaches, joint and back pain were commonly described ailments that started, or became worse, during the process of caring. Older women feel less energetic and more rundown as a result of their responsibilities. Substantial weight loss caused by stress, and in some cases, a reduction in food intake, was highlighted in many instances. A declining physical state increases their vulnerability to illness and disease. General neglect of their health during the provision of care is exacerbated by a reluctance to seek medical treatment due to the increased costs it could bring to the household.

Older women also suffer fatigue due to lack of sleep, caused by the need to provide care during the night and/or constantly thinking and worrying about the situation. In the event that an older woman is required, and physically able, to work during the day to earn extra income, they are often exhausted by having to care for a PLHA/OVC during the evening. Poor health can also be caused by exposure to opportunistic infections experienced by other family members, particularly PLHA.

Social

Older women who are busy caring for a young grandchild or sick adult child find that their workload interferes with their level of social interaction. Spare time is often used to search for food or earn money. Their ability to visit friends, important places such as the temple or pagoda, and attend community events is restricted, which accentuates feelings of isolation.

The social impact is also felt in terms of stigma and discrimination, although it should be noted that experiences differ greatly within countries. The perception that HIV-related stigma and discrimination is widespread may be unjustified. Research conducted in Thailand and Cambodia showed that positive responses to households affected by HIV far outweighed negative reactions.[11] During focus group discussions and interviews, many PLHA and older women indicated that instances of discrimination had decreased due to improved knowledge, and because high prevalence in some communities meant that people were more familiar with HIV. Some older women emphasised the valuable support received from community members. Friends and neighbours were often their only source of external assistance.

Nevertheless, there is still a strong stigma attached to HIV and AIDS in some settings, demonstrated by older women who would not reveal the nature of their child's ill health or death to friends. They did not want to risk being judged unsympathetically by admitting the truth. Some PLHA are reluctant to admit their status, even though this is required to receive formal treatment and care.

"If we expose ourselves, we lose more than we gain"

PLHA, Focus group, Vietnam

Discrimination, where it occurs, is usually directed at PLHA, and to a lesser extent, OVC. Older carers are more likely to be affected indirectly. Discrimination takes many forms, and can occur in a variety of contexts. Examples cited by research participants include: children not wanting or being allowed to play with the child of a PLHA, unpleasant language directed at OVC, refusing to share food and drink with a PLHA or buy produce from them at the market, and commonly, people not visiting the household while an older woman cared for a PLHA. A grandson of an older woman in Vietnam was forced to change schools after a teacher discovered his HIV status. Older women indicated these instances of discrimination increased their unhappiness and emotional distress.

"After people found out about my illness, no one wanted to buy food from the family business anymore"

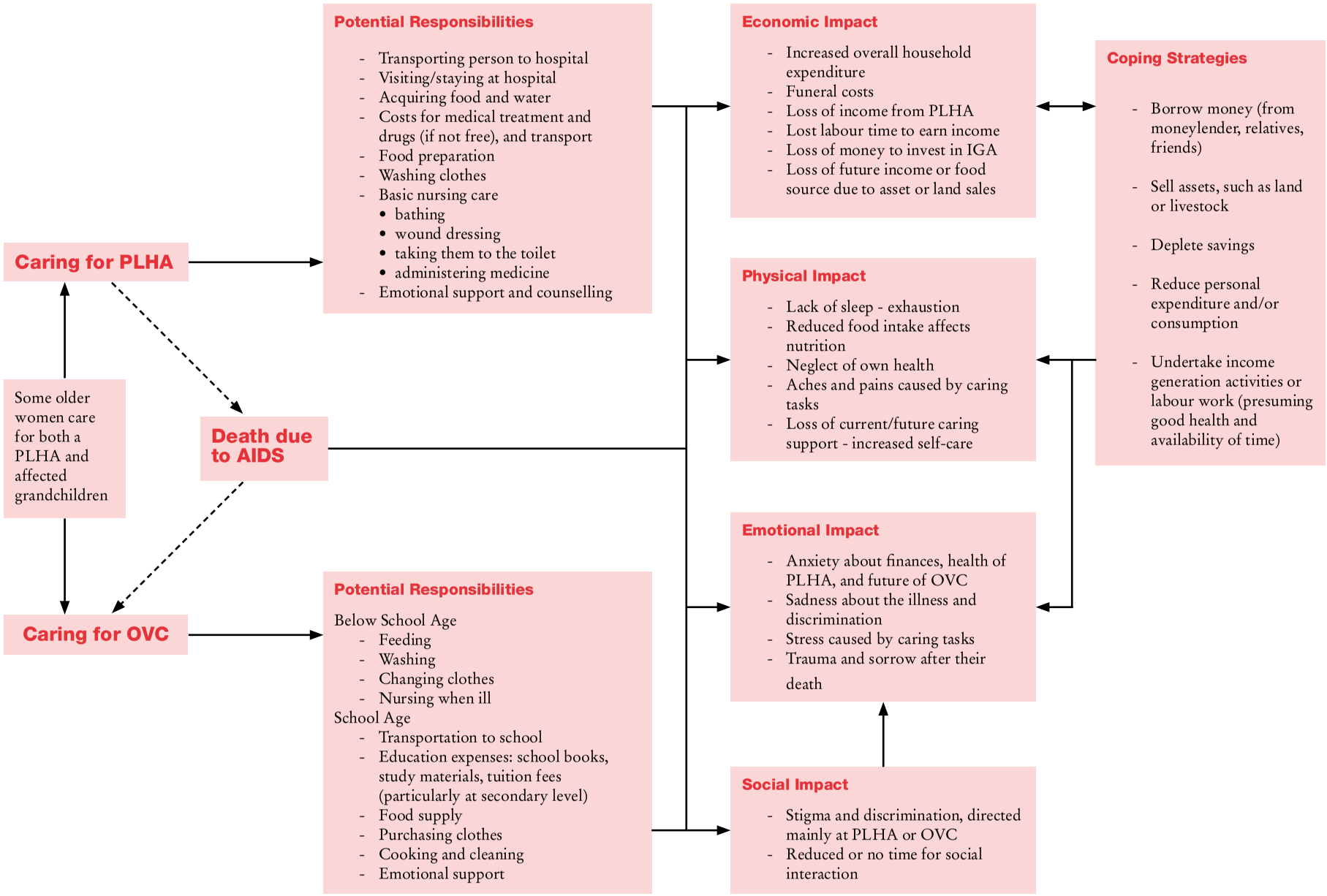
PLHA, Focus Group, Vietnam

Stigma and discrimination against PLHA who are injecting drug users (IDUs) or sex workers is still high. This is most evident in Vietnam, where the epidemic is concentrated among these populations. A study of HIV and AIDS-related stigma and discrimination in Vietnam found that families of IDUs or sex workers living with HIV were often heavily criticised, with particular emphasis placed on the mother's and grandmother's responsibility to ensure their children did not become involved in 'bad behaviours' that make them vulnerable to acquiring HIV.[12] One women interviewed in Vietnam indicated that some people would talk behind her back and say she didn't teach her son properly because he was both an IDU and HIV positive.

Carers no more, but still affected

One group of older women whose needs are often overlooked, even more than present-day carers, are those who have lost a child or children to an AIDS-related illness but have no surviving grandchildren. Though a large number of these women have often provided care until their child's death, external support that follows is very limited (particularly after the funeral). Some may have no other children they can reside with or from whom they can receive support. Programmatic assistance from organisations working on HIV and AIDS is often absent because they are no longer deemed to be 'affected'. Yet, most of these women cared for an adult child before access to ARV treatment was widely available, and often depleted their resources to keep their child alive, selling assets and borrowing money to meet costs. The emotional trauma experienced after a child's death is compounded by their possible isolation, and they may have physical ailments stemming from their period as a carer. In such circumstances, the need for practical support is just as compelling as for those currently providing care.

Figure 1 – Potential Process and Impact of Caring



"ARVs have made a big difference to my daughter's life. Before she couldn't even move herself … now, she feels a lot better and can do many things on her own"

PLHA carer
Focus group, Cambodia

Scaling up ARV treatment: implications for older carers

The recent scaling up of antiretroviral (ARV) treatment programmes (see Table 1), notably in Thailand and Cambodia, and to a lesser extent, Vietnam, is a welcome development. Many PLHA, including those from disadvantaged households, are experiencing improved health and seeing their life expectancy extended. PLHA and affected families that might have exhausted their resources on ineffective therapies are benefiting from the increased provision of free treatment. The dramatic increase in coverage also has major implications for the role of older women caring for PLHA, though this issue has not been explored.

"Without the drugs, I would have had to care for him a lot more, and he would have died by now"

Muenpeng, 61, Thailand

A number of older women that participated in focus group discussions and interviews were caring for children or grandchildren with access to free ARV treatment. Some women were able to contrast providing care to a person without access to treatment (including children that had died) with caring for someone that does have access. They described a significant difference in terms of their responsibilities and the subsequent impact. Presuming adherence to treatment is achieved and maintained, the burden on older women can be reduced in various areas.

Gradually improving health enables PLHA to regain their autonomy, and in some cases, return to work and contribute to household income. Older women may have more time for social interaction, rest, and income-generating or food production activities. Financial pressure on older women will ease if household income can increase and direct costs decline. The enhanced capabilities of the PLHA and the reduced level of care that is required help to lessen the physical strain. The demands on older women diminish further if the adult child is healthy enough to care for their own children. One woman also noted that discrimination towards her son decreased after he became relatively healthy again.

The powerful psychological release and sense of hope that it provides for carers is evident. Though concern about their child's long-term future may persist, there is great relief at witnessing the improvement in their health and being able to relinquish some of their duties.

"Since he received ARV drugs, my son's improved health has been like a spiritual medicine for me"

Phuc, 70, Vietnam

The role of carers can continue to be important even with the provision of treatment, their contribution shifting from intensive caring to facilitating adherence. Many older women emphasised that they administered the drugs or reminded their child to take them at the correct time. Some pay for transport (a major cost for poor families living in remote areas) or accompany them to health facilities. PLHA also require care if there are unpleasant side-effects, typically in the initial stages of treatment, and older women remain a source of emotional support. If they care for a grandchild that receives ARV treatment, the responsibilities of older carers will obviously be extensive regardless of its effectiveness. However, helping grandchildren with adherence becomes a critical part of their role.

Access to adequate food and nutrition is known to have a significant influence on adherence to ARV therapy (ART) and its effectiveness, and helps to increase resistance to opportunistic infections.[13] Older women carers often perform a key role in ensuring their child or grandchild living with HIV is provided with a sufficiently nutritious diet. In households where food insecurity is a persistent problem, this may involve personal sacrifice from an older carer in terms of their own food intake.

For a variety of reasons, PLHA may not adhere to a treatment regimen. Some drug regimens are more complicated to follow than others. Resistance can develop after interruption to a regimen, and some PLHA don't respond to treatment or default from programmes. In Vietnam, it was noted that treating PLHA co-infected with hepatitis C (most likely to be IDUs) can be complex as some ARV drugs are toxic to the liver. Where treatment failure occurs and alternative regimens are not available, the burden on older women caring for PLHA is likely to become intense once again.

Adherence is not the only issue confronting households with access to ART. Living with HIV as a chronic condition in a resource-poor setting can be difficult for many PLHA. They may need to rebuild their livelihoods and economic security after expending substantial resources prior to receiving treatment.[14] The financial pressure on older carers can persist if adult children are not provided with adequate economic and social support to re-establish their lives. Older women carers also require socio-economic assistance for themselves, particularly if they sold important assets or acquired large debts before their child/grandchild gained access to treatment.

The scaling up of ARV treatment, bringing with it a delay in death and serious illness, might actually undermine the ability of older women to look after their children or grandchildren, if and when they eventually become sick. Older parents will be less likely to be alive when this happens, and those older people who are still alive are more likely to belong to the middle-old or oldest-old categories, when they are less able to provide care.[15] The ability of countries to sustain the provision of ARV treatment and provide access to expensive second-line regimens when resistance develops is an issue with ramifications for older carers.

Thus, providing access to ARV treatment for people living with HIV may prove very beneficial for older women carers, but it can also create new challenges. Further research needs to be conducted to determine "the potential of older parents in encouraging treatment and monitoring adherence and how increased access to these drug regimes alters the consequences of having an HIV-infected son or daughter."[16]

Table 1 - Number of people receiving antiretroviral therapy

Country	Overall Number of People (2004)	Number of Children Under 15 (2004)	Overall Number of People (2006)	Number of Children Under 15 (2006)
Cambodia	5,974	452	23,587*	2,155*
Vietnam	1,000	N/A	10,678**	N/A
Thailand	38,260	N/A	89,496	6,637***

N/A - not available
* Mid-2007 figure
** As at March 31, 2007
*** Available figure not as recent as overall national data

Sources: NCHADS (2006), Annual Report 2005; NCHADS (2007), Second Quarterly Comprehensive Report 2007; WHO (2004), Epidemiological Fact Sheets – Vietnam; WHO SEARO (2007), HIV/AIDS in the South-East Asia Region; WHO/UNAIDS/UNICEF (2007) Towards Universal Access: Progress Report; Technical Working Group Subgroup Meeting – Care and Treatment, Vietnam, April 2007.

Country Sections

Cambodia

Population Data

Total population:
14.36 million

Population aged 60 and above: **6%**

Sources: 2007 ESCAP Population Data Sheet, Emerging Social Issues Division, UNESCAP; UNFPA (2007), *Population Ageing in Cambodia: Planning for Social Protection*

Older People

Older women significantly outnumber older men in Cambodia, representing 58.3% of older people, mainly due to longer life expectancy and the legacy of the Khmer Rouge era. 37.4% of older women compared with 5.2% of older men are widowed. The majority of older people rely on transfer payments from children, with approximately 40% of older people reporting that they earn an income, and only 5% reported to have a pension. Compared to older men, women are more likely to be illiterate, single and financially dependent on transfer payments.[17] These statistics suggest that older women are more likely to provide care for a sick child or OVC on their own, and are more susceptible to the impact of caring for and losing an adult child, with a greater need for access to financial and emotional support.

Older Carers and HIV & AIDS

Information from the 2004 Survey of Elderly reveals the important caring role of older people in the context of the HIV epidemic. An older parent was the main personal carer in 80% of cases where an adult child had died due to AIDS, with their role lasting over 7 months on average. Over two thirds of parents paid some medical and funeral expenses, and among those cases, 60% had borrowed money. 64% had provided support to an orphaned grandchild, and 53% of those older people reported it was a serious burden. 17% of older people providing care had received assistance from an NGO, but poor older people were less likely to have received this type of formal support.[18]

Knowledge about HIV and AIDS among women aged 60 and above has been found to be considerably lower than younger women, but they were still more likely to be willing to care for a relative living with HIV. The willingness of older women to provide care increases further if they possess the correct knowledge, underlining the need to include them in HIV and AIDS education campaigns.[19]

Older People and the National Response

Context

Key HIV and AIDS Estimates

Number of People living with HIV – **65,000**

Adult (15-49) Prevalence Rate – **0.9%**

Deaths due to AIDS – **N/A**

New Infections – **N/A**

Source: Statistics are official estimates as of June 2007, see http://www.nchads.org/pressrelease/28-06-07%20en.pdf

Considering its status as a resource-poor and low-income country, Cambodia has produced a very effective response in stabilising its HIV epidemic. Targeted prevention work has contributed to a significant decline in adult HIV prevalence from an estimated high of 3.3% in 1998 to 0.9% in mid-2007. There has also been a substantial increase in the number of people receiving ARV treatment in recent years (see Table 1). The Continuum of Care (CoC) framework, introduced in 2003, seeks to provide a comprehensive approach to prevention, treatment, care and support,

developing linkages between health facility services, and between those services and the community.

Inclusion of Older Carers

Older people are, to date, conspicuous by their absence in major HIV/AIDS documents and guidelines issued by government. Neither the 2002 *Law on the Prevention and Control of HIV/AIDS* nor the *National Strategic Plan 2006-2010* mentions older people, though 'increased coverage of effective interventions for impact mitigation' is a key strategy in the latter plan. A number of proposed activities falling under this strategy could potentially impact on older carers: providing nutritional support to OVC and their families; and improving coverage of and access to quality healthcare and psychological and spiritual support services for OVC, their families and caregivers.

Integrating the needs of older carers as part of the implementation of these activities is a difficult task. There are no standards or guidelines for providing support to older carers. Standard operating procedures in implementing home-based care activities and social care for OVC do not refer explicitly to older carers or older people overall. Furthermore, other than data from the Survey of the Elderly, national statistics about older carers in relation to HIV and AIDS are limited, impeding the development of interventions that focus on their needs.

The *UN HIV/AIDS Joint Support Programme 2006-2010* for Cambodia, a mechanism to support the National Strategic Plan 2006-2010, also fails to include older people (or even caregivers) as a target group for interventions. It acknowledges, however, that limited knowledge and data exists on the impact of HIV/AIDS on families and communities, thus it is intended that the United Nations Development Programme (UNDP) will complete socio-economic studies at community and household levels.[20] Further, a multisectoral National OVC Taskforce is undertaking a situation analysis of OVC in Cambodia, and developing a national strategic plan and five-year action plan for protecting, caring and supporting OVC. The role played by older people as carers, and the impact it has on their lives, needs to be given due consideration in these plans and studies.

Case Study – Chren, 79, Battambang province

Chren lives with her husband, a daughter, and two grandchildren aged 13 and 10. Four years ago, another daughter (the mother of the two children) died of AIDS. She came back to live with Chren once she found out she had HIV, a year before her death. The family was not able to access ARV treatment at the time, so Chren provided constant, round-the-clock care as her daughter became increasingly ill. She would wash and nurse her daughter, give her food and medicine, and change her clothes. "I would get very tired because I would have to look after her at night". Loss of income due to caring work and limited external support forced the family to borrow money to pay for items such as extra food, traditional Khmer medicine, and the funeral after her daughter's death.

Her other daughter and younger grandson have since been found to have HIV. Both of them have been able to access ARV treatment, which has made a significant difference to their lives and Chren's life. Although her daughter has experienced some side-effects, she is much stronger now, can do many things for herself, and even assists Chren with caring for the grandchildren. Once a week, health centre staff visit the daughter and grandson to check on their health, and sometimes give Chren advice and materials in caring for them. It is still a challenge to look

after two grandchildren at her age, especially the younger one living with HIV, but Chren feels "more comfortable and happy" and "better supported" now. Nevertheless, lack of money remains a problem, with insufficient income to cover their basic needs and repay outstanding debts. She worries about providing ongoing care while also trying to secure a regular income for the household, particularly at her advanced age.

Support and Impact Mitigation

Government

Older women carers in Cambodia are unlikely to benefit from government support that directly mitigates the impact of providing care. State provision of social welfare is extremely limited. There is no general social pension scheme for older people, with expenditure in this area mainly used for civil service pensions and veterans benefits that reach a small minority. None of the older women involved in the research (located in rural areas) reported receiving significant socio-economic support from government sources.

A review of the HIV/AIDS response in Cambodia determined that impact mitigation had generally been neglected as part of the national response, resulting in a fragmented approach and limited coverage.[21] Moreover, a 2005 situation and response analysis of the epidemic (which did not refer to older people or carers) found that "impact mitigation interventions at community and sectoral levels are virtually absent".[22]

The burden of older carers is being reduced, indirectly at least, due to the increased number of adult children or grandchildren receiving access to ARV and opportunistic infections (OIs) treatment, and home-based care (HBC), through the CoC framework. Donor funding enables national programs on HIV/AIDS and TB to provide free treatment, facilitating access to services that would normally be unaffordable for many households. As part of HBC teams, health centre staff perform a key role in monitoring the health of PLHA and their adherence to treatment, and referring patients to clinics as required. An HBC team usually comprises a representative from a health centre, NGO, and local PLHA group. The number of HBC teams providing services to PLHA increased from 52 in 2001 to 310 in mid 2007, supporting 22,253 PLHA, with 603 health centres now linked to HBC teams in 18 provinces within the CoC.[23]

"At first, I was afraid of infection but once I gained more knowledge, I felt better able to support my child"

PLHA and OVC carer, 72, Cambodia

HBC teams can help to strengthen the role of carers in looking after a PLHA, with some older women reporting that they received advice and information from health centre staff about providing care, on topics such as basic nursing, appropriate nutrition and hygiene. However, because HBC teams largely focus on the wellbeing of those receiving care, there is minimal attention and support given to the specific physical and emotional health needs of older women carers during their relatively brief visits.

In looking after a PLHA, transport to health facilities remains a significant cost for families in remote areas, and money is also spent on pharmacy drugs and sometimes traditional medicine. Non-HIV medical care for older carers or affected grandchildren can also result in large out-of-pocket expenditures that are a serious financial burden. Nearly 45% of the landless lost their land because of expenses incurred during the serious illness of a single family member.[24] Health Equity Funds that operate in Cambodia may cover the cost of healthcare and transport for poor

patients, but they can be difficult to access and limited in their geographical scope.

Primary level tuition at state schools is free, though many older women caring for school age grandchildren spend a significant amount on pocket money, transport, supplementary tutoring, uniforms, and learning materials. Total household direct expenditure on primary education averages 22% and 11% of poverty line income in urban and rural areas respectively, with the proportion growing increasingly high in upper grades.[25] Older carers sometimes receive assistance with these costs through NGO programmes targeted at OVC.

Case Study – Yoeum, 65, Battambang province

Yoeum lives with her husband, nephew, and three grandchildren aged 4, 5, and 6. The oldest grandchild, a boy, is HIV positive. Her grandson was diagnosed after he became sick two years ago. She has been the primary carer throughout this period – the father lives in Thailand and the mother lives nearby but doesn't assist. Her grandson could barely move as he became increasingly ill, but he has since received free ARV treatment and his health is greatly improved. Home visits from health centre staff have helped her in knowing how to care for him properly. Along with the usual tasks required in caring for three young children - "I do everything you can imagine" – she ensures her grandson gets a good diet and takes the medicine at the right time. There is no time to rest during the day, and she often checks on him during the night.

Looking after three grandchildren, and her ill husband, has proven very physically demanding. She often feels tired and weak, and suffers from headaches and pain in her body. Despite her grandson's improved health, she worries about him and often has trouble sleeping. The financial impact has also been substantial. She must pay for transport to the hospital, extra medical bills, and has lost income because she has no time to work. In response, she and her husband eat less food, borrow rice from neighbours, and buy second-hand clothes. Other than assistance from HelpAge International (food supplies, clothes and a mat) and rice from the local Older People's Association (OPA), the household has received no formal support. Her other children (who work in Thailand) previously sent a small sum of money but they are not wealthy and have to provide for their own families. Yoeum is concerned about how she will pay education costs when her grandchildren start school.

Civil Society

Civil society organisations play a crucial role in the response to HIV and AIDS in Cambodia. They are a key element within the CoC framework, and largely responsible for impact mitigation work in a context where government social service provision is weak. Older people though, are not a priority for most organisations working on HIV and AIDS. Indeed, a baseline survey conducted in Banteay Meanchey province found many older people had been actively ignored in HIV and AIDS education campaigns, refused participation by NGOs because they were considered 'too old'.[26] Income generation and microcredit schemes often exclude them due to perceptions about their capacities as older people. In the region in which it operates - north-west Cambodia – HelpAge International is the only NGO working with and through older people in relation to HIV and AIDS.

Older carers often have contact with NGOs through HBC teams visiting a PLHA, though it is unclear how much time is spent with them, or the extent to which

the carer's own needs are assessed and followed up. There are no provisions in standard operating procedures relating to specific support for older carers. Material support targeted at OVC and PLHA, such as food and household items, and help with education or transport expenses, can ease an older carer's burden. Some organisations have trained monks to provide emotional support to affected families, including older people, but the lack of ongoing psychosocial support for older carers (particularly after a child/grandchild dies) was identified by research participants as a problem.

Other Sources of Support

A number of Older People's Associations (OPAs), with the support of HelpAge International, provide assistance to families affected by HIV and AIDS, through home visits, gifts of rice, low-interest loans for livelihood activities, and assistance with cow-raising. Some groups, such as the Cambodian People Living with HIV/AIDS Network provide financial support for funerals, and pagodas occasionally give basic food supplies and small cash amounts. Direct support is also received through informal sources, such as neighbours and relatives that provide rice and emotional support. Nevertheless, many older women emphasised that their other adult children were poor themselves, had their own families to look after, and could not afford to assist them.

Box 1 – Providing Care and Support for PLHA, Orphans and Vulnerable Children, and their older caregivers in Battambang province

From 2003 to 2007, HelpAge International implemented a project funded by Family Health International (FHI) that aimed to increase care and support to households where an older person was caring for a PLHA or OVC. The project operated in three districts of Battambang province with many of the project villages having an established Older People's Association, through which older carers could receive additional support.

The two main components of the project were Home Based Care (HBC) and OVC activities. The PLHA and OVC supported by the project were all living with an older parent or grandparent who acted as their primary carer. Village volunteers were trained to be part of a HBC team, along with a health centre staff member and community assistant. Teams visited PLHA at least once a month, providing carers and PLHA with information on available services, basic healthcare, nutrition and hygiene, and monitoring health and ARV adherence (where applicable). Older carers of OVC also received regular monitoring visits from volunteers and community assistants, and were given advice on basic healthcare, nutrition and hygiene, and the needs and rights of children. Material support such as rice, school and household items were also provided to families with OVC.

Where necessary, OVC and PLHA were referred to a health centre or hospital, with financial assistance provided for transport and health costs. Older People's Associations (OPAs), which were in 19 of the project villages, provided supplementary support to PLHA and OVC and assisted with many of the project activities.

Other project activities included:

- Community awareness-raising about the role of older people as carers through radio broadcasts and the distribution of booklets to village leaders

and NGOs.

- Annual community education campaigns in each village about HIV and AIDS, health, and nutrition.
- Training of older people, PLHA and older OVC on Integrated Farming techniques for growing vegetables, fruit trees, raising chickens and fish, and home garden management, and the provision of start-up materials such as seeds and tools.

Impact

- Older carers are equipped with the knowledge to provide improved care to PLHA or OVC.
- Discrimination towards PLHA and OVC has decreased.
- Older carers' financial burden was reduced due to assistance with transport and health expenses.
- Home gardens have improved food security and nutrition among older people and their families (particularly PLHA), decreased food costs and increased income through the sale of produce.
- Many OPAs are now specifically targeting families with PLHA and OVC for assistance through the collection of money and rice during ceremonies.

Older women carer planting her home garden

Thailand

Older People

Population Data

Total population:
62.83 million

Population aged 60 and above: **11%**

Source: 2007 ESCAP Population Data Sheet, Emerging Social Issues Division, UNESCAP.

It is estimated that women comprise 50.6 per cent of older people overall and 66.9 per cent of people in the oldest old category (people age 80 and above). According to the 2002 Survey of the Elderly, the poverty rate among older people is 20.7% compared with a national average of 9.8%. Nearly 75% of financial support for older people comes from employment and transfer payments from family members, with only a third reporting their financial resources to be adequate to support themselves. Older women are more likely than men to receive material and care support from a child/child-in-law. There is also a greater likelihood that they have no spouse (45% of older women compared to 15% of older men), lack access to formal social security benefits, and live alone with lower household income.[27] This situation highlights their greater vulnerability to the impacts of providing care and support to a PLHA or OVC.

Older Carers and HIV & AIDS

Extensive research conducted in Thailand (see Further Reading) has helped to improve knowledge about the role of older people affected by HIV and AIDS and its impact on their lives. Findings from one paper[28] show that where at least one parent was alive, they were the main carer for an adult child who died of an AIDS-related illness in 59% of cases. Almost 50% of those parents were aged 60 and above. While it was more likely that an adult living with HIV had a surviving mother, even when both parents were alive, the mother was nearly 3 times more likely than the father to be the main carer. In terms of instrumental help (assistance with shopping, transport, etc), the difference was less pronounced.

The research also indicated that assuming the role as main carer significantly increased the probability that an older person would: experience health problems of their own, be a major contributor to costs during illness, and have to cease economic activity. Parents with lower incomes were more likely to go into debt, sell assets to pay expenses, and lose a child who was the main income earner for the household. Older people who were the main carer or co-resided with sick adult children were also likely to inherit responsibility for any grandchildren, though in about half the cases studied, the adult who died did not have surviving children. A previous HelpAge International study estimated that 240,000 older people in Thailand had lost an adult child due to an AIDS-related illness between 2001 and 2004.[29]

Older People and the National Response

Context

Key HIV and AIDS Estimates

Number of People living with HIV (end 2005) - **580,000**

Adult (15-49) Prevalence Rate – **1.4%**

Deaths due to AIDS (in 2005) – **21,000**

New Infections (in 2005) – **18,000**

Sources: 2005 estimates from UNAIDS (2006), *Report on Global AIDS Epidemic* and *2006 AIDS Epidemic Update*

Thailand is recognised for its strong response to an HIV epidemic that escalated in the 1990s. Over a decade, annual new HIV infections decreased from 140,000 to 18,000 in 2005. The national response has been largely health sector-focused, with a comprehensive range of care and treatment services delivered through different levels of the public health system. ARV treatment and prevention of mother-to-child transmission (PTMCT) programmes have been rapidly scaled up in recent years through collaboration between public health facilities and community-based groups of PLHA.

Inclusion of Older Carers

Until recently, national policies on HIV and AIDS had not acknowledged the situation of affected older people, particularly as carers, and failed to specify approaches to address their distinct needs. Therefore, it is notable that the *10th National AIDS Plan (2007-2011)* includes older people affected by HIV and AIDS as a specific target group for interventions. Under Strategy 2 of the Plan, there is a commitment to develop the provision of care and support to affected older people. Proposed activities include:

- supporting affected older people to provide care to PLHA and affected children
- facilitating access to income generation opportunities
- supporting older people to access information about HIV prevention
- promoting and developing a scheme to provide home care.

The Plan emphasises raising awareness about the impact of HIV and AIDS on older people, and increasing their capacity to be involved in HIV prevention as community educators. Thailand's 2006 report, *Towards Universal Access by 2010*, also states that an aim of the national programme is that social services be accessible to at least 80% of HIV and AIDS affected individuals and families who need them, giving priority attention to vulnerable children and older people affected by HIV and AIDS.

The funding and implementation of policies and commitments is a key challenge. A previous goal to alleviate the social and economic impact of HIV and AIDS has not been adequately developed or funded.[30] Under the process of decentralisation, Tambon (sub-district) Administration Organisations (TAOs) have a key role in implementing policy that relates to families affected by HIV and AIDS. Yet, prior analysis suggests that TAOs often have poor awareness about the impact on older people, limited budgets, and lack clear policy guidelines to support affected older people.[31] There is also a lack of capacity in implementing social development projects as compared to infrastructure projects. The recent National AIDS Plan has recognised the need to support TAOs in their role in assisting PLHA and their families. It is important that they receive both technical and financial support.

National data collection related to affected older people, particularly by key departments and agencies concerned with HIV and AIDS, remains weak. The inclusion of indicators focusing on the caring burden of older people in the 2007 Older People's Survey, conducted by the National Statistical Office, is at least evidence of progress in attempting to quantify their role as carers. This agency undertakes only basic analysis of the raw data, with other government departments and agencies responsible for more detailed analysis that will inform policy and programme development.

Case Study – Som, 74, near Chiang Mai

Som currently lives with a son and two daughters, one of whom is living with HIV. She found out five years ago her daughter was HIV-positive when she fell ill and was admitted to hospital for an extended period with a serious illness. Som looked after her during the day while she was in hospital, and took on most of the caring duties once she returned home, though her son and daughter helped as well. Som would worry and think about the situation a lot, especially at night. "I knew it couldn't be cured, so I thought she would die quickly for sure". There was a major financial impact, with extra costs associated with providing care and her daughter no longer contributing income to the household. Som was not able to work as much due to her caring responsibilities and declining health.

About four years ago, her daughter started receiving free ARV treatment. The daugher has seen her health gradually recover, and she has even been able to start working again, two days a week at a local church. Som doesn't have to do much day-to-day caring for her anymore, but she still worries about her future. The family receives home visits from a local community group, and neighbours and relatives have provided emotional support, but there has been minimal formal assistance to Som during this phase of her life. She is thankful that at least her daughter has begun receiving a monthly allowance from the government.

Support and Impact Mitigation

Government

Presently, specific measures that focus on supporting older carers or reducing their burden are scarce. Rather, there are broad-based mechanisms or systems that can mitigate the impact. Thailand has a public health system providing free universal coverage, which ensures that direct costs for healthcare provided to PLHA or OVC are greatly minimised. Under the scheme introduced in 2001, users of public health services paid 30 baht ($.90) per service, with exemptions for the poor, though this pre-payment has now been removed. Inpatient and outpatient treatment at every level and medicines are covered, with ARV treatment integrated into the scheme in 2005. This system also benefits older carers seeking treatment for health problems associated with the physical and emotional stress of providing care.

Many of the older women interviewed emphasised the importance of this scheme in enabling their family to receive access to healthcare. Improved access to ARV treatment, through the National Access to Antiretroviral Program for People living with HIV/AIDS (NAPHA) and with the aid of a Global Fund grant, has made a significant difference. Older women who cared for a PLHA prior to the roll-out of NAPHA described spending large amounts of money in a vain attempt to keep their child alive. In contrast, older women currently living with a PLHA are not required to pay any treatment expenses, though transport and extra food costs can still prove a major burden.

Some older women carers also benefit from a non-contributory 'old age cash allowance' for people aged above 60. The allowance provides 500 baht ($15) per month, targeting poor older people who are economically inactive, live alone and/or have no one to care for them. There has been a significant increase in the number of beneficiaries in recent years, from 400,000 in 2004 to more than 1.75 million in 2007, covering about 25% of older people in Thailand. The percentage of the budget allocated to the allowance has risen accordingly, from 0.14% in 2004 to 0.7% in 2007.[32] Older women carers receiving the allowance generally stated that it helps to pay household bills, but indicated it was not enough to cover their regular expenses,

particularly in raising an affected grandchild.

The allowance does not necessarily reach everyone in need. It was previously found that only 13% of older people in the poorest quintile were covered and 60% of beneficiaries were non-poor, and that transferring administration of benefits to TAOs may have worsened leakages.[33] Key informants, community members, and older women assert the initial selection process – where a local level committee selects and ranks eligible older people – is not transparent or systematic and subject to personal judgment. It was suggested at a regional seminar in 2007 that the capacity of TAOs to implement this allowance needed to be strengthened.[34]

Targeted income support to affected households is delivered through an allowance for PLHA, providing 500 baht ($15) per month, which may alleviate the burden for older women co-residing with them and/or providing care. In some cases, TAOs have provided financial support for income generation to affected families. Specific government assistance after a PLHA dies is limited, even if an older woman is responsible for surviving grandchildren. Formal support occurs indirectly through education scholarships for vulnerable children affected by HIV, which offsets the cost of schooling and enables carers to spend limited income on other household expenses. In 2006, it was reported that 8,000 scholarships would be available to support the education of affected children, though this is only a small fraction of the 380,000 children estimated to have been orphaned due to AIDS by 2005.[35]

Case Study – Kampun, 75, Chiang Mai

Kampun has lost both a son and daughter due to AIDS, with her daughter leaving behind three children, including an infant son. She currently lives with her husband, another daughter and the grandson, now aged 5. Kampun was the main carer when her daughter was sick, with an older grandson providing some help. She would usually work during the day and care for her daughter during the evening and morning – cooking meals, changing her clothes, and washing her. Sometimes, Kampun would watch over her daughter at night. Looking after her daughter as her health worsened and experiencing her death was devastating. "I would cry a lot and feel very sad". Health expenses were reduced due to the 30 baht scheme, but ARV treatment was unaffordable at the time, and transport and food costs needed to be paid. She also became more socially isolated during this period.

Kampun has been responsible for every aspect of her grandson's care since he was born. She finds it physically tiring to look after a small child and she must also pay for his food, clothing, transport and education. Kampun also cares for her husband, who had a stroke three years ago. She continues to work at a crafts workshop earning 120 baht per day, though she suffers back pain and would like more rest. "Without the money we could not live, what would we eat?". During her time as a carer, support has been limited. FOPDEV, an NGO working on ageing issues, has provided basic material support. Her other children sometimes help, although they also have to look after their own families. Kampun now receives a monthly 500 baht allowance, but combined with her wages, it is not enough to meet ongoing expenses. She is currently paying off a small loan at 20% interest per year.

Civil Society

Among the hundreds of civil society organisations implementing HIV-related projects in Thailand, few target older carers as part of their work. Older women are most likely to receive assistance through initiatives focused on the welfare of people under their care. Where home-based care is provided, some older people receive

training or information about prevention and care. Faith- and community-based groups offering spiritual and emotional support may extend this to affected family members, including older people. Programmes that provide material or educational support also help to reduce costs for older carers. The difficulty for civil society in scaling up their activities means there are large gaps in terms of coverage, and specific assistance focused on older carers is rare. Some of the older women carers participating in the research had received no formal support, even indirectly through OVC or a PLHA.

HelpAge International and partner organisations in northern Thailand, Mother and Child Concern Foundation, Community Care Network, Foundation for Older People's Development (FOPDEV), and Clear Sky Project, are atypical in targeting older people affected by HIV and AIDS. Activities in different project areas have included: community awareness-raising about the impact of HIV and AIDS on older people; formation of peer support groups; establishing revolving loan funds and providing training to support involvement in income-generating activities; training volunteers to undertake home visits focused on providing emotional support; training village health volunteers; intergenerational camps for older people and grandchildren affected by HIV and AIDS; and building the capacity of older carers to raise concerns and access resources. Additionally, the 'Grandma Cares' project implemented by the Chiang Mai Rotary Club trains grandmothers and other relatives caring for children affected by HIV and provides supplements for the basic needs of these families.

Other Sources of Support

In some instances, Older Peoples Associations[36] (OPAs) have been involved in project work highlighted above, but their potential to mobilise and deliver support for older carers on a wider scale remains unrealised, due to lack of understanding among most OPAs about carer's needs. PLHA groups, monks, and traditional healers undertake home visits focusing on PLHA or children affected by HIV, and some older carers benefit from their advice or emotional support. Monks sometimes collect donations on behalf of affected families. Support is also delivered through informal networks, particularly in rural areas. It is customary for communities to contribute financially towards funerals. Neighbours, friends and particularly family can be a source of emotional and social support, and occasionally provide food or small sums of money.

Box 2 – Project: HIV and AIDS and Older Persons in Northern Thailand[37]

Between October 2004 and December 2006, the Faculty of Nursing at Chiang Mai University, in partnership with FOPDEV, HelpAge International, the Northern Region Economic and Social Development Office, and Planned Parenthood Association of Thailand, with financial support from the United Nations Population Fund (UNFPA) Thailand, conducted a project in four districts of Chiang Mai Province focusing on older people affected by HIV and AIDS.

At the beginning of the project, an examination of the impact of HIV and AIDS on affected older people revealed negative impacts on their economic, health, and social status. A review of policy and practice at both local and national levels found that the contribution of older people as carers, and the subsequent impact on their lives, had been largely ignored. 97% of the affected older people in the project area lived on less $0.50 a day, and 76% were primary carers of PLHA,

affected grandchildren, or both.

Project activities were therefore based around two key components: impact mitigation (economic, social and health) and policy advocacy. Activities included:

- Provision of training, seed money and ongoing technical support for older people (and in some cases OVC) to undertake income-generating activities (IGA).
- Training sessions with healthcare providers, health volunteers, monks, and traditional practitioners focusing on care and support for affected older people.
- Establishment of mobile clinics, older peoples' clinics and regular home visits.
- Training older people on self-care, caring for PLHA, and as peer educators.
- Intergenerational activities and community education on HIV prevention and transmission.
- Awareness-raising with both communities and policy makers about HIV and AIDS and older people, through local events, seminars, and the production of IEC materials.
- Working with TAOs to formulate community plans to mitigate the impact of HIV and AIDS on older people.

A post-project evaluation found that it had a number of positive outcomes. More than 90% of affected older people in the project area reported a high or moderate increase in their quality of life, with the provision of health services and training seen as particularly beneficial. IGA started later in the project and thus had not yet shown a significant impact on income, but had lowered the cost of living for some (where food was produced), increased self-esteem, reduced social isolation, and strengthened cooperation through group-managed activities. The project was successful in generating greater awareness at each level of government about the impact of HIV and AIDS on older people. A number of administrators in project districts articulated an increased commitment to address the issue, and other local and provincial leaders expressed an interest in replicating the project model in their areas.

Key lessons learned

- Networking and stakeholder participation were important in ensuring project effectiveness. Collaboration among AIDS network organisations, community groups, district project staff and local government administrators enhanced service delivery and the sustainability of project outcomes.
- Community participation and a sense of ownership over activities contributed to project effectiveness.
- Adopting a multidisciplinary approach and utilising the expertise of each partner organisation had a greater impact than one organisation attempting to address all areas.
- Understanding the needs of differing contexts, eg. rural or urban settings, enabled activities to be modified accordingly.
- The quality of information, education and communication (IEC) and advocacy materials is crucial in transmitting messages and requires wide dissemination among key audiences.
- Evidence-based advocacy is critical for model development and policy influencing.

Vietnam

Older People

Population Data

Total population: **85.59 million**

Population aged 60 and above: **9%**

Source: 2007 ESCAP Population Data Sheet, Emerging Social Issues Division, UNESCAP.

Data from a recent paper looking at the relationship between old age and poverty reveals the importance of intergenerational households for older people in Vietnam. Nearly two-thirds of older people live in three-generation households and another 28% live with working age people. 90% of older people live in households receiving some type of remittance. 43% of women aged 70 are still economically active (compared with 58% of men), working an average of 32 hours per week. 34% of older women that live in multigenerational households undertake economic activity, compared with 79% of those living in households with only grandchildren. Households with older people and grandchildren, though small in number, are poorer than other types of households. Overall, women represent 58% of people over 60, and 66% of people over 80.[38] A separate document estimated that 52% of older women are widowed compared with 14% of older men.[39]

Older Carers and HIV & AIDS

There have been no detailed studies focusing on older carers and HIV in Vietnam, though a national report examining the situation of families and children affected by HIV and AIDS recognised, but didn't explore, the prominent role performed by older women as carers.[40] Further, a study of the impact of HIV and AIDS on household vulnerability and poverty found that a mother was the main carer in 51% of cases where the PLHA required care. It also estimated that approximately 126,000 people became newly poor or fell deeper into poverty because of HIV/AIDS in 2004.[41]

Research looking at palliative care in Vietnam showed that 64% of family carers spent more than 10 hours a day providing care to a family member with HIV or cancer, and that a lack of money was their primary concern. The most common source of support for carers was extended family, with friends, PLHA support groups and home-based care services involved to a lesser extent.[42]

Older People and the National Response

Context

Key HIV and AIDS Estimates

Number of People living with HIV (end of 2005) – **260,000**

Adult (15-49) Prevalence Rate – **0.5%**

Deaths due to AIDS (in 2005) – **13,000**

New Infections (in 2005) – **37,000**

Source: 2005 estimates from UNAIDS (2006) Report on Global AIDS Epidemic and 2006 AIDS Epidemic Update

The HIV epidemic in Vietnam is predominantly concentrated among populations at higher risk, particularly IDUs and sex workers, though there is legitimate concern about possible spread into the general population. Vietnam has a relatively low adult prevalence rate (compared with Thailand and Cambodia), but the number of people living with HIV is estimated to have more than doubled between 2000 and 2006. The number of new infections and AIDS deaths also increased significantly during that time, resulting in an increased need for treatment, care and support services. Services are currently expanding with the assistance of donor initiatives like PEPFAR,

Global Fund, and the Clinton Foundation.

Inclusion of Older Carers

Older people affected by HIV and AIDS, especially as carers, are not specifically recognised at the national policy level. The Government has produced two major documents guiding its response - the *National Strategy on HIV/AIDS Prevention and Control 2004-2010* and *Law on HIV/AIDS Prevention and Control*. In both documents, older people are only referred to as a key group in mobilising people to participate in HIV/AIDS prevention and control, though the nature of that role is not explained. Regarding care and support, the National Strategy emphasises the need to adopt policies to support families, including health and social policies, to care for and support HIV-infected people. In the 2010-2020 period, care of people affected by HIV and AIDS is also identified as a key priority.

The recently enacted HIV/AIDS Law outlines the need for families of PLHA to be responsible for rearing, caring and providing moral support to them, with Article 47 stating that:

"… HIV-infected people and their family members participating in HIV/AIDS prevention and control must be provided with training to improve their capabilities"[43]

Neither document cites older people as a vulnerable group or outlines measures to address their needs as carers. Furthermore, guidelines have not been developed for providing support to older carers in the context of the HIV epidemic, and it is also significant that there are no national guidelines relating to palliative care.[44]

Critically, negligible quantitative data has been collected at national level focusing on older people and HIV and AIDS, and consequently there is a lack of sound evidence about the extent of their contribution and burden as carers of PLHA and OVC.

Case study – Kim*, 65, Vietnam

Kim currently looks after her 7 year-old grandson, who is living with HIV. Kim's daughter and her son-in-law both died of AIDS and she has been the sole carer of her grandson since her daughter's death two years ago. She is isolated from most of her family, who don't want to assist her. She has not told anyone in her community the truth about her situation. Her grandson has been in hospital for 5 months because he is unable to walk or even stand up, and she has left her rural home to sleep in a bed beside him. Even though he is in hospital, she still helps him to eat, wash, change clothes, and take medicine. For the past two months, he has been receiving ARV treatment and his health is slowly improving, though he has experienced side effects. Kim has never received counselling or information about HIV transmission.

The current treatment and medicine is free but Kim previously had to pay entry fees for him to enter hospital. She also spends money on food and clothing. Before her grandson became ill, she earned money by working in the fields, raising chickens and selling vegetables. She has received one-off payments from commune authorities and the Red Cross, but her sole regular source of income is a 65,000 VND ($4) per month allowance for her grandson from the government. This is not enough to cover her ongoing expenses. She has loaned money from a relative and is now considering selling her house. "When I look at my grandson, I am very sad and miss my daughter even more" she says.

*Not her real name

Support and Impact Mitigation

Government

Older people affected by HIV and AIDS do not receive specific government support, but recently introduced social protection measures recognise the need to alleviate the impact of HIV and AIDS on households. A decree issued by the government introduced a benefit of 180,000 VND ($11) per month for PLHA living in poor households who are unable to work. Children living with HIV in poor households and are aged 18 months or less are entitled to the same amount, while children older than 18 months in the same situation receive 120,000 ($7.50). Any orphaned child (regardless of the reason) receives at least 120,000 ($7.50) VND per month.[45] The poverty line is set at 200,000 VND per month in rural areas and 260,000 VND per month in urban settings. These allowances, while not enough to cover their basic needs, may assist older people providing care in these households.

Social protection for older people only targets those deemed most vulnerable, due to budget constraints. There is a non-contributory social pension for older people aged 85 and above (for those without access to a contributory pension or monthly social insurance allowance), providing 120,000 VND ($7.50) per month. A means tested social allowance scheme provides the same amount to poor older people living alone or poor older people living in households with a 'frail' spouse, and without family members that can support them. Only a small proportion of older women are above 85, and few carers qualify under the second category. Some of the women interviewed had access to a modest contributory pension, but this is not typical. 67% of older people in Vietnam have no access to regular formal transfers, and social welfare benefits are received by only 14% (mostly war-related allowances).[46]

The burden of many carers can be greatly reduced if their child/grandchild receives ART, with access to free treatment increasing sharply in recent years. Donors are helping to fund the expansion of treatment programmes, though presently only about a third of PLHA who need treatment are reached.[47] Therefore, it is probable that many older women caring for PLHA continue to provide a high level of care. The cost of treatment and lack of specially trained health workers on HIV and AIDS with a good understanding of treatment regimens, monitoring procedures and drug resistance, are major barriers to scaling up access. There are 11,250 PLHA for every doctor trained in treating HIV cases in Vietnam, compared with 6,700 per trained doctor in Thailand.[48] In areas not covered by project funding, ARV treatment is not widely available or affordable.

Healthcare is a major element in the consumption expenditure of households affected by HIV, with expenses for a person living with HIV estimated to be 13 times higher than the healthcare spending by an average Vietnam household without a PLHA.[49] Many older women describe paying large amounts in seeking treatment for their child/grandchild. As a high percentage of people living with HIV in Vietnam are also IDUs, some older women also pay costs related to detoxification and rehabilitation. Older carers could also face significant costs if they or an affected grandchild become ill. Poor households and those aged 85 and above are entitled to insurance that enables them to receive free primary healthcare, but additional hospital treatment can attract high out-of-pocket payments. Orphans and low income households may receive fee exemptions/reductions in this situation.

Older carers that look after OVC also face education costs. Though primary education is nominally free, contributions (both formal and informal) are expected to be paid, along with expenses for books, uniforms and materials. The financial burden increases further at secondary level. Education assistance programmes aimed

at poor households may enable some children affected by HIV, including orphans, to receive exemptions from fees and contributions, though the coverage rate of exemption mechanisms is low.[50]

Case Study – Hong, 63, Hanoi

Hong lives at home with her husband and a son, 28, who is HIV positive. When she first found out about her son's status two years ago, she was very upset and surprised, and was unable to eat for five days afterwards. After that, "I realised I couldn't change what happened and it was my responsibility as a mother to care for him". She lived in the same room when he stayed in hospital, helping him to eat and giving him medicine. After returning to their home, Hong continued to give him spiritual and practical support, and paid for ARV treatment for five months, after which time it was provided free. She has also sought to buy more fruit, milk and meat to support good nutrition. Consequently, her son is quite healthy at the moment and can do most things for himself, though he has not returned to work.

The experience has had multiple impacts on her life. Initially, there was a great deal of emotional stress – "I felt like I didn't want to live" - and she lost a lot of weight due to anxiety. She spent 20 million VND ($1250) during his time in hospital, 1.5 million ($94) per month on ARV drugs, and extra money on nutritional food. She depleted savings, borrowed money from her sister and used her pension to meet these expenses. Her pension was the sole income source, as the household lost the money that the son used to contribute before he became sick. The provision of free ARV, along with his improving health, has greatly relieved her burden, and she has been helped by emotional support from relatives and friends. Joining an HIV/AIDS Empathy Club for older people last year has benefited Hong and enabled her to assist others. She has shared her story, taken part in school education sessions, and borrowed money from the Club to help her son start a small business. Hong is now the chairwoman of her local Club, and feels happy to help families facing the same challenges.

Civil Society

Few civil society organisations working on HIV and AIDS in Vietnam focus on affected older people as part of their programmes. Material support that seeks to enhance the wellbeing of PLHA or affected children can reduce the burden on older carers, but their distinct needs are usually peripheral to the implementation of such interventions. In any case, many NGO projects are limited in terms of the number of beneficiaries they reach. Some older carers are benefiting from the expansion in treatment, care and support services for PLHA. Health clinics and an increasing number of HBC teams may provide information, advice and materials that assist them in their caring role. One NGO, the STDs/HIV/AIDS Prevention Center, has also utilised affected older people as peer educators in some of its activities.

The most substantial initiative for affected older women has been the establishment of self-help groups, known as Empathy Clubs, in different areas of the country by the Vietnam Women's Union, a mass organisation operating from commune to national level. Though targeting PLHA and affected families overall, affected older people, particularly women, are encouraged to be involved as members. This enables them to receive emotional, financial and practical support through a range of activities. The original model has now been adapted for a project focusing primarily on disadvantaged older people (see Box 3). The Vietnam Association for the Elderly is another organisation increasingly active in addressing the issue of HIV and AIDS. Since 2003, it has received a small amount of funding to raise awareness among older

people about the issue, and recently established a fund to care for older people, which includes supporting affected older people as carers.

Other Sources of Support

Advice and support might be received via PLHA support groups that include affected families in their activities. Some older women carers had received assistance from local people's committees, such as gifts or even medicine. Clearly though, many older women depend on their relatives to provide economic and emotional support. Borrowing money from within the family was a common response to financial stress. Outside of their family and close friends, a number of older women said they had received no practical assistance

Empathy club meeting

Box 3 - Empathy Clubs for Older People in Vietnam: Older people-led mechanisms to mitigate the impact of HIV and AIDS

Since 2005, as part of a four-year project to mitigate the impact of HIV and AIDS on disadvantaged older people, the Vietnam Women's Union (VWU), in conjunction with HelpAge International and a number of local partners, has facilitated the establishment and capacity building of self-help clubs for people infected and affected by HIV that target affected older people, particularly older women carers. Known as 'Empathy clubs for older people', they enable members to meet in a supportive atmosphere to share common experiences, and also develop practical initiatives to address their own needs.

Under the project, 67 clubs are now operating in 4 provinces: Hanoi, Nam Dinh, Quang Ninh, and Thai Nguyen. Each club has a member-elected management board, and aims to have 50-60 members, comprising at least 70% older people, 70% women, and 70% people living with or affected by HIV or AIDS, or higher risk groups such as IDUs, while also including younger people and non-affected people.

Club activities include: promoting home care for PLHA and access to ARV treatment, condoms, clean needles and other medication; training on HIV prevention and caring for a PLHA; regular health check-ups; promoting self care; visiting sick club members and older people affected by HIV and AIDS; providing microcredit loans and training for livelihood activities; raising community awareness about HIV prevention, the impact of HIV and AIDS on older people and their role and contribution; counselling for PLHA and higher risk individuals and connecting them with existing local services; and providing educational and material support for OVC.

Monthly meetings are held that typically include a guest speaker, an education or experience sharing session, information and updates about club activities, and an opportunity for members to highlight current issues concerning them. It is recognised that clubs possess limited resources that cannot meet all the financial, psychosocial and health needs of older women carers, thus the project also seeks to develop the capacity of clubs to lobby for increased resources and services from government authorities, mass organisations, communities and individuals.

Key impacts (to date)

- Improved livelihoods due to increased access to credit and regular income.
- Older people empowered to lead support activities for PLHA and OVC, and communities empowered to lead HIV care and prevention initiatives.

- Reduced HIV and AIDS-related stigma and discrimination within communities and families.
- Increased awareness about the role and contribution of older people in caring for and supporting PLHA and OVC.
- Increased access to ARV treatment for PLHA and support for affected family members.
- Strengthened linkages and collaboration between affected communities, mass organisations, local government agencies and businesses.

Lessons learned

- Ensuring a regular source of income for families affected by HIV or AIDS is critical in helping them overcome the challenges they face.
- People living with and affected by HIV are responsible borrowers, with loan repayment rates as high as any other group.
- Older people are keen to join clubs providing mutual sharing and support and benefit greatly from this support in looking after a PLHA and/or OVC.
- Collaboration among different groups and the integration of economic, health, education and social support is important.

Future steps will include: building the capacity of clubs to fundraise effectively, increasing access to microcredit loans from non-project sources, documenting and disseminating information about the project model, establishing a network to promote and coordinate club activities, and increased advocacy work with policy makers to encourage ongoing funding of club activities and the replication of the model in other areas.

"The Empathy Club provides me with spiritual and emotional support because there are many members in the same situation as me, and I can share my feelings and sorrow with them. They encourage me to keep my belief in life"

OVC Carer, 66, Hanoi

Supporting and Working with Older Women Carers

Many older women are prepared and well positioned to assume responsibility for the care of their child or grandchild, but their love for and sense of duty to family members should not be taken for granted. Supporting them in their role as carers and addressing its profound impact on their lives requires a multifaceted approach. Experience suggests that collaboration among groups with different strengths can broaden the scope of interventions. Improving the financial, emotional and physical wellbeing of older women carers is likely to have a cascading effect within households. Targeting assistance at them should be regarded as an investment in the welfare of families and people that receive their care, strengthening their important contribution as part of the response to HIV and AIDS.

Older women carers require access to a regular, predictable source of income

Financial support was repeatedly cited by older women as an area of genuine need. Access to an ongoing and secure form of income support is crucial for older women whose caring responsibilities or poor health limit their opportunity to earn an income. It also assists carers who bear financial responsibility for OVC, and

older women who have lost current and future financial support due to the illness or death of their child. Non-contributory social cash transfers or pensions can mitigate the economic impact of HIV and AIDS on poor older people by assisting with recurrent household costs, and help reduce the need to sell assets or borrow money. Many older people, especially women, are inclined to spread pension income across households,[51] and research on cash transfer programmes suggests they do not have to target children affected by HIV and AIDS to have a positive impact on their wellbeing.[52] Where targeted schemes already exist, older women may require practical assistance to access their due entitlements.

Provide opportunities for income generation to increase self-sufficiency

Providing opportunities for income-generating activities through start-up grants or microcredit loans can help to increase older women's income and reduce their dependence on external assistance. It is especially useful in households where older people need to rebuild their livelihood following the recovery of a child due to ARV treatment or after their death. Older women who are physically capable express an interest in being involved in such activities. Diversification of activities and ongoing technical support is crucial to ensuring their viability and sustainability. Provision of funds needs to be complemented with financial management training and assistance in developing plans and proposals. Agricultural inputs and training for those in rural areas can increase income and strengthen food security. IGA also have the potential to integrate older carers and their families with other community members. Recent experience in Vietnam indicates older people will repay loans if they receive adequate support, and older people-led groups can be trained to self-manage these processes.

Older women need ongoing psychosocial support

Despite the psychological distress caused by the suffering of an adult child or grandchild and myriad stresses resulting from caring work, formal services that focus on the emotional needs of older carers are lacking. Some older women receive informal support through relatives or neighbours but others are isolated and have nobody with whom they can express their feelings. Training community volunteers (including older people) and respected figures such as monks to provide home visits and counselling specifically to older carers can help them cope with grief and stress, as well as look after family members with emotional and psychological problems of their own. The establishment of peer support groups, where older people in similar circumstances meet to discuss their experiences, can provide further comfort and encouragement, and reduce the isolation and stigma they may experience.

Home-based care policies and programmes must address and integrate their specific needs

Formal home-based care services have the potential to reduce the burden on older women carers, but their distinct needs and concerns are often marginalised by the focus on PLHA and/or OVC. Older carer's socio-economic, health and emotional requirements are just as important as those of the people for whom they provide care. Minimum standards of support for older carers have been developed in Tanzania[53] and these should be adapted and integrated into existing HBC policies and programmes in Cambodia, Thailand and Vietnam. Provisions for the situation of older women carers – their health and literacy challenges, reduced energy and stamina, and income level – should be included in caregiving guidelines.

Provide them with information and training on HIV prevention and care

Some older women received information, and occasionally training, related to HIV and caring work through HBC teams, NGOs or health facilities, but a number of carers said they had received very little or no information. This compromises their ability to provide quality care. Older carers should be targeted with age-appropriate information and materials about HIV prevention and transmission to protect themselves and those in their care from HIV infection. They need further knowledge in providing care and support to PLHA or OVC, and should be encouraged and assisted to attend training sessions and workshops. The rapid increases in ART coverage means older carers also need specific information to support PLHA with adherence, particularly when caring for young children. Older people, including experienced carers, can also play an important role as educators to raise awareness about HIV and AIDS among older people and other affected families.

Collect data and information about older carers of PLHA and OVC

The collation of HIV prevalence data for the age range 15-49 has led to the systematic exclusion of older people in all areas of the HIV response. All HIV-related data should be disaggregated by sex and age (at minimum ten year intervals) with no upper age limit. It is similarly critical that data pertaining to older carers is collected and analysed to ensure that policies and programmes respond appropriately to their needs. Information that is disaggregated by age, sex, location and socio-economic status is needed about the number of households affected by HIV and AIDS; composition of these households; extent of the caring burden (type of care, number of people receiving care, hours spent caring); external support received; household income and expenditure; and income-earning and coping strategies of affected households. Ongoing longitudinal research and data is also required to understand the changing arrangements of households affected by HIV and AIDS, and the impact of caring on older people, PLHA and OVC.[54]

Involve older women carers in programme design, implementation and monitoring

In view of the central role they play in the lives of many PLHA and OVC, older women carers are well placed to contribute to the design, implementation and monitoring of care, support and treatment interventions at household and community level. Older women should be fully included as part of consultations and needs assessments in the development of programmes, and within monitoring and evaluation processes. Older people's groups can help to facilitate the participation of older carers in the implementation of programme activities.

Advocate and raise awareness about the economic, social, emotional and physical impact of caring on older women

There remains a lack of awareness among many communities, policy makers, organisations and governments about the role performed by older women carers and the impact it can have on their life. Awareness and education campaigns, through media, community events, traditional performances, workshops, and seminars, can reduce stigma and discrimination, enhance knowledge, and generate interest in providing older carers with the support and resources they require. The direct participation of older carers in this process may contribute significantly to its success. Awareness-raising can be assisted by the production of advocacy materials such as posters, booklets, brochures, and videos.

Recommendations

All countries

International level

- The UN should ensure that comprehensive reviews in 2008 and 2011 of the progress achieved in realising the Declaration of Commitment on HIV/AIDS, and the 2006 Political Declaration, reflect specifically on commitments made in relation to older carers, especially women. The commitment to achieve universal access to HIV treatment, care and prevention services by 2010 must comprehensively include older people.
- International NGOs, multilateral and bilateral donors should play an influencing role within countries by highlighting the issue of older women carers and financing programs and initiatives that are inclusive of or focus on their needs.
- UNAIDS should review its HIV data collection approaches with the aim of publishing comprehensive HIV prevalence data for women and men of all ages. Prevalence data should be fully disaggregated by sex and age, with data broken down into - at most - ten year intervals and with no upper age limit. UNAIDS should promote the collection of evidence and data on the impact of caring on individuals and households.

National level

- National governments must include older women and men in HIV prevention, care and treatment policies and responses by fulfilling commitments already made to address the needs of older people. In particular, governments must include older people in their efforts to reach Universal Access to Comprehensive HIV Prevention, Care and Treatment services by 2010.
- Governments should design cost and implement social protection measures (including cash transfers and broader protection services) which respond to the needs of older carers, and particularly address the economic burden placed on older women carers who are economically disadvantaged.
- Microfinance institutions need to design credit facilities suitable for older people, and where appropriate, livelihood activities as part of HIV programmes should include affected older people.
- Governments and civil society should increase psychosocial support to older women carers by:
    - o expanding current HIV projects to establish social support networks specifically for carers of PLHA and OVC.
    - o utilising Older Peoples Associations or similar to assist older women carers.
- Governments, civil society and research institutes need to study the implications of improved access to ARV treatment, and the availability of second-line regimens, for older carers.
- Government service providers and civil society should collect and analyse HIV prevalence data for people of all ages and measure the impact of caring on carers and households.
- Governments and civil society should document and share good practice models that are effective in addressing the needs of older carers to advocate for their replication and expansion.

Cambodia

- The National AIDS Authority should ensure that the current revision and extension of the National Strategic Plan (2006-2010) specifies the need to support older people in their role as carers.
- National guidelines on HIV and AIDS programming, OVC and HBC should incorporate strategies for increasing support for all carers, especially older women.
- The National OVC Taskforce should include appropriate support measures for older carers of OVC as part of the plans currently being developed.
- The Ministry of Social Affairs, Veterans and Youth Rehabilitation and Ministry of Economy and Finance should assess the feasibility of introducing a cash transfer scheme for vulnerable older people, with financial support from donors.

Thailand

- The government should ensure adequate resources are allocated to implement the commitment in the National AIDS Plan (2007-2011) to support and raise awareness about affected older people, with specific attention given to older women.
- Government and civil society should sensitise both TAOs and OPAs about the issue of older people and HIV and AIDS, and strengthen their capacity to contribute to the implementation of initiatives that focus on affected older people.
- The government must improve the implementation and monitoring of the Old Age Cash Allowance to ensure that poor older people, particularly those providing care to an adult child or grandchild, receive this benefit.
- The National AIDS Committee should analyse data on the impact of HIV and caring on older people collected through regularly conducted surveys on: older people; children; and people living with disabilities, to inform the national HIV response.
- Government and civil society should use the review of the 2nd Long-term Plan for Older Persons currently being conducted to analyse and respond to the issues faced by older women carers.

Vietnam

- The government should ensure that the role and contribution of older carers, particularly women, is acknowledged and addressed in any revisions/additions to the National Strategy and/or Law on HIV/AIDS.
- The government should allocate sufficient funding in the national HIV response to ensure that family members, including older people, involved in providing care and support to adult children or grandchildren, are provided with adequate and appropriate training.
- The government should include poor older women who are the sole carer of a PLHA or OVC as a direct beneficiary for a regular social allowance.
- Government, civil society and research institutes should collaborate to allocate resources and develop partnerships to support detailed research in Vietnam focusing on the situation of older people affected by HIV and AIDS, particularly older women.
- Government and civil society should ensure that the forthcoming Law on the Elderly includes references and recommendations for action related to the situation of older people, especially women, affected by HIV and AIDS.

Endnotes

[1] Y Teng (2007), 'Living Arrangements Among the Elderly in Southeast Asia', Seminar on the *Social, Health and Economic Consequences of Population Ageing in the Context of Families*, UNESCAP

[2] United Nations (2002), *Political Declaration and Madrid International Plan of Action on Ageing*, Second World Assembly on Ageing

[3] United Nations General Assembly Special Session on HIV/AIDS (2001), *Declaration of Commitment on HIV/AIDS*, p.31

[4] UNGASS (2006), *Political Declaration on HIV/AIDS*, Resolution adopted by the General Assembly, p.5, URL: http://daccessdds.un.org/doc/UNDOC/GEN/N05/503/32/PDF/N0550332.pdf?OpenElement

[5] HelpAge International, *Ageing and Development*, August 2006

[6] J Cabassi (2004), *Code of Good Practice for NGOs Responding to HIV/AIDS*, The NGO HIV/AIDS Code of Practice Project. URL: www.ifrc.org/what/health/hivaids/code/

[7] J Knodel (2006), 'Parents of Persons with AIDS: Unrecognized contributions and unmet needs', *Global Ageing: Issues and Action*, August, p.49

[8] For full analytical framework, see Figure 1 in J Knodel (2006), *Poverty and the Impact of AIDS on Older Persons: Evidence from Cambodia and Thailand*, Research Report, Population Studies Center, p.26. URL: http://www.psc.isr.umich.edu/pubs/pdf/rr06-597.pdf

[9] Cited in P Lloyd-Sherlock (2006), 'Identifying vulnerable older people: insights from Thailand', *Ageing and Society*, 2006: 81-103, p. 98

[10] M Kelly (2006), *HIV and AIDS: A Justice Perspective*, Jesuit Centre for Theological Reflection.

[11] J Knodel (2006), op. cit

[12] J Ogden, H Khuat, and A Nguyen (2004), *Understanding HIV and AIDS-related stigma and discrimination in Vietnam*, International Center for Research on Women, p.20

[13] F Samuels and S Simon (2006), *Food, Nutrition and HIV: What next*, Briefing Paper, Overseas Development Institute, p. 2

[14] S Russell, J Seeley, E Ezati, N Wamai, W Were, and R Bunnell (2007), 'Coming back from the dead: living with HIV as a chronic condition in rural Africa', *Health Policy and Planning*, 22: 344-347

[15] J Knodel, Z Zimmer, K Kiry and P Sina (2007), 'The Effect on Elderly Parents in Cambodia of Losing an Adult Child to AIDS', *Population and Development Review* 33(3): 479-500, p.496

[16] M Khan and M Lee (2007), 'How does HIV/AIDS Affect the Elderly in Developing Countries', *Today's Research on Aging*, Issue 6, Population Reference Bureau, p.3

[17] Secretariat of the National Committee for Population and Development, Office of the Council of Ministers (2007), *Population Ageing in Cambodia: Planning for Social Protection*, UNFPA

[18] J Knodel, et. al (2007), op. cit, p.486

[19] J Knodel and Z Zimmer (2007), 'Older Persons' AIDS Knowledge and Willingness to Provide Care in an Impoverished Nation', *Asia-Pacific Population Journal* 22(1): 11-28

[20] Joint United Nations Team on HIV/AIDS (2006), *United Nations HIV/AIDS Joint Support Programme 2006-2010 Cambodia*, p.19

[21] M Buhler, D Wilkinson, J Roberts, and T Catalla Jr (2006), *Turning the Tide: Cambodia's Response to HIV & AIDS 1991-2005*, National AIDS Authority, p.68

[22] National AIDS Authority (2005), *A Situation & Response Analysis of the HIV/AIDS Epidemic in Cambodia*, p.13

[23] National Center for HIV/AIDS, Dermatology and STDs (2007), *Second Quarterly Comprehensive Report 2007 – HIV/AIDS & STI Prevention and Care Programme*, Ministry of Health

[24] UNESCAP, UNDP, and ADB (2007), *Achieving the Health Millennium Development Goals in Asia and the Pacific: Policies and Actions within Health Systems and Beyond*, Asia-Pacific MDG Study Series

[25] C Badloe, J Flanagan, R Gore, T Hozumi K Imhof and P So (2007), *Universal Primary Education: Reaching the Unreached in Cambodia*, UNICEF East Asia and the Pacific

[26] HelpAge International - Cambodia (2007), *Older people's understanding of HIV: knowledge, attitudes and belief survey*

[27] UNFPA Thailand (2006), *Population Ageing in Thailand: Prognosis and Policy Response*, p.4

[28] J Knodel and C Saengtienchai (2002), *AIDS and Older Persons: The View from Thailand*, Population Studies Center

[29] Calculations are based on people aged 50 and above, in B Dodge and U Khiewrord (2005), *Coping with Love: Older People and HIV/AIDS in Thailand*, HelpAge International

[30] United Nations Development Programme (2004), *Thailand's Response to HIV/AIDS: Progress and Challenges*

[31] L Photiban, S Panuthai, and W Puengchompoo (2006), *HIV/AIDS and Older Persons in Northern Thailand: Development of a Model Package for Enhancing the Quality of Life of HIV/AIDS Affected Older Persons*, Faculty of Nursing – Chiang Mai University

[32] W Kosolpisitkul, 'Non-Contributory Social Pensions for Older Poor: Thailand's Experience' - Presentation to *'Social Cash Transfers for Asia' seminar*, 29 January 2007

[33] Country Development Partnership for Social Protection - Thailand (2006), *Issues and Directions for Social Protection*, p.20

[34] HelpAge International (2007), *Social cash transfers for Asia: Ensuring social protection/social pensions in old age in the context of rapid ageing*, p.13

[35] East Asia and Pacific Regional Consultation on Children and HIV/AIDS (2006), *Country Report: Thailand*

[36] Also referred to as 'Elderly Clubs' in Thailand

[37] L Photiban, S Panuthai, and W Puengchompoo (2006), op. cit

[38] Data collected from 2004 Viet Nam Household Living Standards Survey in M Evans, I Gough, S Harkness, A McKay, T Huyen, and T Ngoc (2007), *The Relationship Between Old Age and Poverty in Viet Nam*, UNDP Vietnam

[39] Calculated from figures in Country Statement – Vietnam (2007), Seminar on the *Social, Health and Economic Consequences of Population Ageing in the Context of Families*, UNESCAP

[40] Ministry of Labour, Invalids and Social Affairs and UNICEF (2005), *The Situation of Families and Children Affected by HIV/AIDS in Vietnam: A National Overview*

[41] UNDP (2005), *Impact of HIV/AIDS on household vulnerability and poverty in Viet Nam*

[42] K Green, K Ly, and K Luong (2006), *Palliative Care in Vietnam: Findings from a Rapid Situation Analysis in Five Provinces*, Ministry of Health and FHI

[43] Ministry of Health (2006), *Law on HIV/AIDS Prevention and Control*, Health Legislation Department, p.27

[44] K Green et. al (2007) op. cit

[45] Government of Vietnam (2007), *Decree No.67/2007/ND-CP of April 13, 2007 on Support Policies for Social Protection Beneficiaries*

[46] M Evans et. al (2007), op. cit, p.16

[47] VietnamNet (2007), 'A third of nation's AIDS patients treated with antiretroviral drugs'

[48] UNESCAP, UNDP, and ADB (2007), op. cit

[49] UNDP (2005), op. cit

[50] UNDP (2005), *User Fees, Financial Autonomy, and Access to Social Services in Vietnam*, p.39

[51] A Barrientos and P Lloyd-Sherlock (2002), *Non-contributory pensions and social protection*, Issues in Social Protection: Discussion Paper 12, International Labour Office

[52] Working Group on Social Protection (2007), *Cash Transfers: Real benefit for children affected by HIV and AIDS*, Inter-Agency Task Team on children and HIV and AIDS

[53] HelpAge International Tanzania (2007), *Building bridges: a model for supporting older carers of people living with HIV/AIDS in Tanzania*

[54] C Miller (2006), *Counting Carers: How to improve data collection and information on households affected by AIDS and reduce the poverty of carers, people living with HIV and vulnerable children*, HelpAge International

Further Reading

Global Coalition on Women and AIDS (2006), *Support Women Caregivers: Fight AIDS*. URL: http://data.unaids.org/Publications/IRC-pub07/JC1279-GCWA-5_en.pdf

J Ogden, C Esim and C Grown (2004), *Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus*, International Center for Research on Women

International HIV/AIDS Alliance and HelpAge International (2003), *Forgotten families: older people as carers of orphans and vulnerable children*

HelpAge International (2006), *Counting Carers: How to improve data collection and information on households affected by AIDS and reduce the poverty of carers, people living with HIV and vulnerable children*

HelpAge International (2005), *Coping with Love: Older People and HIV/AIDS in Thailand*

HelpAge International (2004), *The Impact of HIV/AIDS on Older People in Cambodia*

HelpAge International (2003), *HIV/AIDS and Ageing: A Briefing Paper*

A Mehta and S Gupta (2005), *The Impact of HIV/AIDS on Women Care Givers in Situations of Poverty: Policy Issues*, Indian Institute of Public Administration and UNIFEM

Population Council (Research Project), *Impact of AIDS, Poverty, and Social Upheaval on the Elderly: The Case of Cambodia*. Publications at: http://www.popcouncil.org/projects/SS_CambodiaAIDSImpactRI.html

Population Studies Center (*Research Project*), *The Impact of the AIDS Epidemic on Older Persons (with a focus on Thailand)*. Publications at: http://aidseld.psc.isr.umich.edu/

Save the Children UK, HelpAge International and Institute of Development Studies (2005), *Making cash count: Lessons from cash transfer schemes in east and southern Africa for supporting the most vulnerable children and households*

E Schatz and C Ogunmefun (2007), 'Caring and Contributing: The Role of Older Women in Rural South African Multi-Generational Households in the HIV/AIDS Era', *World Development* 35(8): 1390-1403

VSO (2006), *Reducing the Burden of HIV & AIDS Care on Women and Girls*, Policy Brief

Website

Research Network on HIV/AIDS and the Elderly

http://agingaidsnet.psc.isr.umich.edu/

HelpAge International's publications are available free to download or can be ordered from our website:

www.helpage.org

Committed to Caring
Older Women and HIV & AIDS in Cambodia, Thailand and Vietnam

HelpAge International Asia/Pacific
6, Soi 17 Nimmanhemin Road
Suthep, Muang
Chiang Mai 50200 Thailand
Tel: +66 53 225 440
Fax: +66 53 225 441
Email: hai@helpageasia.org

HelpAge International
PO Box 32832
London N1 9ZN, UK
Tel: +44 20 7278 7778
Fax: +44 20 7713 7993
Email: hai@helpage.org

www.helpage.org

HelpAge International

Leading global action on ageing

www.helpage.org