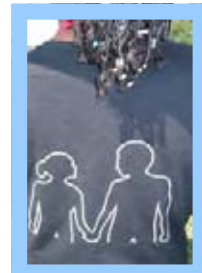
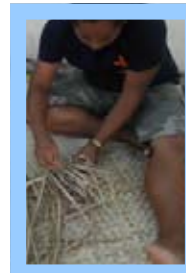
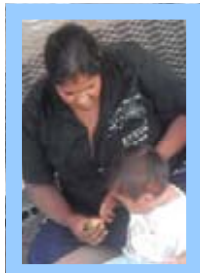


# Experiences and Perspectives of Women Living with HIV in Fiji and Papua New Guinea



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# Experiences and Perspectives of Women Living with HIV in Fiji and Papua New Guinea

## A Qualitative Study



## DEDICATION

In January 2011 one of Papua New Guinea's national daily newspapers printed an article titled "Women beats odds to reveal HIV status." The article tells this story:

A young woman from a village in the Trobriand Islands in Milne Bay braved all odds to be the first woman in her community to come out and declare her HIV/AIDS status in the hope of raising awareness against the epidemic. Lucy Kwemwai, a young mother of two, spoke of her experience last Christmas during an awareness programme at the village.... Kwemwai said she had contracted the virus from her husband but she did not know until after the birth of their children. She said her first child is also HIV positive. Her husband then divorced her because he blamed her for infecting their baby with HIV. Meanwhile, Kwemwai is currently admitted at the Losuia health centre seeking medical treatment. She is also the first PLWHA on the island to receive anti-retroviral treatment (ART) as there is a short supply of this important drug for the people there. (Wrakule, The National, January 12, 2011).

Sadly in the end Lucy was unable to beat the odds and passed away before the news article went to press.

The stories of the women featured in this report are similar to Lucy's story in many ways. Many other women living with HIV in Papua New Guinea, Fiji and other countries in the Pacific Islands region face similar situations and have also suffered from the effects of gender inequality, poverty and stigma and discrimination. This report is dedicated to the women living with HIV who shared their life experiences and perspectives.

---

## ACKNOWLEDGEMENTS

This study was made possible by the HIV-positive women in Fiji and Papua New Guinea who bravely and kindly agreed to share their experiences and perspectives. Thank you for sharing your stories, they help to shed light on the issues of HIV and gender inequality.

This study was born out of the vision of Maire Bopp, who for many years has advocated that there is a great need to know more about the experiences of HIV-positive women in the Pacific and better understand the ways in which gender inequality impacts upon vulnerability to HIV.

### **Lead researcher and author**

The tasks of collecting the stories of HIV-positive women through fieldwork in Fiji and Papua New Guinea, compiling and analyzing the data, and developing, writing, revising and editing the report were carried out by Hilary Gorman the Research Officer of the Pacific Island AIDS Foundation (PIAF).

### **Collaboration and support**

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### **Design, lay-out and editing**

Design and lay-out of the report was completed by Salome Vincent, Communications Officer, PIAF. Copyediting was completed by Wendy Evans.

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## LIST OF ACRONYMS

ANC	Antenatal care
ART	Antiretroviral therapy
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
FJN+	Fiji Network for People Living with HIV
IDU	Injection drug use
MSM	Men who have sex with men
NGO	Non-government organization
PIAF	Pacific Islands AIDS Foundation
PLHIV	People living with HIV
SPC	Secretariat of the Pacific Community
STI	Sexually transmitted infection
UNDP	United Nations Development Programme
VCCT	Voluntary confidential counselling and testing

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## EXECUTIVE SUMMARY

This study focuses on the experiences and perspectives of HIV-positive women living in Fiji and Papua New Guinea. The purpose of the study is to give voice to women living with HIV and to allow their stories and views to inform an improved HIV response where the dignity of each and every woman and man is respected and protected.

By paying attention to the experiences of these Pacific women, whose lives were dramatically changed on the day when they found out that they were HIV-positive, this study expands upon the knowledge and data on HIV in the Pacific Islands region.

### Study Objectives

The Pacific Islands AIDS Foundation (PIAF) initiated this study in 2008 as a means of mobilising women's groups and women's rights activists, first and foremost because PIAF believes that it is time for women to take more ownership of the HIV response. This study also aims to mobilize decision-makers, health care workers, churches and community groups by providing them with recommendations to direct actions aimed at improving the life conditions of our Pacific women, mothers and grandmothers. The absence or inadequacy of support will continue to expose more and more of our people to HIV and limit the hopes of HIV-positive Pacific women to gain or regain a sense of happiness, dignity and peace.

The key objectives of this study are to:

1. Explore the experiences of HIV-positive women in Fiji and Papua New Guinea;
2. Understand the impact of past and current prevention, treatment, care, and support programs on the lives of

HIV-positive women;

3. Explore the impact of gender inequality in shaping the experiences of HIV-positive women;
4. Develop recommendations to support advocacy for changes in policies, practices and programs to support the needs and rights of HIV-positive women and ultimately improve their lives as well as preventing the further spread of HIV.

### HIV in the Pacific

The Pacific Islands region reported 33,424 HIV cases as of the end of 2009 - 96% (32,005 cases) of the reported cases were in Papua New Guinea. HIV cases in New Caledonia, Fiji, French Polynesia and Guam account for the majority of the rest of the cases in the region.<sup>1</sup> Unprotected sex is the primary mode of transmission of HIV in the Pacific Islands region.

Following the global trend, men in the Pacific region (excluding Papua New Guinea) make up the majority of the HIV cases, while the cases among women are steadily rising. Papua New Guinea has followed this trend and there were initially more cases among men. However, since 2003 the number of new cases has been consistently higher amongst women – reaching a male to female ratio of 0.8:1. Some of the increase among females is likely due to increased HIV testing at antenatal clinics.

Factors that have been facilitating the spread of HIV in the Pacific Islands region include:

- High rates of unprotected premarital sex among Pacific youth;

<sup>1</sup> The latest figures on HIV can be found at the Secretariat of the Pacific Community website. See: [http://www.spc.int/hiv/index.php?option=com\\_docman&task=cat\\_view&gid=108&Itemid=148](http://www.spc.int/hiv/index.php?option=com_docman&task=cat_view&gid=108&Itemid=148)

- High rates of sexually transmitted infections which often go untreated;
- Unprotected male-to-male sex and commercial sex that is highly stigmatized and often illegal;
- High rates of migration and mobility within and between countries and
- Substantial gender inequalities.

Women's vulnerability to HIV is heightened where gender inequality, harmful cultural traditions, limited economic choices, violence against women, restrictive gender ideals and sexual double standards prevail. These issues also influence the experiences of HIV-positive women.

PIAF used a qualitative approach to explore the experiences of HIV positive women and gain a deeper understanding of their lives. Twenty-five HIV-positive women were interviewed, 8 in Fiji and 17 in Papua New Guinea. Participants were recruited through positive support networks and NGOs offering support to people living with HIV (PLHIV). In Fiji, interviews were conducted in urban centres and towns on the main island of Viti Levu. In Papua New Guinea, they took place in Port Moresby, Milne Bay Province and Southern Highlands Province. Interviews were semi-structured yet informal, and were recorded, transcribed and analyzed by theme.

## Study Findings

### Perceptions about Women and HIV and PLHIV

- The participants attributed women's HIV risk and vulnerability to either shifting social and sexual practices or gender inequalities particularly in marriage. They also alluded to the idea that women tend to be blamed for HIV

transmission.

- The participants demonstrated two opposing attitudes about PLHIV. These were an "existing attitude" that was formed before treatment became available and is rooted in fear and stigma; and an "emerging attitude" that included notions of human rights and the idea that HIV is a chronic manageable illness.

### Diagnosis and Disclosure

- Frequent illness experienced by the women, their husbands or children was the main reason that drew the women to have an HIV test.
- Shock, disbelief, sadness, fear, anger and shame were the immediate reactions that the women had post-diagnosis. The future of their children and the reactions of their families were their main concerns after diagnosis.
- Pre and post-test counselling was provided to only a few women. Some women were tested without their consent.
- Disclosure extended to the public (four women), their community (ten women), their family only (seven women), a friend (one woman), and three women disclosed to no one.
- Reactions post-disclosure varied between immediate support, subtle discrimination, and social as well as physical isolation imposed by family members and the community.

### Treatment and Health Services

- Antiretroviral therapy (ART) was described as greatly improving the health and quality of life of the participants and assisting a number of them to have HIV-negative children, although

the side-effects of ART are difficult to overcome.

- Distance and cost associated with travelling to clinics were noted as the key barriers to accessing health services - this was true for women living in cities and suburban areas, but especially for those who lived in isolated locations.
- Health workers can have a positive influence particularly for women who have no one else to support them but they have a negative impact when they are not sympathetic or discriminate. Breaches of confidentiality were the most common form of discrimination by health workers.
- The women suggested several areas where health services could be improved including steady access and provision of treatment (ART); systems that would allow patients to register at different clinics; and wider promotion of PLHIV support networks.

### **Stigma and Discrimination**

- Self-stigma is intense – the participants felt that they would be blamed and judged more harshly than men. Self-stigma prevented women from socializing, going out in public, looking for a job and often led to women isolating themselves further.
- Discrimination from families and community members ranged from subtle actions such as gossip to outright physical isolation.
- Family members, friends and male partners were sources of support which aided women to cope with HIV. Support from NGOs and PLHIV networks in particular helped them to get on with their lives.

### **Motherhood and HIV**

- Women still wanted to have children or more children in spite of their HIV status. Many participants expressed confusion as to whether or not they could have an HIV-negative child.
- Being HIV-positive was an extra burden the women faced in addition to poverty and being a single mother.
- Seven women had had HIV-positive children – many of whom had passed away.
- Mothers who had lost their child(ren) often received limited or no support.
- Mothers and female partners living with HIV were usually the caregivers of their children and husbands.

### **Relationships, Violence, Sex and Condoms**

- Many of the women lost their husband or partner to AIDS (10 of 20 women in a relationship) or separated after they were diagnosed (5 of 20 women in a relationship).
- Infidelity of the male partners was the norm (19 of 20 women in a relationship).
- Among couples, women tended to be blamed and viewed as the source of the infection.
- Violence including sexual violence from their male partners appeared to be common (18 of 20 women in relationships experienced violence).
- Violence from male partners was often triggered by jealousy, men's infidelity, men wanting sex against their partner's wishes and anger associated with an HIV diagnosis.
- Condom usage was reported to be rare due to male dominance and men's preference not to use them.
- Condom-use was also influenced by

- the perceived association between condoms and sex work, religious opposition and as a result of poor understanding of condom usage.
- Confusion and concern were expressed by the women as they stated their views on having relationships in the future. Many of them felt that they ought to remain single. Disclosure to current and potential partners, condom-use and social non-acceptance of sero-discordant relationships were common concerns.<sup>2</sup>

### Key Recommendations

To reduce self-stigma and increase the effectiveness of HIV prevention messages:

- All agencies and organisations involved in the HIV response in the Pacific, as well as the media, should ensure that they promote messages about HIV that are culturally appropriate, gender sensitive and do not perpetuate stigma towards PLHIV.

To create an enabling environment where the rights of women and PLHIV are recognized:

- In Pacific Island countries and territories (PICTs) without HIV specific protective legislation, governments should introduce the required laws and policies based, as appropriate, on legislation adopted in other PICTs.
- Legal literacy programmes should be conducted to improve awareness of laws and policies, rights and responsibilities particularly amongst PLHIV.
- Strategies to reduce gender-based violence should be integrated with HIV interventions to strengthen laws and policies to protect women.

To assist HIV-positive women in dealing with self-stigma:

- Increase awareness and understanding of "self-stigma" amongst counselors by providing them with training to ensure that they can recognize self-stigma and the potentially different impacts it has on women and men.

To help HIV-positive women to live healthy and happy lives:

- Promote human rights-based approaches to HIV – to ensure that their rights to sexual and reproductive health services, to have children and have relationships are equally accessible to women who are HIV-positive.
- Promote ART as a means of broadening the reproductive options of women living with HIV.

To increase understanding of the rights of PLHIV and support efforts to reduce further transmission of HIV:

- Promote the concept of rights and responsibilities of PLHIV during sessions and training amongst PLHIV, counselors and other stakeholders.

To address the impact of gender inequality on women's vulnerability to HIV and the negative impact that it has on the lives of HIV-positive women:

- Scale up programs that encourage "community conversations", dialogue and consensus building at the local level as a means to address harmful gender norms, gender inequality, use of drugs and alcohol and violence, and thus promote sexual health and healthy relationships.<sup>3</sup>

<sup>2</sup> A sero-discordant relationship is where one partner is HIV-positive and the other is HIV-negative.

<sup>3</sup> For example, the Stepping Stones program which is being implemented in the Pacific by the Foundation of the People's of the South Pacific International. Information about this program is available at <http://www.fsipi.org.fj/index.php/stepping-stones.html> See Reid (2010) for discussion of the "community conversations" approach in Papua New Guinea.

# CHAPTER 1.

## INTRODUCTION

Agnes<sup>4</sup> is a Papua New Guinean woman in her mid-twenties. Both Agnes and her five-year-old son are HIV-positive. She struggles to maintain their health and provide for her son – she is softly spoken and has a sad demeanour and seems tired and worn out. Agnes has a grade four education. As a young woman she moved to Mount Hagen where she lived with her relatives and sold cooked food at the market. At the age of 19 she met her husband, she soon fell pregnant and they were married. While she was receiving antenatal care, she was informed that she was HIV-positive. At the time treatment to prevent mother-to-fetus transmission was unavailable in many parts of the Pacific including Papua New Guinea and Agnes's son was born HIV-positive. When Agnes informed her husband that she was HIV-positive, he did not believe her and refused to get tested. Shortly after she gave birth her husband took another wife, which led to conflict in their relationship.

Agnes then decided that she wanted to move with her son to her hometown, as the child was unwell. At first her husband did not allow her to move and then later changed his mind. Agnes and her husband separated. She described how her life then changed:

*We used to argue, and fight a lot. But when I left him, and I came and I'm staying here, and I feel that nobody is bothering me (anymore). When I was with my husband, like he bossed me (around), he bossed me to do things... I must always listen to*

*him but him he won't listen to me. So when I left him and I came here... I'm free. I can do what I want to do.*

Agnes's marital situation exemplifies the impact of gender inequality in marriage – her husband dominated the relationship and there was a lack of mutual respect.

At home, Agnes lived with her sister's family. Soon after arriving she visited the local health clinic and both she and her son were put on ART. Yet they were both frequently ill with tuberculosis and malaria.<sup>5</sup> Furthermore, she chose not to disclose her status to her family as she feared their reaction. Although Agnes lived with her family and received some financial support from them, emotionally, she was isolated. She said:

*Before, I used to enjoy. I (would) go and walk around with my friends. But now, I'm not interested in walking around and talking to my friends. When I see them I feel shy to talk to them. But then later I said (to myself) I mustn't do that. I must talk to them and, make myself like I'm normal.*

When Agnes said "like I'm normal", she meant that she must make it seem as though she was HIV-negative. When asked what she wanted for the future, she stated, "I'm trying my best to market...market and support myself. That's my aim." In other words, she wanted to gain economic independence.

<sup>4</sup> Pseudonyms are used throughout this report to protect the identities of the participants. In some cases identifying factors have also been omitted.

<sup>5</sup> This occurs frequently among HIV-positive people in Papua New Guinea. For further discussion on this issue see Chapter 8 in Hammar's book *Sin, Sex and Stigma: A Pacific Response to HIV and AIDS* (2010).

Agnes's story embodies many of the issues that women living with HIV face: fear of rejection upon disclosure to family and friends; insufficient access to ART to prevent parent to child transmission; dealing with chronic illness; social isolation experienced by many PLHIV; the difficulties of raising and caring for an HIV-positive child; the impact of HIV upon intimate partnerships especially between husband and wife; and deep-rooted norms and forms of gender oppression. This report focuses on the experiences and perspectives of women living with HIV in Fiji and Papua New Guinea to better understand women like Agnes.

Studies focused on HIV in the Pacific briefly discuss women's vulnerability to HIV (Buchanan-Aruwafu, 2007; Jenkins, 2005; Commission on AIDS in the Pacific, 2009) yet these works pay little attention to the lived experiences of HIV-positive women. A UNDP, UNIFEM and Secretariat of the Pacific Community (SPC) sponsored study titled *Gender and HIV in the Pacific Islands Region: A literature review of evidence and recommendations* discusses the issue of gender and HIV in greater depth. This report states that regional studies have failed to "sufficiently emphasize that unequal gender relations is one of the most significant factors in the spread of HIV and cross-cuts almost all other factors driving the epidemic" (UNDP, 2009, p. 38). In the edited volume titled *Making Sense of AIDS: Culture, Sexuality, and Power in Melanesia* several chapters examine the relationship between HIV and gender inequality (Eves & Butt, 2008). Yet in the introduction of this volume Eves and Butt acknowledge that the accounts they present are not "derived from people who have direct experience of AIDS" and that this is an important area

for future research (p. 5).

Research focusing on the experiences of PLHIV in the Pacific is limited. PIAF has produced a study focused on *HIV and AIDS-Related Stigma and Discrimination: Perspectives of HIV-Positive People in the Pacific* (2009). A report titled *The art of living: the social experience of treatments for people living with HIV in Papua New Guinea* was recently produced by the Papua New Guinea Institute of Medical Research and the University of New South Wales (Kelly et al., 2009). Within this study they noted that "there has been no published social research on people with HIV in Papua New Guinea to date" (p. 16). UNDP produced a study titled *MDG 3 and 6: What do they say?* that looked at the experiences of HIV-positive women through focus group discussions held with 135 women living with HIV in India, Papua New Guinea, and the Philippines (UNDP, 2010). Labbé (2011) conducted research focused on the experiences of HIV-positive people in Fiji, including 17 women and 11 men. Yet, to date, there are no studies that focus specifically on the experiences of HIV-positive women in the Pacific Islands within the context of gender inequality.



The lives of HIV-positive women in different countries and regions of the world have been studied through various methods.

These studies have examined the women's experiences of:

- **stigmatization** through interviews with 27 HIV-positive Australian women (Lawless, Kippax, Crawford, 2002);
- **sexual and reproductive health** through 209 demographic health surveys, 59 in-depth interviews and community workshops with HIV-positive Zimbabwean women (Feldman, Manchester & Maposhere, 2002);
- **sexual and reproductive health** through 329 socio-demographic surveys and 60 in-depth interviews with HIV-positive Thai women (ICW, 2004);
- **life and survival** through interviews with 62 HIV-positive African women living in the United Kingdom (Doyal & Anderson, 2006);
- **stigma** through in-depth interviews with 10 HIV-positive women in a poor black township in Cape Town, South Africa (Rohleder & Gibson, 2006);
- **sexual and reproductive health** through 93 in-depth interviews and 11 focus group discussions with HIV-positive Brazilian, Ethiopian and Ukrainian women and their male partners (EngenderHealth & UNFPA, 2006);
- **motherhood** through interpretative phenomenology and ethnography with 24 HIV-positive Brazilian mothers (Monticelli, dos Santos & Erdmann, 2007);
- **desire for motherhood** through in-depth interviews with 43 HIV-positive Indian women (Kanniappan, Jeyapaul & Kalyanwala, 2008);
- **access to services** through questionnaires administered to 1,306 HIV-positive

women and 38 focus group discussions with HIV-positive Cambodian, Chinese, Indian, Indonesian, Thai and Viet Nam-ese women (APN+, 2009);

- **reproductive dilemmas** through interviews with 13 HIV-positive Vietnamese women who had induced abortions (Chi, Hnh, Rasch & Gammeltoft, 2009);
- **ART adherence** through interviews with 47 HIV-positive Zambian women receiving ART (Murray et al., 2009);
- **stigma and support groups** through in-depth interviews with 26 HIV-positive Thai women (Liamputtong, Haritavorn & Kiatying-Angsulee, 2009); and
- **pregnancy decisions** through in-depth interviews with 22 HIV-positive women and focus group discussions with 45 HIV-positive Ugandan women receiving antenatal care (Kisakye, Akena & Kaye, 2010).

These works offer extensive insights into the lives of HIV-positive women, and in most cases use qualitative methods to study the experiences of a small number of HIV-positive women.

HIV is often said to have arrived late in the Pacific (Eves & Butt, 2008) and prevalence rates in most countries are low compared to other regions. Perhaps this is part of the reason why the experiences of HIV-positive women in the Pacific have not been explored. Study of the experiences of HIV-positive men and masculinities are important to understand their experiences and how they are affected by gender norms. Yet the complex and multifaceted ways in which gender inequality and discrimination against women heighten women's HIV risk and vulnerability have not been adequately considered in the Pacific HIV re-



sponse (UNDP, 2009). Sharing the stories and giving voice to HIV-positive women is an ideal means to understand how to address gender inequality within the Pacific HIV response.

### Study Objectives

This study of the lives of HIV-positive women in Fiji and Papua New Guinea aims to use their experiences and perspectives to explore the connection between HIV and gender inequality. A qualitative approach was used to gain a deeper understanding of the participants' lives. Twenty-five in-depth interviews were conducted with 8 HIV-positive women in Fiji and 17 in Papua New Guinea. This report will demonstrate in no uncertain terms the impact of gender inequality on the lives of HIV-positive Pacific women. Particular attention is paid to their experiences of being influenced by ideas about HIV, diagnosis and disclosure, treatment and care, stigma and discrimination, motherhood, and relationships and vio-



lence. The Pacific Islands AIDS Foundation believes that understanding the realities of HIV-positive women can inform actions, not only to improve the rights of HIV-positive women, but also to prevent the further spread of HIV.

The Pacific Islands AIDS Foundation (PIAF) initiated this study in 2008 as a means of mobilising women's groups and women's rights activists, first and foremost because PIAF believes that it is time for women to take more ownership of the HIV response. This study also aims to mobilize decision-makers, health care workers, churches and community groups by providing them with recommendations to direct actions aimed at improving the life conditions of our Pacific women, daughters, mothers and grandmothers. The absence or inadequacy of support will continue to expose more and more of our people to HIV and limit the hopes of HIV-positive Pacific women to gain or regain a sense of happiness, dignity and peace.

The key objectives of this study are to:

1. Explore the experiences of HIV-positive women in Fiji and Papua New Guinea;
2. Understand the impact of past and current prevention, treatment, care, and support programs on the lives of HIV-positive women;
3. Explore the impact of gender inequality in shaping the experiences of HIV-positive women;
4. Develop recommendations to support advocacy for changes in policies, practices and programs to support the needs and rights of HIV-positive women and ultimately improve their lives as well as preventing the further spread of HIV.

**Structure of the Report**

This study focused on the experiences of HIV-positive women as well as the broader issues of HIV and gender inequality in the Pacific. Chapter 2 provides an overview of the literature on HIV, gender inequality, and women and HIV in the Pacific Islands region. Chapter 3 describes the project methodology. Chapter 4 sections 4.1 to 4.6 describe the experiences of study participants. Chapter 4 section 4.1 explores the women's ideas about HIV, specifically their perceptions about women and HIV and their views of PLHIV. Section 4.2 focuses on their experiences of being diagnosed HIV-positive and the women's views and experiences in disclosing their status to their partners, family, friends and communities. Section 4.3 explores the women's experiences of using health services, particularly their experiences of treatment. Section 4.4 describes the women's experiences of living with HIV, with a focus on stigma and discrimination, coping and support. Section 4.5 examines issues related to HIV and motherhood, such as their experiences and desires related to having children and care giving. Section 4.6 focuses on the issues of how women deal with HIV in their various relationships, with violence, with use of condoms during sex and what their ideas and expectations are regarding future relationships. The end of each section of Chapter 4 includes a summary of key findings and specific recommendations related to each aspect of participants' experiences. Lastly, Chapter 5 concludes the report.

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## CHAPTER 2.

# LITERATURE REVIEW OF WOMEN AND HIV IN THE PACIFIC

### HIV in the Pacific

This chapter provides background information about HIV in the Pacific and reviews literature on HIV and gender inequality in the Pacific.

The Pacific is a diverse region With many languages and considerable variation in terms of culture, ethnicity, population, geography, politics, and level of economic development. The Pacific is divided into three sub-regions: Melanesia, Micronesia and Polynesia. There are 22 Pacific Island Countries and Territories (PICTs). As of December 2009 there were 33,424 reported cases of HIV among all of the PICTs. The number of HIV cases varies by sub-region and country. With 32,005 reported cases, Papua New Guinea accounts for 96% of the HIV cases found within the Pacific Islands region.<sup>6</sup>

Other countries in the region are classified as having low prevalence. As shown in Table 1, the majority of the rest of the cases are found within four Pacific island countries, Fiji, New Caledonia, French Polynesia and Guam, which account for 84% of Pacific HIV cases excluding those found within Papua New Guinea (SPC, 2010b). This could be attributed to the fact that these countries have larger populations and, in the French and American territories, possibly more testing takes place (SPC, 2010b). Other factors such as migration to France and the United States and the presence of

military bases may also have played a role in increasing transmission of HIV in these territories (Buchanan-Aruwafu, 2007).

There are several reasons why we must be cautious in drawing conclusions based on the number of reported cases in Pacific Island countries. First, inadequate surveillance systems may have led to under-reporting and under-estimating the number of HIV-positive people (Commission on AIDS in the Pacific, 2009; Sladden, 2005). Second, voluntary confidential counselling and testing (VCCT) services tend to be limited to centralized locations and concerns about confidentiality may deter people from getting tested in smaller countries and communities (Commission on AIDS in the Pacific, 2009; Sladden, 2005). Third, selective testing for example among MSM or sex workers may obscure the data on routes of transmission (UNDP, 2009). Fourth, routes of transmission may also be misreported as heterosexual due the stigma associated with male-to-male sex (UNDP, 2009). Fifth, Pacific people may also be seeking testing and treatment overseas (Sladden, 2005). Lastly, although Papua New Guinea has a more extensive reporting system the evidence is not comprehensive (see Hammar, 2010).

It is also important to note that recently there has been speculation that the rates of transmission in Papua New Guinea have begun to decrease and are not rising as was predicted (Toole, 2010). In sum, the

<sup>6</sup> There are different numbers for the total cumulative cases for Papua New Guinea, depending on which method is used to report the cases. According to "Data Previously Reported and Obtained from Case Reporting Forms and Data Collector's Workshop" the total is 32,005. According to the "Data In Current NDoH (National Department of Health) Database Obtained only from Case Reporting Forms" the total is 27,041 reported cases (see Papua New Guinea National Department of Health, 2010, p. 14).

Table 1: HIV in the Pacific to December 2009

Country/ Region	Mid year Population 2009	New cases 2009	Cumulative HIV cases	HIV Cases by Gender			HIV Cumulative Incidence Per 100,000
				Male	Female	Unknown	
<b>Melanesia</b>	<b>8,478,155</b>	<b>3,768</b>	<b>32,700</b>	<b>14,229</b>	<b>17,100</b>	<b>1,314</b>	<b>385.7</b>
<b>Melanesia* (Excluding PNG)</b>	<b>1,868,409</b>	<b>57</b>	<b>695</b>	<b>417</b>	<b>276</b>	<b>2</b>	<b>37.2</b>
Fiji Islands	843,888	43	333	181	152	0	39.5
New Caledonia	250,612	13	344	230	112	2	137.3
Papua New Guinea	6,609,746	3,711	32,005	13,815	16,878	1,312	484.2
Solomon Islands	535,007	1	13	4	9	0	2.4
Vanuatu	238,903	0	5	2	3	0	2.1
<b>Micronesia</b>	<b>539,439</b>	<b>9</b>	<b>352</b>	<b>257</b>	<b>90</b>	<b>5</b>	<b>65.3</b>
Fed. States of Micronesia	110,899	1	37	24	13	0	33.4
Guam	182,207	4	196	166	30	0	107.6
Kiribati	98,989	0	52	33	19	0	52.5
Marshall Islands	54,065	3	22	8	10	4	40.7
Nauru	9,771	0	2	2	0	0	20.5
Northern Mariana Islands	63,112	1	34	19	15	0	53.9
Palau	20,397	0	9	5	3	1	44.1
<b>Polynesia</b>	<b>660,026</b>	<b>16</b>	<b>372</b>	<b>261</b>	<b>110</b>	<b>1</b>	<b>56.4</b>
American Samoa	65,113	0	3	2	1	0	4.6
Cook Islands	15,636	0	2	1	1	0	12.8
French Polynesia	265,654	12	314	223	91	0	118.2
Niue	1,514	0	0	0	0	0	0.0
Pitcairn Islands	66	0	0	0	0	0	0.0
Samoa	182,578	3	22	15	7	0	12.0
Tokelau Islands	1,167	0	0	0	0	0	0.0
Tonga	103,023	1	18	10	8	0	17.5
Tuvalu	11,093	0	11	9	1	1	99.2
Wallis and Fatuna	14,183	0	2	1	1	0	14.1
<b>All PICTs</b>	<b>9,677,620</b>	<b>3,793</b>	<b>33,424</b>	<b>14,747</b>	<b>17,300</b>	<b>1,320</b>	<b>345.4</b>
<b>All PICTs * (Excluding PNG)</b>	<b>3,067,874</b>	<b>82</b>	<b>1,419</b>	<b>935</b>	<b>476</b>	<b>8</b>	<b>46.3</b>

Sources Secretariat of the Pacific Community (2010a) &amp; Papua New Guinea National Department of Health (2010).

data below gives an indication of the possible number of HIV cases in PICTs but ought to be viewed as tentative.

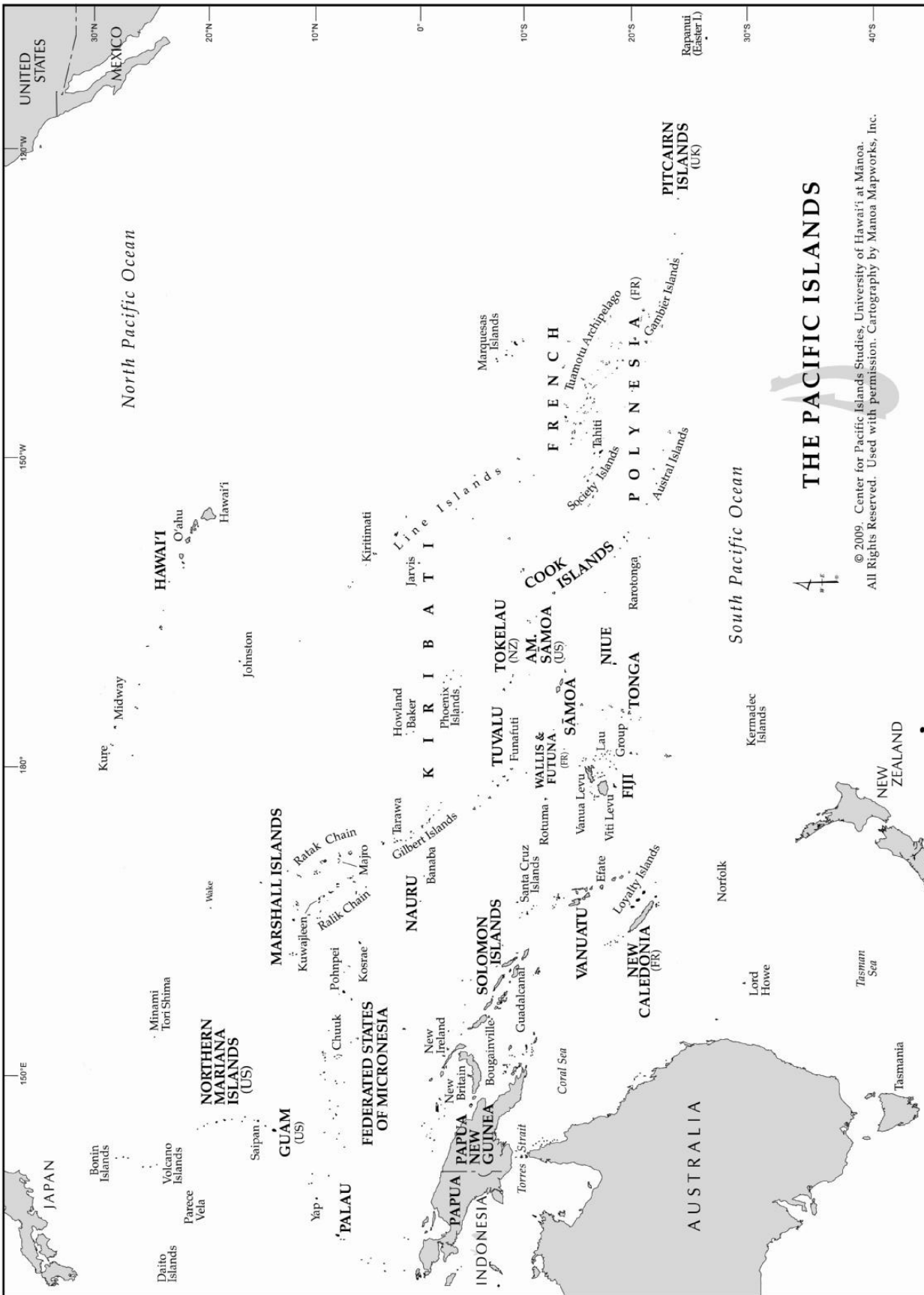
Several factors have been identified in facilitating the spread of HIV in the Pacific (ADB, 2007; Buchanan-Aruwafu, 2007; Commission on AIDS in the Pacific, 2009; Hammar, 2010; UNDP, 2009). The role of rapid social change in fostering the spread of HIV in Papua New Guinea has been noted and is likely applicable to many other Pacific Island countries. "Compared to the past described by elders, people today have far greater freedom to engage in sex. This sense of freedom is personal, engendering less fear of personal damage; and social, instilling less fear of social sanctions" (ADB, 2007, p. 46). Other factors include high rates of unprotected premarital sex among Pacific youth (Buchanan-Aruwafu, 2007); high rates of sexually transmitted infections which often go untreated (Buchanan-Aruwafu, 2007); male-to-male sex that is highly stigmatized and consequently often hidden (Commission on AIDS in the Pacific, 2009); commercial and transactional sex that is frequently unprotected (Commission on AIDS in the Pacific, 2009; McMillan & Worth, 2010); high rates of migration and mobility both internally and internationally (UNDP & SPC, 2010); and gender inequality (Buchanan-Aruwafu, 2007; Hammar, 2008, 2010; UNDP, 2009). As well, stigma and discrimination may also facilitate the spread of HIV by deterring people from seeking testing and treatment services (Commission on AIDS in the Pacific, 2009).

In the Pacific Islands, heterosexual transmission is the primary mode of HIV transmission. Within the Pacific (excluding Papua New

Guinea) the modes of transmission include heterosexual transmission (51% of infections), male-to-male sex (27% of infections), injection drug use (5% of infections), perinatal (4% of infections), blood (3% of infections), and other/unknown (10% of infections) (SPC, 2010b). Yet, the modes of HIV transmission vary between the sub-regions and countries. Heterosexual transmission accounts for 63% of infections in Melanesia (excluding Papua New Guinea), 43% of infections in Micronesia, and 41% of infections in Polynesia (SPC, 2010b). HIV transmission also occurs through male-to-male sex and accounts for less than 20% of infections in Melanesia, 34% of infections in Micronesia, and 37% of infections in Polynesia. Injection drug use accounts for less than 5% of HIV infections in Melanesia and Micronesia and nearly 10% in Polynesia (SPC, 2010b).

There are marked differences between the male to female ratios of people diagnosed HIV-positive. As of the end of 2009 the male to female ratio was 1.5:1 in Melanesia (excluding PNG), 2.9:1 in Micronesia, 2.4:1 Polynesia (SPC, 2010b). The differences in the male versus female ratios reflect the different modes of transmission in the region (SPC, 2010b). The Pacific as a region has followed the global trend, whereby men initially make up the majority of HIV cases and then the absolute number and proportion of women steadily increases (Commission on AIDS in the Pacific, 2009; SPC, 2010b). However, some of this increase is likely due to increased HIV testing of women at antenatal clinics (Commission on AIDS in the Pacific, 2009, SPC, 2010b).

The following discussion provides country specific information on the epidemiology of HIV in Fiji and Papua New Guinea.



**THE PACIFIC ISLANDS**

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**HIV in Fiji**

Fiji remains classified as a low prevalence country although the prevalence of HIV appears to steadily increase each year. At the end of 2010 the total number of cases among the ethnic groups in Fiji included 302 indigenous Fijians (iTaukei), 44 Indo-Fijians, and 19 other (Fiji Ministry of Health, 2011), a total of 365.

In Fiji there are three Hub Centres located in Suva, Lautoka and Labasa that provide information, counselling, testing and treatment (including ART) for STI including HIV. In 2009 Fiji MoH reported 333 cases. Out of 95 Hub Centre clients, 48 people were on ART, 2 people who were eligible were not on ART and the remainder were presumably being monitored. Taking into account 28 recorded deaths (SPC, 2010b) and the 95 Hub Centre clients, it appears that 210 HIV-positive people (approximately 63% of cases) were either lost to follow up or had died without having their deaths being attributed to AIDS-related illnesses. In other words, the majority of PLHIV diagnosed have been lost to follow-up.

According to the UNGASS 2010 Country Progress Report Fiji (2010), in Fiji, the main modes of HIV transmission included 88.3% heterosexual, 6.6% peri-natal, 2.4% men who have sex with men (MSM), 2.1% unknown, 0.3% IDU and 0.3% blood transfusion. In the same report it was also noted that it would be more accurate to say that sexual transmission is the main mode of transmission as the term "heterosexual transmission" does not take into account the complex sexual networks that exist, and also, the phenomenon of men having sex with men is likely underreported in this context.

In Fiji, as of 2009 the male to female ratio was 1.2:1, with 181 male, 152 female individuals having been diagnosed HIV-positive (SPC, 2010). Hence in Fiji slightly more men are infected than women. Yet, if Fiji follows the global trend and the trend that occurred in Papua New Guinea, the absolute number and proportion of women will steadily increase and overtake the number of men infected.

**HIV in Papua New Guinea**

Papua New Guinea was the first and remains the only country in the Pacific to have declared a generalized epidemic – this occurred in 2003.<sup>7</sup> Data from the Papua New Guinea National Department of Health (2010) suggest that as of December 2009 there were 32,005 reported cases of HIV and an unknown number of deaths due to HIV-related illnesses.

According to the *2009 STI, HIV and AIDS Annual Surveillance Report (2010)*, 6,794 PLHIV are on ART out of the 8,790 people who are estimated to be in need of it. The UNGASS 2010 Country Progress Report Papua New Guinea (2010) notes that there are issues with delivery of ART that can lead to stock running –out and failure to provide treatment to prevent parent-to-child transmission and post-exposure prophylaxis. It also states that, "clients already on treatment may be forced to take an unplanned treatment break and new clients may experience a delay in commencing treatment" (p. 23). This report also acknowledges that clinic staff may not fully understand the treatment guidelines which can lead to people not receiving ART even when they are eligible.

There were 32,005 reported cases, 6,794

<sup>7</sup> More recently there have been discussions as to whether the previous estimates overestimated the prevalence of HIV, which could mean that Papua New Guinea is not experiencing a generalized epidemic.



people were on ART, 1,996 people were in need of ART, as of December 2008 there were 353 deaths attributed to AIDS-related illnesses (Commission on AIDS in the Pacific, 2009) and an unknown number of PLHIV were being monitored. If the number of people being monitored was between 3,000 and 6,000 people, there were still 16,000-19,000 cases that were unaccounted for. What has been the fate of those thousands of people? As Biehl (2007) has stated of Brazilian PLHIV a "large number of AIDS sufferers remained epidemiologically and medically unaccounted for, thereafter dying in abandonment" (p. 14). Presumably thousands of them have died and thousands of others have been lost to follow-up. Perhaps these people have opted not to seek health services after discovering that they are HIV-positive as they perceive treatment to be inaccessible or more likely they fear stigma, discrimination and disclosure.

In Papua New Guinea, the modes of transmission are recorded as follows: 60.3% heterosexual; 33.8% unknown; 2.4% perinatal;

1.7% homosexual; 1.3% body piercing or tattoo; 0.4% occupational exposure; 0.1% blood transfusion (1 case); 0.0% Injection drug use (IDU). Including only the cases where modes of transmission were reported, the percentage of the main modes of transmission are: 91.1% heterosexual; 3.6% perinatal; 2.6% homosexual (Papua New Guinea National Department of Health, 2010). Hence, the majority of HIV transmission in Papua New Guinea is from heterosexual transmission.

According to the *2009 STI, HIV and AIDS Annual Surveillance Report (2010)*, since 2003, the number of women reported to be HIV-positive has consistently been greater than the number of men. The male versus female ratio of reported HIV cases is 0.8:1 (Papua New Guinea National Department of Health, 2010). However, it is important to note that the greater number of women reported to be HIV-positive could be due to more tests being conducted among women especially among pregnant woman who are tested while receiving antenatal care (ANC). At the same time, at counselling centres when a similar number of men and women were tested, the HIV prevalence rate was 4.7% in women versus 3.8% in men (UNGASS 2010 Country Progress Report Papua New Guinea, 2010). Hence, it is possible both that more women are being tested through ANC and that the 'real' prevalence is slightly higher amongst women.

### **Responses to HIV in the Pacific**

As noted in the Report of the Commission on AIDS in the Pacific (2009), there is a perception that Pacific political leaders have remained silent on protecting the rights of people who are vulnerable to and af-



ected by HIV (Commission on AIDS in the Pacific, 2009). Existing legal frameworks generally condemn behaviour such as anal sex, sex between men, and sex work and drive these practices underground (Stewart, 2006). Public Health Acts also reflect mentalities of the colonial periods and “these Acts usually provide wide powers to public health authorities, impose heavy duties on infected people and others who must notify and take precautionary measures—but rarely give privacy to people who are subject to these provisions” (Commission on AIDS in the Pacific, 2009, p. 55). These legal frameworks are outdated and are in many instances inappropriate for HIV.

Most legal systems in the Pacific lack legislation that protects the rights of PLHIV. Papua New Guinea has stand-alone HIV legislation under the HIV Management and Prevention (HAMP) Act. Other legislation includes The HIV/AIDS Decree 2011 in Fiji and the Pohnpei AIDS Prevention and Control Act of 2006. Under the HAMP Act, PLHIV are ensured the right to confidentiality and non-discrimination. Access to protection from HIV infection and partner notification are also guaranteed under this Act. However, it is important to note that the HAMP Act is rarely enforced and no cases of prosecution have occurred under the Act as everyday Papua New Guineans find the court system difficult to access (Commission on AIDS in the Pacific, 2009; Hammar, 2010).

### **Gender Inequality and HIV in the Pacific**

Gender inequalities and the overall status of women vary across the Pacific Islands region (Buchanan-Aruwafu, 2007; UNDP, 2009). The ways in which women experi-

ence gender inequality are influenced by socio-cultural, political and economic factors. The disadvantages that women often face as a result of gender inequality include harmful cultural practices; limited political representation and involvement; more limited income earning opportunities; and exposure to gender based violence (Buchanan-Aruwafu, 2007; UNDP, 2009).

### **Cultural Traditions**

In some Pacific Island countries the ways in which cultural traditions are practiced today disadvantage women. The tradition of bride wealth is common in most Melanesian countries including Solomon Islands, Vanuatu and Papua New Guinea. The payment of bride wealth is a tradition that involves the transfer of wealth from the groom's lineage to the bride's lineage. Yet, as the transition to cash economies has occurred factors which have acted to protect women in the past have today decreased (Buchanan-Aruwafu, 2007; Eves, 2010). “As the cash economy took hold in PNG, the cost of marriage rose in most groups, a social change that has had numerous negative consequences. Now, as people in Bundi say, ‘*Meri em i samting bilong bisnis*’ (women are something to make money on) (ADB, 2007, p. 19). Bride wealth as it is now practiced is noted as a factor that perpetuates violence by men against their wives as women feel that they must obey their husbands because the woman has become property of the man (AusAID, 2008; Eves, 2009, 2010).

In many parts of Polynesia and Micronesia, gifts are exchanged between both the bride's and the groom's families but this is done in a way that does not disadvantage women as the practice of bride wealth

does (UNDP, 2009, p. 20).

The way in which elopement (*veidrotaki*) is practiced in Fiji is another example of a cultural practice that disadvantages women. *Veidrotaki* in Fiji typically involves a woman spending the night at a male partner's place and this amounts to the promise of marriage (Labbé, 2011). Men are generally granted the freedom not to go ahead with the union but, because sexual intercourse is assumed to have occurred, women feel significant pressure to proceed with the union to maintain the ideal of female virginity at marriage (Labbé, 2011). Polygyny as it is practiced in some societies in Papua New Guinea is a clear example of a distorted form of "custom".<sup>8</sup> Among certain societies within Papua New Guinea, polygyny was practiced only when men had enough resources to sup-

port multiple wives. Yet, as Lepani (2008) has noted, polygyny "now proliferates in truncated forms under the guise of customary practice, and young mobile men 'marry' a succession of wives in different locations without the economic means to support them and their children or to maintain the inter-clan exchange relations that are central to traditional conjugal unions" (p. 155).

In addition to limiting women's social choices, cultural practices can also negatively affect women's economic choices.

#### **Economic Choices**

In many parts of the Pacific, women have limited rights to property and there is a preference for educating boys rather than girls, which in turn leaves women with limited income-earning opportunities



<sup>8</sup> The arrival of Christianity and missionaries encouraged monogamous marriage which had the effect of altering and decreasing polygyny (Hammar, 2010; Wardlow, 2007). In Fiji, polygyny was practiced among Fijian chiefs but was halted by early missionaries (Kaitaini,

(Buchanan-Aruwafu, 2007; Labbé, 2011). As noted in a UNDP (2009) report, it is generally true that "Throughout the Pacific women have less independence than men, less opportunity than men do to meet their needs and aspirations, to earn their own money, to control their sexuality or to own or control property" (UNDP, 2009, p. 1). As Labbé (2011) notes of the situation in Fiji, accepting an offer of marriage from man, even if they do not know him well, is often viewed as a means for improving their quality of life.

In some Pacific contexts poverty and a lack of economic choices impel women and fewer men to engage in sexual exchange (Labbé, 2011; UNDP, 2009). Many people who engage in sexual exchange do not necessarily view themselves as sex workers (UNDP, 2009). Sex work generally involves the exchange of sex for money. Transactional sex is a form of sexual exchange which involves the exchange of sex for food, drinks, drugs, clothes or gifts.

Various studies have examined the different aspects and types of sex work in the Pacific (Hammar, 2010, 2010b; Kelly et al., 2011; McMillan & Worth 2010). McMillan & Worth (2010b) have documented the experiences of i-Kiribati women who have sex for money or goods with foreign seafarers and note that they would benefit from tailored HIV awareness programs. Holly Wardlow has documented how women in the Highlands of Papua New Guinea engage in transactional sex for economic benefits, but also as a form of revenge against their husbands and kin for their poor treatment (Wardlow, 2006). Hammar describes how some women in Daru, Western Province, Papua New Guinea are pressured by their

husbands and male kin to sell sex for money in oppressive and dangerous conditions (Hammar, 1996). Women who engage in sex work and transactional sex in the Pacific generally do so as a result of the conditions imposed by poverty and gender inequality.

The factors of poverty and gender inequality also expose many women to violence.

### **Violence against Women**

Eves (2010) states that "Gender-based violence is any form of violence used to define or keep in place strict gender roles and unequal relationships" (p. 49). High incidence of violence against women is viewed as a consequence of severe gender inequality. Miliakere Kaitani has written about gender inequality in the Fijian context and relates gender inequality to the issue of violence against women. Kaitani notes that:

Male domination in the Fijian society also comes out as domestic violence. It is not uncommon for a man to hit his wife. Domestic violence in Fiji is widespread and it is another way that male dominance can be seen in the culture (Kaitani, 2003, p. 127).

Strong patriarchal norms and beliefs are present in many Pacific Island countries and support male dominance, gender inequality and violence against women. Violence against women appears to be high across much of the Pacific. For example, in Fiji, 66% of women surveyed had experienced violence from their partners and 74% of the respondents choose not to report it (UNDP, 2009, p. 33). Counsellors from the Fiji Women's Crisis Centre stated that

violence is likely to be underreported by women because “they have been taught to accept violence, or because of family pressure, or because of fear of reprisals if a complaint is made” (UNDP, 2009, p. 33). Violence against women is also noted to be high in Papua New Guinea where the national average of wives who had been beaten by their husbands was 67% (Ausaid, 2008).

Gender inequality supports and perpetuates harmful cultural practices, economic dependence, and violence against women along with influencing gender ideals and sexual norms (Lepani, 2008; Salomon & Hamelin, 2008, 2008b; Seeley & Butcher, 2006; Wardlow, 2007).

### **Gender Ideals and Sexual Norms**

In many parts of the Pacific, feminine sexual norms focus on notions of restraint, virginity and purity. For example, in Fiji, Tonga, Samoa and Kiribati, the sexual norm is to be a virgin at marriage (Kaitani, 2003; UNDP, 2009). In other parts of the Pacific, in Eastern Polynesia for example, in the Cook Islands, French Polynesia and also in parts of Micronesia, attitudes about female sexuality before marriage are more relaxed (UNDP, 2009).

Honour and shame are important in the regulation of sexual norms and of expectations of women. Female virginity among young women and fidelity among married women are the crux of female honour. Fidelity is supported by both Christian and traditional values and is expected of men and women. However, conflicting cultural norms create a sexual double standard whereby there is a cultural tolerance and tacit acceptance of premarital sex and

infidelity among male youth and men yet women's perceived indiscretions are condemned (AusAID, 2008; UNDP, 2009). Cultural norms support control, restriction and subordination of girls and women and promote female virginity and fidelity in marriage (Buchanan-Aruwafu, 2007). Women and girls who fail to adhere to the ideals promoted by sexual double standards often face violence or other forms of punishment (Buchanan-Aruwafu, 2007; Cummings, 2008; Salomon & Hamelin, 2008).

Upholding sexual double standards is a form of gendered culpability. Cummings (2008) referred to gendered culpability as the tendency to blame and punish women. Eves and Butt (2008) noted that this is a general pattern across Melanesia (p. 20). Women are typically blamed for HIV and other sexually transmitted infections (STIs). This is true in marriage and relationships even when it is the male partner who has been unfaithful. The sexual double standard is similarly illustrated by the fact that 70% of Solomon Islands women and 15% of Solomon Islands men who were in a relationship believed that having an affair while in a relationship was wrong (Buchanan-Aruwafu & Maebiru, 2008, p. 172). Kaitani (2003) asserted that double standards are also common in Fiji where, although it is not culturally accepted, extramarital affairs are common amongst men. Cummings (2008) referred to findings from the Vanuatu Young People's Project which suggested that when it comes to sex and condom use “young women are usually told that they must *stap kwæet* (stay quiet), lest they be blamed for the spread of sexually transmitted infections (STIs), and that they must not insist on condom use, for fear of being labelled promiscuous” (p. 138).

Gender norms, sexual double standards and gendered culpability are forms of sexual inequality. Eves and Butt (2008) defined “the sexual inequality that exists in much of Melanesia is essentially a lack of reciprocity in regard for the other” (p. 18). They also noted that “it is the women of many Melanesian countries who express a desire for more equitable treatment” (p. 18). Sexual inequality contributes to spread of HIV and especially to women’s vulnerability to HIV.

### **Women’s Vulnerability to HIV**

Vulnerability to HIV refers to personal experiences of social, economic or other forms of inequality that can increase the likelihood of HIV exposure (Buchanan-Aruwafu, 2007). Women are often said to be more vulnerable to HIV through vaginal intercourse due to biological factors, untreated STIs and violent penetration (UNDP, 2009). Yet it is social and cultural factors that most greatly affect Pacific women’s vulnerability. The term “sexual citizenship” encompasses this idea. Many women and girls in the Pacific and other parts of the world lack sexual citizenship meaning they lack the individual, social and legal rights to protect and control their bodies and sexuality (Hammar, 1999; Scheper-Hughes, 1994). Cultural norms and social expectations often play a key role in limiting females’ sexual citizenship (Hammar, 1999; Scheper-Hughes, 1994). For example, sexual double standards play a key role in increasing women’s vulnerability to HIV.

All females who are disadvantaged through gender inequality are vulnerable to HIV whether they are young women, sex workers or married females. In the Pacific, marriage is considered to be a high risk set-

ting for women (Hammar, 2010; Labbé, 2011; Lepani, 2005; UNDP, 2009; Wardlow, 2007). Buchanan-Aruwafu (2007) has noted that “while married women can be at risk of HIV infection through their own sexual practices, they are primarily vulnerable and at risk from the sexual relationships of their husbands, and from violence that occurs outside of and within marriages including rape and forced sex” (p. 36). In discussing the HIV epidemic in Papua New Guinea, Lawrence Hammar states that “the epidemic is caused by the severely imbalanced state of gender relations in Papua New Guinea. By ‘gender relations’ I mean the relations of power that exist between men and women, especially in marriage but also generally. The troublingly poor status of women has ill effects on many aspects of life and very markedly on sexual relations” (Hammar, 2008, p. 61).

Violence against women also increases female vulnerability to HIV and limits women’s power in making decisions related to sex and risk (Hammar, 2010; Labbé, 2011; Lepani, 2008). In discussing HIV vulnerability among Kanak women in New Caledonia, Salomon and Hamelin (2008) argued that they “consider that it is necessary to treat HIV/AIDS and violence against girls and women as co-epidemics that thrive in the same cultural, social, and political environments” (p. 80). The belief that a married woman does not have the right to refuse sexual intercourse with her husband appears to be common in many Pacific Island cultures (UNDP, 2009). Fear of violence from male partners and abandonment make women reluctant to refuse sexual intercourse, to discuss sexual health, to suggest or insist upon condom use, to challenge infidelity, and to get tested for HIV and

other STIs (AusAID, 2008; Lepani, 2008).

In sum, gender inequality and the sexual inequality, limited sexual citizenship and violence against women that it produces are key factors in intensifying women's vulnerability to HIV.

### **Women and the HIV Responses in the Pacific**

Within the Pacific HIV response, gender inequality has been viewed as contributing to vulnerability but not as a cross-cutting issue. Hammar (2010) affirmed this in stating that "Curbing HIV transmission and preventing AIDS demands that gender and other harmful social relations be healed. Neither health bodies nor most external donors yet 'get' gender relations very deeply, because they see gender as a variable, not a social relation, and because they don't see themselves in it" (p. 14). This holds true for the *Pacific Regional Strategy on HIV/AIDS 2004-2008* and in the more recent *2009-2014 Pacific Regional Strategy on HIV and other STIs*, where gender is identified as an issue but is not prominent in the background situation analysis (UNDP, 2009). Although, the new strategy does include a recommendation for the need for coordination of the response to gender and HIV as a key action, greater emphasis could be placed on the issue of HIV and violence against women and the role that women play as care-givers for PLHIV (UNDP, 2009).

There are limited laws and national policies in place that specifically address gender inequality within the HIV response, but most Pacific National Strategic Plans do not pay sufficient attention to gender issues. For example, women's vulnerability to HIV is only recognized in the context of parent to child

transmission, sexual violence, and/or sex work. To date, Papua New Guinea is the only Pacific Island country that has produced a *National Gender Policy and Plan on HIV and AIDS, 2006*, that is intended to complement the *National Strategic Plan on HIV/AIDS*.

Policy and law reform is also needed in other areas to protect the rights of women and PLHIV. Sex work remains illegal in most Pacific Island countries and reinforces discrimination against women. As well, customary practices and traditional law that "determine control over land and resources as well as inheritance and property issues also often discriminate against women, underscoring the need for constitutional guarantees of equality rights" (UNDP, 2009, p. 46). Although most Pacific Island countries have ratified the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (Nauru, Palau, and Tonga are exceptions) many existing laws are not CEDAW-compliant. Law reform that is CEDAW-compliant would also support HIV law reform (UNDP, 2009, p. 47).

Since the mid 1990s gender has been included as an issue that must be considered in addressing HIV, yet many programs still fail to consider the gender aspects of HIV (Scheper-Hughes, 1994; UNDP, 2009). HIV prevention messages have in many cases not been culturally relevant and are often misunderstood, making them ineffective (Eves, 2010; Eves & Butt, 2008; McPherson, 2008; UNDP, 2009). For example, the widely implemented ABC (abstinence, be faithful, use condoms) approach does not take into account gender inequality, such as the limited ability of many wives to insist upon abstinence, fidelity or condom use with their

husbands (Eves, 2010; Hammar, 2010; Reid, 2009). In referring to the use of the ABC approach in Papua New Guinea, Hammar stated "in the case of Papua New Guinea, a field of normative multi partner sexual networking, extreme mobility and ubiquitous sexual violence, I cannot imagine two behavioural sanctions less likely to work ... than abstinence and fidelity, and yet they remain the discursive and funding cornerstones of the national response" (Hammar, 2008, p. 76-77).

The participants' perspectives and experiences described in this report reflect many of the issues related to HIV prevention, gender inequality and the gendered stigma associated with HIV.

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## CHAPTER 3.

# METHODS

This study aims to increase understanding of the experiences of HIV-positive women. A qualitative approach was utilized to collect the stories and perspectives of HIV-positive women in Fiji and Papua New Guinea. In-depth interviews were conducted with 8 HIV-positive women in Fiji and 17 in Papua New Guinea. The paragraphs below describe in detail how in-depth interviews were conducted to learn about the experiences of HIV-positive women.

### Locations

In Fiji, interviews were conducted with HIV-positive women living in urban centres and towns on the main island of Viti Levu. Approximately 70% of Fiji's population of 850,000 people lives in cities, towns and villages on Viti Levu. The two predominant ethnic groups in Fiji include indigenous (iTaukei) Fijians (57%) and Indo-Fijians (38%) (Fiji Bureau of Statistics, 2007). All of the interviews were conducted with indigenous Fijian women. Although efforts were made to recruit Indo-Fijian women, these efforts were unsuccessful. Indo-Fijians make up 44 (12%) of the 366 cases of HIV in Fiji, it is unknown how many of these cases are women. As well, there are no Indo-Fijian members of the Fiji Network for People Living with HIV (FJN+).

Viti Levu is the hub of the Fiji Islands, hence much of the health infrastructure is centred on this island. Within Fiji there are three Hub Centres that offer sexual health services including provision of information, counselling, testing and ART.<sup>9</sup> Fiji Network for Peo-

ple Living with HIV (FJN+) has an office in the capital Suva (located on the south-west coast). The Pacific Islands AIDS Foundation has an office in Lautoka (in the western division of Viti Levu) and hosts a support group there.

In Papua New Guinea, interviews were conducted with HIV-positive women living in Port Moresby, Milne Bay Province and Southern Highlands Province. Port Moresby is the capital of Papua New Guinea and 255,000 of Papua New Guinea's total population of approximately 6,500,000 people live there. As the capital of a geographically large and diverse country with 20 province-level divisions, Port Moresby functions as a national hub of infrastructure and health services. Within Port Moresby there are a number of clinics operated by health authorities and NGOs that offer HIV-related treatment, care and support. Igat Hope is the national umbrella support network for HIV-positive people in Papua New Guinea. Igat Hope, along with other NGOs such as Anglicare Stop AIDS, hosts support networks for PLHIV.

Interviews were also conducted in Milne Bay Province, which is located at the eastern tip of Papua New Guinea and includes over 600 islands, of which 160 are inhabited. The population of Milne Bay Province is approximately 210,000 and a few more than 10,000 people live in the provincial capital of Alotau. Oil palm is one of the main industries within the province, and there are several plantations in Milne Bay Province to which people migrate from other areas of the country. In 2009 there

<sup>9</sup> The Hub Centres are located in Suva and Lautoka, both on the island of Viti Levu, and in Labasa on the island of Vanua Levu.



were 8 HIV testing sites within the province; 6 of the 8 sites were located in and around Alotau. The Hagu Clinic in Alotau is the only site within the province where ART is available. Igat Hope Milne Bay is a budding provincial PLHIV network established in 2006. The majority of Milne Bay's population live in isolated areas including inland areas with no road access and coastal areas and islands that can only be reached by boat.

Tari is a town in the Southern Highlands Province where women living with HIV were also interviewed. Southern Highlands Province has a population of approximately 545,000 people. The province is rich in natural resources, particularly natural gas, and it is also known as an area where civil unrest has occurred due to tribal warfare. Tari is connected to other highlands towns through the Highlands highway. It has a population of around 8,100 people and is the centre of Huli country – the Huli are a distinct ethnic group.<sup>10</sup> Tari town consists of an airstrip, a few shops, a hospital compound, a few schools, residential dwellings and a couple of guest houses. It is the site for the main market in the area. On market days Tari is a busy place where people come to meet, buy and sell their food and goods. Many of the women in Tari depend on agriculture or marketing to make a living. Within the Southern Highlands province there are 10 HIV testing sites and 4 ART distribution sites. In Tari, HIV testing is available at Saint Francis Care Centre and Tari Hospital. ART became available at Tari hospital in 2009. In Tari a PLHIV support network has yet to be established, although there is an informal group of HIV-positive people who seek to support other PLHIV.



### Participants

The 25 women who participated in this study were all HIV-positive Fijian (8) and Papua New Guinean (17) women from different social and economic backgrounds. Their ages ranged from 22 to 45-years-old and the average age was 29-years-old. All of the women identified themselves as Christians, belonging to various denominations. The majority of women spoke English as a second language in addition to their first language, which included Fijian, Tok Pisin and Huli, among others. Three of the women identified themselves as single, while four were married, one was remarried, and one was engaged. Six were divorced or separated and ten were widowed.

Some of the women lived in urban or semi-urban areas, while others lived in more isolated areas where access to primary health services is limited. Only one of the women had completed university, many others had completed diploma courses, some had completed high school and some had an education that was limited to secondary school. The participants earned a living through a range of means. Some had full-time steady jobs, some were

<sup>10</sup> Southern Highlands province, especially Tari, is noted as place where violence is particularly common (Kopi, Hinton & Robinson, 2010). Therefore the women's experiences of violence could be more extreme than those from other provinces of Papua New Guinea.

supported by their husbands or families or through limited social assistance, while many others earned a living through marketing, for example by selling cooked food or selling produce and small goods at markets. A few women were involved in volunteer work through NGOs. Only two of the women interviewed were involved in sex work before they were diagnosed HIV-positive. The majority of the participants already had children; of the 25 participants, 7 had not had any children yet. Eighteen of the 25 women were on ART. Nearly all of the women were connected to a PLHIV support group, although some were more involved than others. Only a few of the women had publicly revealed their HIV status.

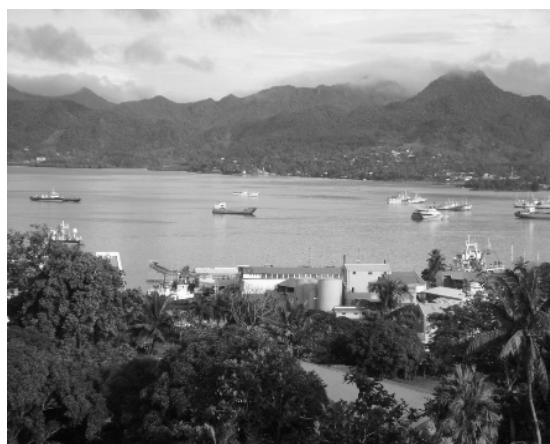
### **In-depth Interviews**

In-depth interviewing was the method used to gain a detailed understanding of the lives of the participants. The participants were recruited through PLHIV support networks or through NGOs that offer support to HIV-positive people. Participants were selected to ensure that women who had limited contact with the networks and NGOs were also included. Attempts were made to include women who were not part of support networks through snowball sampling; for example, other PLHIV, known to participants, who were in hospital were contacted indirectly. However, these women chose not to participate. Their decision reveals an important issue in working with hard-to-reach or vulnerable populations about whom little is known. In discussing these populations Liamputtong (2007) stated that "The reasons for their invisibility are many and may include their marginality, lack of opportunity to voice their concerns, fear of their identity being disre-

spected, stigma attached to their social conditions, heavy responsibilities and scepticism about being involved in research" (Liamputtong, 2007, p. 4). It is important to note that some of the women who participated had limited contact with NGOs and hence their experiences are likely to have some resemblance to those who chose to remain isolated.

The interviews were conducted between May and August 2009. The interviews were semi-structured yet informal, and took place in a private room. An interview guide was used, and it included the following themes: personal background; life before HIV; being diagnosed HIV-positive; life after HIV; experiences of stigma and discrimination; treatment, care, and support; HIV and motherhood; care giving; and perspectives on women and HIV.

The majority of the interviews were conducted one on one by Hilary Gorman, Research Officer of the Pacific Islands AIDS Foundation (PIAF). In Fiji, most of one interview was translated from Fijian to English, and in PNG, three of the interviews in Tari were translated from the Huli language to English. The duration of the interviews ranged from 45 minutes to 2 hours. Partici-



pation was voluntary and informed consent was obtained. The participants were given a small sum to cover their travel costs and FJD20 or K20 as an honorarium after the interview took place. The interviews were audio recorded and later transcribed in each respective country. The interview transcripts were read and themes were developed based on the interview themes and new themes that arose from the interviews. The transcripts were then coded and analyzed through the use of NVivo qualitative data software. After the first draft of the report was produced, it was reviewed, revised and edited.

### **Study Limitations**

All studies have limitations against which findings, conclusions and recommendations need to be considered. What is important is that these limitations are acknowledged and their potential impacts on study findings explicitly assessed.

The limitations to be considered in reviewing the findings of this study are as follows. First, the stories of these women cannot be said to be representative of all HIV-positive women in Fiji and Papua New Guinea, yet they do reflect the experiences of women who are receiving support, and they do shed light on some of the issues that HIV-positive women living in isolation may well face. Second, the experiences of women from two Melanesian countries do not represent the entire Pacific, as the Pacific is a diverse region. The experiences of these women may be different from the experiences of women in Polynesian or Micronesian societies and countries. Third, the study focused on women and therefore the experiences of men were not explored, although the women often noted the be-

haviour and social expectations of their male partners. It is also important to understand the experiences of HIV-positive men; this is an area for exploration in future research.

## CHAPTER 4.1

# HIV-positive Women's Perceptions about Women and HIV and PLHIV

HIV prevention messages delivered via governments, NGOs and faith-based organizations, as well as media coverage of HIV, have had a lasting impact on people's perceptions of the issue of women and HIV and HIV-positive people. This section discusses the participants' views and ideas on the themes of women and HIV and HIV-positive people and notes how these perceptions are shaped through ideas and messages about HIV.

HIV prevention messages which are thought to be "objective, non-judgemental programs also unintentionally shape ideas about what constitutes 'normal' sexual practice" and "However generous and good the intention of these public health interventions, they may generate widespread consequences that range significantly beyond the initial stated aims" (Hirsh, Wardlow, Smith, Phinney, Parikh & Nathanson, 2009, p. 8). For example, these messages and activities may have "heightened gendered tensions" and "exacerbated stigma" (Hirsh et al, 2009, p. 8). The participants' perceptions of women and HIV and their views on PLHIV reflect ideas about HIV that are generated partly through prevention messages and media coverage and partly through cultural and social norms.

Early HIV prevention messages focused on death and powerlessness caused by AIDS and drew attention to risk groups. In the Pacific, the risk group categories formu-

lated during the early response included sex workers, homosexuals and expatriates (Hammar, 2010). The prevention messages often focused on the idea that AIDS equals death (Hammar, 2010), which may have seemed like an effective deterrent in the pre-ART period, yet the fear and stigma they created has had a lasting effect. Cullen (2000), who analyzed reporting of HIV in Pacific newspapers and other popular media, noted that, initially, reporting focused on the harmful effects of HIV and risk groups, but that, around 1999, it began to provide educational information on risk. He noted a further shift between 2000 and 2010 whereby, after 2005 reporting began slowly to become more sensitive towards PLHIV (Cullen, 2010). Christian Churches have also played a key role in shaping views on HIV in the Pacific (Butt & Eves, 2008; Hammar, 2010; Wardlow, 2007). The association of HIV with sin and immorality has been promoted by some Christian Churches and leaders while other Churches and religious leaders have also developed prevention and support programs. Nonetheless, the association of HIV with immorality, risk groups and death promoted via prevention programs, media, and religious organizations and leaders has intensified the stigma surrounding HIV.

Stigma and misinformation surrounding HIV have led to discrimination and inhumane treatment of PLHIV. There are numerous accounts from Papua New Guinea. For example, while working for the Institute of

Medical Research Lawrence Hammar encountered a situation where a young woman was socially rejected, physically isolated, beaten, burnt in a house fire (which may have been intentional) and then left to die because she was HIV-positive (see Hammar, 2008). The British Broadcasting Corporation (BBC) reported that PLHIV were being buried alive in the Highlands and the article stated that "Church leaders have described AIDS patients being thrown off bridges or left to starve in back gardens in the past" (Anon., 2007). In 2009 it was reported that a young woman in Mount Hagen was burnt alive for being accused of sorcery and infecting a man with HIV (Muri, 2009).<sup>11</sup> It is worth noting that in both of these cases the individuals who were killed by stigma were women. No such disturbing accounts of treatment of PLHIV exist in Fiji or other Pacific Island countries.

HIV prevention messages and HIV media coverage as they relate to women have had numerous effects on general perceptions of women and HIV. As Lepani (2005) has noted "embedded in HIV prevention messages are dangerous assumptions about women's ability to control the circumstances in which sex takes place" (p. 17). Both prevention efforts and media coverage have often put the responsibility of prevention, if not the blame for the spread of HIV, upon women, including young women, housewives, (single) village girls and sex workers (Hammar, 2010, 2010b; Lepani, 2008). Hammar (2010) stated of early media coverage of HIV in Papua New Guinea "Women already dubbed *pamukus* (prostitutes) and *tu kina meri* (K2women) by two decades' worth of newspaper articles were further constructed linguistically and serologically as ... reservoirs and carriers of infection, and

worse, as the signs and signifiers of rapid socioeconomic change and breakdown in family values" (p. 110). In Papua New Guinea HIV has been alluded to as being out of control because of women's sexuality, which "underscores how the language of HIV can negatively influence people's perceptions of risk and prevention, and reinforce gender inequities, stigma and blame" (Lepani, 2008, p. 158). In addition to having negative unintended effects, prevention messages may also have been ineffective as they have misunderstood the nature of marital relationships (Hammar, 2010b).

#### **HIV-Positive Women's Perceptions of Women and HIV**

The experiences of the women interviewed indicate the many ways in which stigmatizing messages and attitudes affect their lives. The insights that the participants provided on the topic of women and HIV generally fall under two interrelated categories. One was the view that women are at risk because of shifting social and sexual practices that some women (and men) engage in. The other is that women are vulnerable to HIV because of gender inequality, particularly in marriage. Their perspectives and insights are important as they demonstrate how many prevention and educational messages perpetuate stigma, which these women often internalize as self-stigma.

#### **Shifting Social and Sexual Practices**

While the women interviewed described their views on women and HIV, many of them described how social and sexual practices make women vulnerable to HIV. The quotes below highlight some of the key issues the women noted when it comes to shifting social and sexual practices:

<sup>11</sup> Hayley (2010) has explored the links between HIV and sorcery in Papua New Guinea.



Another thing I see in women in PNG is that, we have this, most women have this 'no care' business (where) the husband goes out and the wife also goes out. That leads to broken-marriages and then, they continue to do that. And that's where they get into the problem. They just go out, they say "who cares" if you're going out, and these are your children, then who cares about your children, me too I will go out. You know, (that) way of thinking. (27-year-old Papua New Guinean woman)

Women too get drunk and go from one man to another, men too go from one woman to another and they can spread the virus. If your husband is faithful then he is faithful. Women can be like rats... and unfaithful (too). So women and men can (be unfaithful). We are in a sinful world, we can't trust anybody. (22-year-old Papua New Guinean woman)

Nowadays, when women want sex they will just go for it. When they want it they just go. It becomes easier for them to get the virus because they never used condoms and they do not know (about HIV). (28-year-old Fijian woman)

Nowadays, women and men are going for sex. Sex is becoming like – what can I say – *kaukau!* [sweet potatoes!]. Especially in Tari, I saw it and I knew it. It's becoming like *kaukau* – *kaukau* is the staple food, everyday food. Men is dishonest with his wife. Wife is becoming dishonest with her man. When men are going for work company, woman is pretending to be a house-wife. I mean, when men are going away for their work, women are looking for money [by engaging in transactional sex]. (33-year-old Papua New Guinean woman)

Many different issues related to women and HIV vulnerability are identified in these quotes. Broadly, the women's ideas refer to social and sexual practices that occur outside of both traditional gender norms and traditional marriage. The perception that sex and infidelity nowadays tend to be taken lightly by both women and men which increases vulnerability to HIV, was a common amongst many of the participants. Specifically, they refer to people going out to parties, discos and nightclubs where people are presumed to drink alcohol and engage in sex outside marriage and sex for money.<sup>12</sup> Labbé's (2011) study of the experiences of PLHIV in Fiji similarly found that PLHIV associated nightclubs and alcohol with premarital and extramarital sex. Alcohol was also associated with

<sup>12</sup> Only two women in this study and two out of 226 female participants in the Kelly et al. (2009) study identified as sex workers.

sexual violence. As one Fijian woman said, "When men are drunk they will force women, rape them."

There are also strong sentiments that it was especially young women and older (married) men who engaged in risky sexual behaviour. One Papua New Guinean woman stated, "Like now in Tari, the young girls are not enjoying themselves, they don't know the colour of men. They are going with one man, two men... and pretending that they are prostitutes."

Another woman described her thoughts on why young women were engaging in transactional sex:

*Again, young ladies too, especially the young ones who are really sexually active. We have young girls age eleven and upwards. Like they're not married yet, but married men want to use them a lot, to gain maybe pleasure out of it by having sex. And maybe pay them K50 or K20 a day, just for that lousy sex. They're paid that money... and that's really bad and that's why HIV is becoming really an issue here. Coz I think the ladies, the young people are also involved, and they're not saying no to it, they're just giving themselves to this type of behaviour. And though, there have been so many awareness (programs) on HIV, but still people are not using their head. They're not thinking properly. Like they're not thinking... they should think it's good to go out or maybe wear condom or something like that. But they just want to go out and have sex just for that lousy K20 or K10, to buy something for them, maybe food or what... so that's where they*

*survive from – selling themselves.*  
(29-year-old Papua New Guinean woman)

This woman's statement alludes to what McPherson (2008) noted is an "attitude that reflects a common theme in gender relations: in the face of feminine wiles, men cannot be blamed for succumbing to them" (p. 229). She makes it clear that it is women and young women "sex workers" in this case that are to blame for the spread of HIV. Similarly another woman said:

*When a man sleeps around it is acceptable, it is normal. So for a man it is acceptable, but if a woman does... then she deserves it, she deserves to get HIV. Especially if she has kids, then people will say she is stupid.*  
(31-year-old Fijian woman)

The tendency to blame women is a theme that runs throughout this report and affirms what has been similarly argued by those who have written about gender and HIV in Papua New Guinea (Hammar, 2008, 2010a, 2010b; Lepani, 2008; Stewart, 2006).

### **Gender Inequality in Marriage**

There are particular aspects of gender inequality in marriage that the participants said make women vulnerable to HIV. Although the women stated that both men and women are unfaithful in marriage, the women generally felt that men's infidelity was not only more common but also more socially acceptable. Some of the participants described how gender inequality in marriage enables men's infidelity to their wives, which in turn makes the wives vulnerable to HIV:



*If the men are womanizing, they come and sort of say, [orders the wife] "You, you don't go there!" And that man will go drinking, and the woman stays at home. She's always busy in the house doing nothing. Because she wants to go for party, this man goes there and comes and fight (bashes) her. And commands her to sleep with him. And that's where HIV is starting.*

(37-year-old Papua New Guinean woman)

*Sometimes, because PNG men they bash a lot, they abuse women's rights, and we women always want to respect men. Like what they say, we think we must do it. If we can't, then they might give us a bashing or something.*

(27-year-old Papua New Guinean woman)

*And for a lot of the women, they have this mentality that ... they've become HIV positive because it's their fault. They weren't good wives or they didn't look after their husbands or they did something to their husbands ... so it's their fault.*

(30-year-old Papua New Guinean woman)

These quotes acknowledge the dominant relationship of husbands over wives and how this makes women vulnerable to HIV. Several key issues were identified in making married women vulnerable to HIV, including alcohol abuse, infidelity, rape, violence, control and marital conflict. The messages conveyed by the women emphasize women's submission to their husbands and they, to varying degrees, describe themselves as passive victims. The last quote alludes to the gendered culpability or the blame that is imposed on women, especially the blame that they impose on themselves even when they have become HIV-positive through the actions of their husbands.

#### **Attitudes about People Living with HIV (PLHIV)**

The women also had much to say about PLHIV, their own attitudes and the attitudes that they felt other people had. The attitudes and beliefs described demonstrate both an "existing attitude" and an "emerging attitude" about PLHIV.

By "existing attitude" we mean the way of thinking that is common in many countries in the Pacific, whereby people feel that they are at risk of HIV exposure from casual contact with PLHIV and that PLHIV cannot



live long healthy lives. This attitude developed when HIV first became known in the Pacific during the late 1980s and early 1990s.<sup>13</sup> At that time ART was unknown and many people were dying shortly after being diagnosed due to HIV-related illnesses or even dying without being diagnosed.

During this period the media acted as people's main source of information about HIV (Cullen, 2000). The media promoted the idea that HIV equals death – a scare tactic meant to frighten people from (sexual) contact with people who were thought to belong to risk groups. This approach to HIV prevention was seen as an appropriate way to respond to a virus that killed. A report titled *Sik Nogut O Nomol Sik* on the socio-cultural factors contributing to sexual health in Southern Highlands and Simbu Provinces, Papua New Guinea discussed the use of fear tactics and stated that "health workers we spoke to said that fear can motivate people to change behaviour in the short term, but that it does not endure in the long term" (Gibbs & Mondu, 2010, p. 58). This approach is ineffective in the long term as it fosters the notion that PLHIV cannot be happy and healthy, ought to be feared, should be isolated from the rest of society and cannot live "normal" lives.

By "emerging attitude" about PLHIV we mean the mind-set where PLHIV are viewed as having a chronic manageable illness and with treatment can live long happy and healthy lives. The emerging attitude also encompasses the idea that PLHIV have rights and should be treated with compassion. The emerging attitude about PLHIV was conceived during the early 2000s as human rights were pro-

moted in relation to HIV. This attitude has continued to gain momentum over the years.

The participants' accounts indicate that the "emerging attitude" is common among those who are part of PLHIV networks, donor organizations and, to varying degrees, among NGOs in both Papua New Guinea and Fiji. The Papua New Guinean women indicated that the "existing attitude" appears to be diminishing in Port Moresby where the bulk of services are available. In Fiji, where there are far fewer cases of HIV both in terms of actual numbers and percentage of the population who are HIV-positive, the existing attitude remains prevalent.

The women at times alluded to the "existing attitude" about PLHIV. One Papua New Guinean woman said, "*Before, when I was hearing about AIDS, it was very fearful,*" and now that I am HIV-positive the fear is "*right in the depths of my heart as a problem*". This young woman has disclosed her status to one person, she lives in a sort of self-imposed isolation and is tormented by her HIV status. Another woman said, "*Sometimes I feel hurt, I cry, like I feel really painful in my heart,*" because her in-laws say, "*You got AIDS; you will die now,*" because many of her relatives are from the village and they are unaware of treatment and support for PLHIV. The attitude about PLHIV displayed by this woman's family has led her to be further isolated from them.

Many of the women's accounts demonstrate how some families and communities still believe that HIV is a death sentence and that PLHIV should be isolated. As well PLHIV also internalize this attitude which

<sup>13</sup> The majority of Pacific Island countries reported their first cases of HIV in the mid 1980s and 1990s (Commission on AIDS in the Pacific, 2009, p. 18). Marshall Islands was the first country to report an HIV case, in 1984, followed by French Polynesia in 1985 and Guam in 1985. Papua New Guinea reported its first case in 1987 and Fiji in 1989 (Commission on AIDS in the Pacific, 2009, p. 18).

results in self-stigmatization. After noting that many PLHIV self-stigmatize and feel that they cannot engage in everyday activities such as having a job, fishing and gardening, one woman said of other PLHIV:

*I push them to go and find a job. If you have to go back to the village and make your garden – then go and do it! Or if you want to go back to school, then go for it. For a lot of them, they think that because of their status, they can't. They have to be dependent on whatever the AIDS office gives them or whatever, you know, if they have to go for a testimonial.<sup>14</sup> They can't live a life outside of charity and charity has become the comfort zone.*

(30-year-old Papua New Guinean woman)

Despite increased availability of ART and the “emerging attitude” of PLHIV, many people are held back by the “existing attitude” and the stigma and discrimination that it fosters.

The “existing attitude” about PLHIV assumes a difference between PLHIV and “normal” people. Many of the women referred to this idea, for example saying:

*I lived with that treatment and I came back (to) normal. So now people see me as normal; they say, “We thought that lady is living with HIV, but she must be negative, not positive.” My sister she tells me (that) I am normal now.*

(22-year-old Papua New Guinean woman)

*And now the medicine like ART is in. The medicine like Bactrim is in. The good medicine like “positive living” is here the good medicine like counselling to share one plate together, share bed together is here! I (feel) sorry for the passed ones (who have died from AIDS). So today, we just hand in hand, we stay like other people. We are normal, as they are.*

(33-year-old Papua New Guinean woman)

*I'm not scared about HIV and AIDS. I can accept this HIV. And it's like any sickness, and like anybody. And I'm like anybody; something is not showing out my body or even sores or weakness. So I'm a normal person like anybody else, so I don't care about HIV and AIDS.*

(29-year-old Papua New Guinean woman)

These women noted the changes that have come about recently due to improvements in treatment and care resulting from the availability of ART and other medicines in addition to counselling. At the same time, awareness-raising has also begun to focus not only on how HIV is (and is not) spread, but also on HIV-related stigma and discrimination, and promotion of the idea that PLHIV should receive support and compassion and not judgment and hostility.

The “emerging attitude” about PLHIV entails the idea that PLHIV have rights and deserve to live fulfilling lives just as “normal” HIV-negative people do. This attitude has been emerging among PLHIV support networks and human rights organizations for several years now. However, amongst the

<sup>14</sup> Testimony referred to here, is the personal testimony provided by HIV-positive people to supplement and strengthen HIV prevention programs.



general public this attitude is neither strong nor yet fully endorsed. Similarly, although the push for the advancement of women's rights has been ongoing for many years now and there has been some success, there is still much to be achieved. The "emerging attitude" was exemplified among some, but certainly not all, of the women who participated in this study.

Some of them spoke about standing up for the rights of women, but at the same time questioned how that could actually be done. One woman felt that she no longer wanted to feel sorry for herself, nor did she want other PLHIV to feel that way. She questioned the contradiction between the "existing" and "emerging attitude" about PLHIV and said:

*Yes, that's one thing that confuses me is that, at first, when they said "you*

*have the right to live just like any other human being," but then "don't have kids". Don't live your life the way you want it. So it didn't make any sense to me at first. But then, I just made the decision myself. To live my life the way I want it. And if I want to have children and I've seen around, and read books and all that, and there's so many women everywhere who have kids, and they are HIV-positive. I'm all for empowering women to understand that they have more choices regardless, and they don't have to depend on charity. To me, it's an existence. They don't have to exist, they can have a life.*

*(30-year-old Papua New Guinean woman)*

Many of the women exemplified the "emerging attitude" about PLHIV when they decided that, although they were HIV-positive, they wanted to get on with their lives.

Judy is a woman who suffered from the harmful effects of stigma and discrimination based on the "existing attitude", but she has also taken on the "emerging attitude" about PLHIV.

**Box 1. Judy's Story**

Judy is a well-spoken woman and she has much to say about her experiences living with HIV. She is 32-years-old and from a small town station in Western province. She is a trained primary school teacher by profession. Judy met her husband five years ago. They met in Port Moresby and then moved back to their home province. At the same time as Judy was expecting her first child, her husband became very sick. She suspected that it could be HIV so she was tested, but asserts that the health workers never shared the positive results with her. She assumed that was because there was no treatment there at that time. Her child was born and she breastfed the child. As her husband continued to be ill she went for another test and then she learned that she and her child were both HIV-positive. She said:

*I was very disappointed with my husband because I knew he was the one who contracted the virus and passed the virus onto me as an innocent mother. And the child is also an innocent one and he infected us. So I just got so disappointed with my husband and then I took off. I told him, "I'm going to travel to Moresby and I will make sure that I will take you to court."*

Judy has taken on ideas about women and HIV and described herself and her child as innocent victims but she was not passive as she wanted to take her husband to court. A few months after she travelled to Port Moresby she learned that her husband had passed away.

In addition to maintaining her own health and caring for her daughter, Judy has also suffered as a result of HIV-related stigma and discrimination. She said:

*Like back at home, when I was there, everyone knew about my husband's situation and they were suspecting that he had AIDS. And there was so much stigma and discrimination. And because I was a teacher, everyone knows me there.*

Port Moresby has much to offer in terms of support for Judy. Many of Judy's immediate family members live in Port Moresby. She has disclosed her status to them and says that they care for her and support her and her child. She has also received ART treatment from an HIV clinic and says that it has helped to boost her immune system and increase her CD4 count. She has received NGO support including counselling, attended training workshops, and joined a PLHIV support network. The PLHIV support network has been particularly helpful. With the support of an NGO she conducted an awareness-raising session for her community in Port Moresby and disclosed her status to them. She felt that:

*The awareness just made me feel free from stigma and discrimination. It's when you open up and tell the people that you're like this and that [living with HIV], and people need to know the basic information on HIV and AIDS, so that you're not*

*discriminated [against], you're not stigmatized – you'll get the best care and treatment and love from your neighbourhood as well. I think back home (in my Province), people don't know the basic information on HIV and AIDS. There's just so much discrimination, back at home, (and) in the rural areas.*

She later went on to explain that she feels that stigma and discrimination are not really a problem in the city, because people are better informed. Yet she noted that others may face a different situation.

Judy still has questions and concerns about stigma and discrimination in Papua New Guinea. For example, she is concerned about how PLHIV can truly seek justice. She noted:

*I know the HAMP Act is there but I don't see it very effective. If I am discriminated and stigmatized, where do I go or what do I do? People are not really aware of the HAMP Act. They don't understand the HAMP Act. That's why discrimination and stigma is around. There is a lot of telling people that you're not supposed to be discriminating and stigmatizing the PLHIVs but if they don't understand it [the HAMP Act], (then) we will still have discrimination and stigma.*

The mentality of not caring about legal frameworks such as the HAMP Act that Judy refers to is an apt observation as the HAMP Act has rarely been enforced.<sup>15</sup> She also had concerns about legal issues relating to HIV.

*I want to say something about how I feel. I know that I'm an innocent person, an innocent mother, and there are so many issues that we women face in Papua New Guinea. If I am bashed up by my husband, I know where to go; I can take him to the police station and lock him up in the cell. And if my husband contracted HIV or STI and infected me, is there a law on that? Can I take him to court for that? This is one thing that most women in PNG don't take into consideration. I really want women to stand their grounds and, you know, fight for their rights.*

Although Judy has suffered the effects of the “existing attitude” about PLHIV, she has chosen to take on the “emerging attitude” about PLHIV – she wants to stand up for her rights as a woman and a person who is HIV-positive.

### Summary of Key Findings

The participant's perceptions about women and HIV tended to view women as being at risk either due to shifting social and sexual practices or due to gender inequality in marriage. The shifting social and sexual practices that they described included relaxed attitudes towards sex, infidelity, going out, parties, nightclubs, alcohol consumption, and women having sex for money. The underlying view was that women were more at fault for the spread of HIV. On the other hand, women were also viewed as being vulnerable to HIV because of gender inequality in marriage which resulted in wives experiencing infidelity, marital rape and violence. Yet, there was an assumption that women would still be blamed in the context of marriage and their husbands' infidelity.

The "existing attitude" that many of the women noted and some had internalized demonstrates the lasting effect of HIV prevention messages. The "existing attitude" towards HIV and especially PLHIV appears to be present amongst those who have minimal understanding of HIV, for example some of the women's families and community members. By contrast, the "emerging" and often empowering attitude has been internalized by some PLHIV who have support. The empowering impact of this attitude demonstrates the importance of continued support for PLHIV. The pervasiveness of the "existing attitude" serves to remind us of the importance of delivering information on HIV that is culturally appropriate, gender-sensitive, and focused on care and compassion for PLHIV, which will help to ensure that the messages are effective and do not perpetuate

### Recommendations

- All agencies and organisations involved in the HIV response in the Pacific, as well as the media, should ensure that they promote messages about HIV that are culturally appropriate, gender sensitive and do not perpetuate stigma towards PLHIV. Part of this process should be the pre-testing of messages among PLHIV as well as regular monitoring of the impact of messages.
- National AIDS Committees and NGOs should offer training to the media on how to report sensitively on HIV. Media have an important role to play in dispelling myths about HIV and promoting the idea that HIV is a chronic manageable illness and that prevention is important, but that with treatment and support PLHIV can live healthy and happy lives. These messages could have a powerful impact in breaking down the barriers that currently prevent some PLHIV from seeking treatment care and support and others from undergoing testing to determine their HIV status.

<sup>15</sup> The recent report of the Commission on AIDS in the Pacific (2009) stated that "ordinary people find the court system difficult to access, the provisions under the HAMP Act have rarely been enforced and there has not been a successful case of prosecution under the Act" (p. 56).

- In PICTs without HIV specific protective legislation, governments should introduce the required legislation based, as appropriate, on best model legislation adopted in other PICTs. National and civil society organizations could conduct awareness on the legislation so that people, especially PLHIV understand their rights and responsibilities under the legislation.
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## CHAPTER 4.2

### Experiences of Diagnosis and Disclosure

This section discusses participants' experiences of being diagnosed HIV-positive and disclosing their HIV status. The women's stories show how they faced the complex issues surrounding disclosure such as involuntary disclosure; disclosing to family, friends and partners; and how people reacted when their status was disclosed.

#### Diagnosis

The participants' experiences around testing and diagnosis varied. As noted in Table 2, they had been aware of their status for varying lengths of time. Table 3 indicates the main reasons why women choose to get tested.<sup>16</sup> The quote below comes from a woman whose husband was ill and learned that he was HIV-positive but did not disclose his status to her. Later she became frequently ill. She stated:

*I had sores and whatever on my skin and I started to lose weight and ... I felt tired a lot, sweating at night, my cough just got worse and worse. So I decided to go up and I forced myself to go up the hospital, I went up to the hospital. While I was in the hospital, they had to refer me down to the disease control – that's where the PLHIV go there for treatment or for a blood test.*  
(29-year-old Papua New Guinean woman)

The majority of women chose to get tested because of their own frequent illness or because of their child's or husband's illness, which in some cases means that they had been HIV-positive for months or even years. From a treatment perspective it is ideal to be tested and treated earlier, yet many of these women were married and

**Table 2: Length of time the participants were aware of being HIV-positive**

	1 year or less	1-4 years	5-9 years	Over 9 years
# of women	9	10	4	2

**Table 3: Participants' reasons for having an HIV test**

	Illness			Antenatal	Husband diagnosed	Suspected infidelity
	Self	Husband	Child			
# of women	10	6	2	4	2	1

<sup>16</sup> Other studies from Asia and the Pacific indicate that frequent illness of women or their partners is the main reason for getting tested and the secondary reason was testing during pregnancy (APN+, 2009; Labbé, 2011).



did not feel that they had a reason to get tested.<sup>17</sup>

Women's descriptions of their experiences brought up important issues related to HIV testing and diagnosis. Several of the women were tested for HIV by doctors without their consent, and they only learned that they had been tested when they were informed that they were HIV-positive. This highlights two important issues: first a lack of consent, and second a lack of pre-test counselling.

Varying levels of counselling were offered. A few women received no counselling (4 women), the majority received some counselling (17 women), and the rest received pre- and post-test counselling (4 women). The two women who were diagnosed over nine years ago received counselling that today would be considered sub-standard. For example, one woman was told, "Just eat plenty of greens, go back to your village, and here is some money for bus fare and a meal. Now go on your way." Another woman described how she was told in a room in front of 8 people that she was HIV-positive and should then "prepare yourself to die". Yet, of those who have been diagnosed more recently, few received comprehensive pre- and post-test counselling.

### **Women's Reactions to a Positive Diagnosis**

The women described how they felt after learning they were HIV-positive. Their main reactions included shock, disbelief, sadness, fear, anger, shame and a sense of being lost. A couple of the women did not react with disbelief because they had husbands who had already been diagnosed and disclosed their status to their wives.

One Fijian woman conveyed her reaction by saying, "*I just couldn't believe it. I was so shocked, and I just feel like crying. I could not believe that I have HIV. I just felt lost, very lost.*" Another woman said:

*From there when they told me at first I was surprised, because I'm not the type of girl that goes around from place to place ... I was surprised and at first I was worried because our friends did the awareness and they told us about the sickness.*

(31-year-old Papua New Guinean woman)

The sense of disbelief and idea that "*I am not that type of woman*" or "*I am not a prostitute*" was expressed by many of the women, thus demonstrating how the women have internalized the idea that HIV is associated with sex work. It also shows that women often feel that they are not at risk because they are married women.<sup>18</sup> Yet only two women in this study were involved in sex work, the majority were married women.

Some of the women felt that they had contracted HIV from their husbands who had been unfaithful and they were angry with their husbands. One woman's husband worked at the mines as a rigger, travelled throughout the country and had many girlfriends.

*He was diagnosed and he got the result that he was positive, but he didn't tell me that he was positive. And then, maybe after two or three months, he was really down [ill]. I saw rashes and his hair was falling out and his lips had sores. So there was a sister, a nurse. She*

<sup>17</sup> It is common for people from Pacific small island countries to seek health care late into the disease process (OSSHM, 2008).

<sup>18</sup> Labbé (2011) similarly found that many HIV-positive women felt safe from HIV as they did not belong to a "risk group".



got married to my uncle. And she knows that maybe something is going on with my husband, so she told me to go the clinic to try and test the blood. And then they told me that your husband is diagnosed with HIV. At that time I got really mad with him. I felt like murdering him or something, because I was forced to marry him, ah? And when I found out that he was HIV-positive I was really mad and worried about my children. Who is gonna look after them? I feel like there's no hope in my life.

(29-year-old Papua New Guinean woman)

This woman was forced to marry her husband when she was 16-years-old. This is a clear example of the lack of sexual citizenship as this woman had little or no say in marrying, having sex with and eventually contracting HIV from her husband.

Overwhelmingly, the concerns expressed by the women when they were diagnosed were in relation to their children and how their families would react. A 32-year-old Fijian woman expressed a sentiment felt by many of the women and said, "I was afraid that I will pass it to my son ... and I felt scared because I was thinking that my family is going

to push me away."

Fear of rejection stems from the stigma and shame surrounding HIV. Other women said:

*In some provinces, they kill them [PLHIV] alive. Sometimes they bury them. They don't want (to bring) shame into their village or community, so they do that. I was thinking of that and I was really scared. And I tried to get my baby and just run away from them, because people were doing that. So it was really hard, like, I can't stay. I just feel like killing myself.*  
(25-year-old Papua New Guinean woman)

*I wanted to kill myself or just run away, you know, jump from a building or something. But the people around me were offering support and told me that God loves me ... I was also wondering (to myself), "what will my family say?" Even after I knew I had HIV for some time, I still kept thinking, "I am going to die." I still shed tears everyday.*

(29-year-old Fijian woman)

The stigma and shame surrounding HIV is so strong that many of the women said that they contemplated suicide when they received their diagnosis. In these two cases it is ideas about HIV, the idea that they will suffer severe discrimination and the idea that they are going to die, that lead the women to contemplate suicide.

Counselling services offered to HIV-positive women are essential to aid them in coping with their diagnosis. One woman attested to the positive impact of counselling, stating:

*From the beginning I always knew that I should get on with my life. I just didn't know how or where to start or what to do. And when I went in for counselling, they helped me a lot. They sort of pushed me and didn't stop pushing me until they could see I was standing on my own.*

(30-year-old Papua New Guinean woman)

Counselling plays an important role in aiding PLHIV to cope with their status and is an important source of support for those who are considering disclosing their status to other people in their lives.

### **Disclosure**

For HIV-positive women the decision of whether or not to disclose their status and choosing when to disclose to their partners, families, friends and communities is a difficult process. On the one hand they would like to have support, yet they also fear that they will be judged and ostracized. Some women disclosed their status voluntarily while other women had little or no choice at all in the disclosure process due to breaches in confidentiality. Breaches of confidentiality appear to be routine in Fiji and Papua New Guinea (Labbé, 2011;

Hammar, 2006). Table 4 demonstrates who the participants disclosed their status to and whether or not it was voluntary.

### **Minimal Disclosure**

Two of the women interviewed had disclosed their status to neither family members nor friends, but were aware of PLHIV support networks through health workers. These women carried an enormous emotional burden by keeping their status to themselves. They struggled with depression, anxiety and loneliness. For those who chose minimal disclosure, the support provided by health workers was crucial. They also described the sense of relief they felt by sharing their stories even with just the interviewer. The experiences of a woman who chose minimal disclosure are explored later in a case study in Box 4. It is highly likely that a significant proportion of HIV-positive women choose minimal disclosure, yet they are likely underrepresented in this study as they are difficult to reach.

### **Disclosure to Family and Friends and the Community**

Most, but not all, of the women voluntarily disclosed their status to their families. Reasons varied and included wanting the support of their family, feeling that they had to

**Table 4: Participants disclosure of HIV status**

	To No one	To Selected friends only	To Family	To their Community	To the Public
Total Number of Women	3	1	7	10	4
Voluntary verses involuntary	Not applicable	1 voluntary	5 voluntary 2 involuntary	3 voluntary 7 involuntary	4 voluntary

lift the burden of being the only one to know, thinking their family would notice their loss of weight or change in appearance. One woman described how she came to tell her family that she was HIV-positive:

*When I was feeling very sick, it was my Mum who began to question me. And I just had to open up and tell her that my results were positive, I was HIV-positive and this has also affected my little girl as well.*

(32-year-old Papua New Guinean woman)

This woman felt that she had to tell her family but others did not decide to disclose their status to their families and had their status involuntarily disclosed by health workers. This indicates that principles of confidentiality and voluntary disclosure are not always adhered to.

Some women found that once they had disclosed to their family, a family member then disclosed their status to the community without their permission. These women then had to deal with the reaction of their families and the reaction of their community and after hearing accounts of PLHIV having been burnt and buried alive it can be a petrifying ordeal.

### **Reaction of Families and Communities**

The families and friends of the women reacted in different ways. Many, but not all, family members were supportive. Some were supportive but the women still felt that they were treated differently. For example, one Fijian woman explained that once her family learned of her HIV status, they offered her financial support and sym-

pathy. Yet her sister-in-law said that she no longer wanted her to hold or hug her niece. Other women explained how their families reacted:

*It sort of burdened me and I was thinking and worried and it made me feel lost ... my mind was not working. I was all confused. And then it came to a time when I just opened up. I called my Dad and Mum, I sat them down and I told them, and I said, "Look, I'm in this situation and I have no choice but just to tell you, if you people can help me or support me or give me hope." And then my Dad and Mum told me, my Dad he accepted me. He's the type of person who cares about when we're sick or in this type of situation, he's always there. So he told me, "No, you are just like part of us and you are not a dog or a pig or something that we would chase out from our house." But my Mum is, she, you know, she sort of rejected me. She said, "You've been looking for it and now you got it and you're gonna live with it until whatever happens to you." So, when I heard that, it sort of made me go down again.*

(29-year-old Papua New Guinean woman)

*When I was in the hospital I asked the doctor to tell lies to my family, not to say that I was HIV-positive. So he told them that I had blood cancer. I thought that if they knew about my status, they would think that I was some sort of prostitute woman or something ... Later on I asked the doctor to tell my family that I have HIV and my family said, "That is ok. We will sup-*

*port you and we will still take care of you."*

(32-year-old Fijian woman)

Although this woman was supported by her family, her parents then told the village chief who asked her to come to the Church and disclose her status. She felt that people in the village stared at her and gossiped about her, but she had tried to just move on.

When people in the community became aware of the women's status, in many cases they reacted in a stigmatizing way. One Fijian woman described how she felt that the people in her village didn't want to physically touch her, and gossiped about her. She felt that she was judged, and stated that, *"In the village the way they act is like by saying it is your fault (that you have HIV) because you used to drink and go to pubs and all of that."*

Another Fijian woman described how people in her village no longer wanted to visit her house, share food with her, or share the toilet and water facilities which they had previously shared. Some women were stigmatized by some in their community but



were supported and accepted by others while other women felt that they were generally embraced by their community. One woman who lives in an isolated village in Milne Bay Province, Papua New Guinea said, *"Yeah, all of them are, like, when they meet me anywhere, they just say 'Morning' to me or they support me. I feel the community people support me. They don't ignore me or anything."*

### **Disclosure to and Reaction of Partners**

Disclosure to partners generated stress and anxiety for many of the women. Of the 13 women who thought that their husbands were unaware of their status some (10 women) chose to disclose their status to their partners while others (3 women) chose not to. Labbé notes that for married women disclosing their status entails many risks including abandonment by their partner, losing their place to live and loss of their partner's income. One young Papua New Guinean woman from the Highlands who ran away from her husband after learning of her status stated that:

*So, I did not admit to have that we're this and that we're HIV-positive. So I feel like it is hard, I can't approach (him), I can't tell him that we have this thing [HIV]. We have this sick in our blood, or we are this and that ... I can't tell him. So I just kept it secret.*

(22-year-old Papua New Guinean woman)

This woman was angry with her husband because she felt he had been unfaithful, so she chose not to disclose her status to him.

Of the women who did disclose their status, their partners reacted in different ways. Some of the women discovered that their partners were already aware of their HIV status (five partners), some partners denied that they were HIV-positive and became angry (three partners), and others (two partners) were supportive (even when they had not been diagnosed HIV-positive). One young Fijian woman described why she felt that her husband must already be aware of his status as when she told him he responded casually and told her “don’t worry”. This confused her because he did not react violently in the way that she had anticipated and he was already frequently ill.<sup>19</sup>

Another young woman from Papua New Guinea describes how her partner became aware of her status and how he reacted:

*My husband didn't know that I was HIV-positive. So when I started getting sick, my husband used to come and visit us only and go, but I didn't tell him that*

*the baby was HIV-positive and (that) I was HIV-positive too. And my husband didn't go for a blood test, and after three years, I went back to him and we stayed together, and I got pregnant with my second baby. They got my blood and they told my husband that I was HIV-positive. But I already knew I was HIV-positive from the first one [baby]. So that was new in my husband's ear and then he started blaming me and he said, “You gave me this HIV.” I said, “I didn't know I was HIV-positive, that was from that small girl, so I'll blame you or me?” I told him that. He said, “I'm gonna kill you.” So we fought on the issue.*

*(25-year-old Papua New Guinean woman)*

Blame was a reaction experienced by women as well as men, yet because of the inequality within marriage and intimate relationships, women often have limited recourse when they blame their husbands. This issue is discussed in section 4.6.

## **Box 2. Josephine's Story**

Josephine's story provides details about her experience of being diagnosed and the struggles that she faced as an HIV-positive woman who has very limited support.

Josephine is a young woman who keeps her HIV status hidden from the people in her life. She is a single mum, in her mid-20s. She struggles to earn money to support her children. Lately she has been making and selling *roti* (a type of Indian bread) to earn some money. When she sells *roti* she gets up at 2am to prepare it; by 10am she has already completed a day of work, so she takes a short rest. She makes about FJD10 profit each day.

<sup>19</sup> A study on the Perspectives of Women and Girls Living with HIV in Asia and the Pacific highlights the fact that confidentiality clauses allow their male partners to avoid disclosing their status to their wives (UNDP, 2010).

Josephine met her husband Naca when she was 20-years-old. She quickly fell for him even though he was not the type of guy that her family approved of. She says, *"I was so in love, so I looked the other way ... I was not brought up to go with a guy like that, but I went with him anyway."* They got married and she had a child the following year. They had a volatile relationship, which involved him running around with other women, heavy drinking, and they would get into heated arguments. Sometimes he would become violent and throw things at her, punch her, pull her hair, slap her and each time she got a beating she would want to run away. Sometimes she did run away, but then she always came back and despite all of their problems they stayed together.

One day Naca's hair started to thin, he began losing weight and he told her that they should get tested. They were tested for STIs including HIV and were notified that they had an STI. Then six months later when Josephine went to the clinic she found out that they were both HIV-positive. She described her reaction and said:

*Oh I was shocked. Really shocked that I could have HIV ... I thought I was dreaming. My doctor said, "Ok, I won't beat around the bush, ok? I'll just tell you right now you're HIV positive." I'm, like, "What?" And the rest of the day I was, like, crying, crying, and crying. It was like I was in another world.*

Upon diagnosis she was not offered counselling and was left to deal with things alone. At the time when Josephine received her diagnosis her husband was away and she was in the hospital looking after her auntie. She decided to tell her auntie, who was on her death bed and who died soon after, and she and her auntie and her husband are the only people to whom she has ever disclosed her status. Josephine copes by drinking grog, booze and smoking. She says, *"I try not to let it get to me.... And just try to forget about it."*

There are a number of reasons why Josephine has chosen not to reveal her status to anyone that she is close to. She says that, *"It was good that it happened to me, because before, I was one of those type of people who was really, really judgmental. I was not the type of person who would want to do NGO work or have any contact with people with HIV. And so God punished me for the way that I was thinking."*

She says that her family also are very judgmental and that is why she has not disclosed her status to them.

Josephine struggles to get by as a single mum. She faces fatigue, hunger and loneliness on a daily basis but is not giving up. She says, *"I want to live a normal life. I don't want to let it get to me..."*

### Summary of Key Findings

The women's experiences of diagnosis and disclosure demonstrate the difficulties they face. The majority of women were tested because of illness and not because they wanted a routine voluntary test. There were also women who were tested without their consent. Stigma and shame associated with HIV generate intense reactions as women fear that they will be judged. The women's reactions after learning that they were HIV-positive included shock, disbelief, shame and considering suicide. Pre- and post-test counselling can help women to deal with these reactions and are shown to have a positive impact when they are provided. Counselling that results from referrals provided by health workers is especially important for women who have chosen not to reveal their status to family and

friends and who therefore lack support.

The women's experiences related to disclosure illustrate the difficulties women face in maintaining control over disclosure of their HIV status. Many of the participants experienced breaches of confidentiality. The reactions of the women's families and partners after disclosure varied. Their experiences ranged from isolation and disassociation to unconditional support immediately after they disclosed their status. When it came to partner disclosure, most of the women chose to disclose their status to their partners. The partners' reactions in some cases included anger and denial while other partners were supportive. Importantly, many of the women felt that their husbands were already aware that they were HIV-positive.

### Recommendations

- Provide appropriate testing services and promote routine testing via effective educational messages directed across the community to help remove stigma associated with testing. Testing services need to be widely available and provided in an environment that encourages and enables all people to be tested. Testing services should be non-judgmental; include adequate pre- and post-testing counselling, information and support; and fulfil the guarantee of confidentiality.
  - Ensure sufficient resources and numbers of skilled personnel to provide on-going support and assistance to PLHIV and their families and communities, including through outreach services. Counselling and support are particularly important at the time a PLHIV chooses to disclose his or her status to his or her family and community.
  - Train more health workers as counsellors and provide regular refresher training and support for them.
-



## CHAPTER 4.3

# HIV-positive Women's Experiences of Treatment and Health Services

Many of the women attested that ART had an immensely positive impact in helping them to live healthy lives. This section discusses the women's experiences of using ART and other forms of treatment and their experiences with health workers. Despite the positive impact of treatment there are still issues that impede both access and adherence to ART. The women interviewed noted a number of ways in which treatment and health services could be improved.

The majority of women interviewed had experienced health problems that ranged from minor opportunistic infections to being severely ill with full-blown AIDS and bedridden for several weeks. The deteriorating physical condition that some women experienced meant that they could no longer work in their gardens, carry heavy loads or even carry their children. Many of the women had to be treated for conditions such as tuberculosis, malaria and STIs. Some of the women said they frequently experienced cough, flu, diarrhoea, fatigue, skin problems and weight loss. All of the women interviewed had at some point had utilized health services to access treatment after they were diagnosed HIV-positive.

Some of the women were unhappy because their appearance had changed. One woman stated, "*HIV has changed the way I look; it took away my prettiness. And*

*now I don't feel good (about myself)."*

Other women described the consequences of poor health:

*When I was first diagnosed, I was really sick. I couldn't do anything physical, like I can't walk, I was sleeping (a lot), losing weight, started coughing, all my hair was falling out, sores, all those signs were coming. I know I was like that, so I was hiding in the house. So, I didn't do my normal work in my home, I used to just lock myself in the house. I felt ashamed (to be seen) by my community. And I used to hide.*  
(25-year-old Papua New Guinean woman)

This woman's experience and the experiences of other women interviewed demonstrate how poor health can lead to social isolation. Yet, for many, access to health services and treatment, especially ART, can have a life-changing effect.

### **Impact of Treatment on Women's Lives**

Many of the women who were taking ART described the positive impact that it had on their health and their lives in general. Of the 25 women who were interviewed, 18 were currently taking ART. Of the seven women not on ART, one had taken it while she was pregnant to prevent mother-to-fetus transmission and one woman had stopped due to the long distance she had to travel to access treatment. Generally,

women taking ART said that health problems such as diarrhoea, skin sores and severe weight loss diminished. ART also led the women to gain weight and increased their strength, which enabled them to resume regular daily activities. The following two women described the positive impact that ART had on their health and lives:

*After two weeks (on ART) I realized I don't have diarrhoea anymore. I begin to realize the dandruffs were fading away. It gave me confidence and strength that I will maintain my health back and get back my strength.*  
(27-year-old Papua New Guinean woman)

A 25-year-old Papua New Guinean woman said, "I'm getting a bit happy, walking around. Before, I used to get sick and after the treatment, I feel like I'm like the others ... walking around, talking and taking food."

These women's descriptions show the impact that ART had on their physical health, which in turn works to improve their emotional health. Several of the participants stated that taking ART made them feel like they were like "normal" people again. The *art of living* study (2009) similarly found that ART allowed PLHIV to live healthier and happier lives (Kelly et al.).

ART affects the way that people view HIV, including those who are living with the virus. One 29-year-old woman from the Southern Highlands whose husband had died of an HIV-related illness a few years earlier felt that there was no reason to get tested because she assumed that she was HIV-positive; she thought that there was nothing

she could do about it. But in early 2009 when an NGO came and conducted workshops on ART for PLHIV, which had become newly available in the area, she decided to get tested. She felt that she no longer had a reason to hide herself. She tested positive and is now on ART and says she feels good.

However, not all people want to begin treatment which has to be taken twice daily and can have many negative side-effects. One woman described the positive impact that ART had on her health and the health of her five-year-old HIV-positive son, yet she also noted that her husband refused to take ART:

*We're putting on weight, and we're staying properly. Not like before; (before), we looked really no-good [bad]. Now we are orait [good]. And then he [her husband] said, "What did you people do?" And I said, "Oh, we are on treatment." And then I asked him, "Did you go for check-up?" and he said "No." And I kept on telling him to go for check-up. I don't know if he went for check-up. But he kept on ringing and telling us that he's getting sick. And I told him, "You have to go for check-up." I said, "If you go for check-up, you'll be on treatment." I said, "Me and this small boy, we're on treatment so we're orait." And then I said, "This medicine that we're taking now is..." I said, "This is our life. The rest of our life, we'll be drinking this medicine." And then he said, "Why?" I said, "This is to protect us, to stay long." Then he spoke up and said, "I'm tired of... I don't want to drink medicine every now and then," and I said, "No this medicine is good because it is really*

helping.”

(26-year-old Papua New Guinean woman)

There may be other reasons why people such as this woman's husband refuse treatment. Perhaps they do not want to be seen at HIV clinics or they may feel that they do not need it.

Side effects also affect ART uptake and adherence. Another woman simply stated:

*... when I first got my status, I tried taking whatever the doctors gave me ... Septrin® and all sorts of other stuff that they gave me and it was like, they told me, you'll get used to it, taking medicine and all that. But I got sick more when I took the medicine. I think it was just a mind thing, it was just my mind probably. I'm not willing to adapt to taking medicine everyday. They actually told me that I could start taking the*

*ART. But one day I just threw my medicine out of the window. I'm not taking it anymore. I don't take Panadol®. I don't take any of the stuff.*

(30-year-old Papua New Guinean woman)

Other women also experienced side effects from taking ART. Some women experienced significant weight gain; some of them gained more weight than they wanted to. Another woman who had recently switched the type of ART that she was taking experienced hair loss, itchiness all over her body, diminished eye sight and swollen feet.<sup>20</sup> ART can have an immensely positive impact on people's lives, yet there are a number of factors, such as side effects, that affect people's attitudes and behaviour in relation to taking it.

Increased appetite is a common side-effect of ART. *The art of living* (2009) study found that 73% of those surveyed experi-



<sup>20</sup> Some of the issues this woman described are recognized side-effects of ART and may only be short-term.

enced an increase in appetite and 33% of them did not have enough food to satisfy their hunger (p. 12). One Fijian participant was happy to have regained weight after she lost a significant amount, but at the same time her appetite increased so much that she often felt hungry but could not afford to eat because her only source of income was the money her sister sent from abroad. This only allowed her to pay her expenses and purchase a limited amount of food. A Papua New Guinean woman said that she often felt uncomfortable cooking food for herself and not sharing with her family members, so she sometimes took her medication on an empty stomach although she had been instructed to take it with food.

### **Adherence**

Some women also raised issues related to ART adherence while discussing their experiences of treatment. One key issue is the person's understanding of ART. For example, a woman from Fiji described how, when she began taking ART in 2008 when she was unwell, the health worker gave her instructions about how to take the medicine but she did not understand. She says, "I went home and I thought that you were supposed to take the medicine [ART] like Panadol®. So I just took it whenever I was feeling sick, like if I had a headache or diarrhoea or something, I would take it then." When she went for her next check-up she learned that she should be taking her ART twice daily at the same time each day. Other women in Fiji and Papua New Guinea also described how they did not adhere to their treatment when they first began taking it, especially if they were not experiencing signs and symptoms. Some women said they had not yet started ART

but would do so in the future. They also felt that they wanted to know more about it. Many of the women on ART were vigilant about taking their medication and felt that it had basically become a habit. Some of these women described ART as a lifeline, especially those women who had been very ill.

### **Use of "Traditional" Medicine and Herbs**

Some of the women used traditional medicine to treat their health problems.<sup>21</sup> The women used traditional medicine, or "herbs" as it is commonly referred to in Papua New Guinea, in different ways. Some women took herbs before they began ART. One young woman from Milne Bay Province was extremely ill and confined to bed. She described how she lost a significant amount of weight, her hair fell out, her body was covered with sores, and she was "at the AIDS stage" and close to death and then she was given herbs, which she took and slowly regained her health – her hair grew back, her skin cleared up and she gained weight. At that time, she was not on ART. She said:

*I explained to the doctor, I said, "I was in the worse condition, I was already dying and I got this herb. And these herbs that I drank, it was really strong. Really strong. So it sort of, like... all my skin and the sores just come out. And every time I drink that cup, I go the toilet and all the rubbish come out." So after we talked and everything, the doctor told me, "I think we have to put (you) on the ART medication now." I said, "Doctor, I'm already fine and I don't want to be put on the ART treatment," and he said, "No, for your safety, you have to be put on treat-*

<sup>21</sup> It is common for people in the Pacific to try traditional medicine to treat STIs before seeking health services (OSSHM, 2008).

ment." And then I was really strong. So I said, "No, I'll continue on my herbs and whatever happens, I can always come (get ART)." But he was so strong and persistent, he convinced me to take the drugs. And I asked my parents and my dad said, "It's up to you," because he explained that the first time when you are taking the ART treatment, it will make you feel side effects. That's why I didn't want to take it at the first place. But because my dad was asking me, I had to take it. Then I started taking the ART treatment – that was in 2005, up until now. And then, from there up until now, I didn't even get sick. Like, I had sort of headache and that, but not anything worse (than that).  
(29-year-old Papua New Guinean woman)

This woman felt that herbs helped her to recover. Her story also shows the comfort she had taking herbs as opposed to apprehensions over taking ART as a form of Western bio-medicine.

Other women had different views on herbs:

*I tried all kinds of herbs. Before, there (wasn't) anything like ART or there was no counselling school like 2000, 1999, during those years. That time, it was very hard for me. But I didn't know (that) God had a plan for me, so I survived then. Before, (when I was taking) herbs (I was) not good. Now I'm with Bactrim, I'm okay. With herbs (I) just wasted my time on herbs, looking for everything, every leaf and (they) nearly made me sick, too. Big kus [mucus] used to fill my throat up. Because right in the morning I run to the bushes, thick*

*bushes, look for leaves... now, I like Bactrim.*  
(33-year-old Papua New Guinean woman)

While these women took herbs before starting ART, other women used herbs to supplement ART. Labbé (2011) noted that some Fijian PLHIV use traditional medicine to treat symptoms, but that they were also afraid of potential drug interactions. Generally health practitioners do not recommend use of traditional medicine given the potential for interactions between them and ART which could possibly decrease the effectiveness of ART (Babb, Pemba, Seatlanyane, Charalambous, Churchyard, & Grant, 2007).

#### **Treatment to Prevent Parent to Child Transmission**

When HIV-positive women who are pregnant receive ART generally transmission of HIV from mother-to-fetus is prevented. In 2009, five women in Fiji and 263 women in Papua New Guinea received treatment to prevent parent to child transmission (UNGASS Fiji, 2010; Papua New Guinea Department of Health, 2010). Of the 25 women interviewed, 4 had taken ART to prevent transmission of HIV to their child either in utero or during delivery. Three of these women had HIV-negative babies, while one woman's baby had not yet been tested. There were eight women who did not receive treatment because they were unaware of their HIV status while they were pregnant. All but one of these women had a child who was HIV-positive. Two of the women had HIV-positive babies who died and both were tested because of their ill health and the ill health of their babies. Both women became pregnant

again and received treatment to prevent transmission from mother-to-fetus.

Participants' experiences of receiving treatment to prevent parent to child transmission and of giving birth in a hospital as an HIV-positive woman were varied. Some women had very positive experiences, while others had negative experiences insofar as they were mistreated by health workers. One Fijian woman found out that she was HIV-positive during her fourth pregnancy. She felt that the doctor was very respectful and always made sure to lock her file away in order to maintain her confidentiality. Later, when she became pregnant again, she went on ART to prevent parent to child transmission. She felt the health workers were well prepared when she went into the hospital to have a caesarean section. Another Fijian woman described her experience in the hospital:

*The staff at the maternity ward treated me so well. I loved them. They were so kind and caring. The doctors didn't even wear gloves and so I didn't feel bad or different – I was touched....This is the sort of thing that keeps me going.*  
(29-year-old Fijian woman)

These women's descriptions of their experiences of being treated with care and compassion in the hospital show that this attention made giving birth a positive experience which helped to improve their overall outlook on living with HIV.

Other women, however, felt that they were stigmatized while in the hospital giving birth as HIV-positive women. One woman's story of discrimination from health workers in the

hospital is profiled in a case study later in this section.

### **Access to Treatment**

As the women discussed their use of health services they identified several factors that impeded access to health services and treatment. The main factor they noted was the distance and cost associated with travelling to clinics. Many women who live in and around urban centres said that they found it difficult to come up with the bus-fare they needed to get to the clinic. One woman who received social assistance which amounted to approximately FJD60 a month often had no money left when it was time to go the clinic. The return bus-fare was about FJD5, but it was money that these women often do not have. Other studies of the experiences of PLHIV have also found that distance and money to travel are the key obstacles to accessing health services (APN+, 2009; Kelly et al., 2009; UNDP, 2010). Other factors that limited the women's access to health services included being too unwell to go to the clinic and having to take time off work to visit the clinic during regular operating hours.

People who live in isolated areas face greater difficulties in accessing HIV-related health services. For example, Rina is a 31-year-old Papua New Guinea woman who lives in an isolated coastal area of Milne Bay Province. For Rina to travel to the clinic in Alotau she has to either pay K30 to travel by boat, which takes approximately five hours, or walk for three hours up and down a mountain and then travel by bus or truck on the highway, which costs around K10-20. Rina and her family have a garden and grow their own food. Sometimes they earn



cash by selling their crops at the local market or by making copra. They spend their earnings to buy rice, tinned food and occasionally to travel to Alotau. When she was initially diagnosed HIV-positive Rina stayed in the hospital for three months receiving treatment. The following year she travelled to Alotau five times but this year she travelled to Alotau only once to receive treatment. She began taking ART last year and was initially given a two-month supply. She has gone back twice to get a two-month supply each time. However, recently, she has not been able to travel because of bad weather and because she has no money to pay for transportation. Hence, Rina has not been taking ART for just over three months and is contemplating taking herbs instead. Rina's situation exemplifies the circumstances faced by many women in Papua New Guinea who live in isolated areas - travelling to the clinics for treatment services in towns and cities is a challenge.

Another woman's struggle to receive ART in Port Moresby revealed other issues related to treatment access. This young woman, Raka, had recently moved to Port Moresby. Soon after she arrived her health began to deteriorate, so she sought health

services in Port Moresby yet still faced challenges within the system. When she went to the clinic she was told to bring her medical papers from the clinic that she had first attended in her hometown, which is an expensive plane ride away. She felt she was treated poorly by the health workers and did not want to return to the clinic in spite of having diarrhoea, itchy skin and sores all over. Raka spent months trying to get treatment at the hospital and went to the clinic four times. During this period her health continued to deteriorate. She became extremely ill, lost weight and she felt very weak. Three months later she learned about the VCCT services offered by Anglicare. She went there and asked for a test, pretending that she was unaware of her status.

Raka managed to find her way through the system to gain access to the health services she needed. Two weeks after she visited Anglicare she went on ART. From when she began to seek treatment in Port Moresby to when she went on ART, her weight dropped from 80 to 40 kilograms. After being on ART for one month she had gained 20 kilograms, she felt stronger, the diarrhoea had ended and sores had disappeared. While discussing treatment and care, Raka said:

*It's good that they give us that treatment because it helped us to restore our strength and help us to gain our weight, build our strength and everything. Now we're living like normal people. So I'm very happy. I will always be faithful to drink my medicine ... I always carry it in my bag, and my cold water, because I might be late (getting home). I never miss my medi-*

*cine – this is very important.*

After becoming extremely ill she was able to comprehend the importance of adhering to the medicine she was prescribed. She noted the medical and emotional support that Anglicare provided in helping her to live a “normal” life.

### **Health Workers**

The women described the immense impact that health workers have in shaping their experiences of using health services. In some cases health workers had a positive impact through providing emotional support and information that helped them to deal with their condition. In other cases health workers treated the women poorly and discriminated against them, which often increased feelings of stress, anxiety and isolation.

### **Positive Impact of Health Workers**

Many of the women noted the positive impact that health workers had on their lives. Some of the women said they were treated well and that the doctors, nurses and counsellors they met with were friendly, kind and helpful. One young woman, who lives in a small town in Papua New Guinea, said:

*So I explain it to the Sister to expect me during lunch hour so she's good. She helps me. Sometimes, when I don't turn up, she comes down and asks why? What (happened)? But she tried to keep away from coming to see me at the shop because friends might ask many questions. So she's good.  
(27-year-old Papua New Guinean woman)*

This young woman noted the lengths that some health workers went to in order to

provide support to their patients. Another Fijian woman said, “*The doctors, they all take such good care of me and I don't feel afraid. They were so kind and they, you know, they told me how to take care of my life.*”

### **Negative Impact of Health Workers**

In other cases women had negative experiences with health workers. Some women felt that health workers were too busy and did not give them enough attention, while other women felt the health workers were not sympathetic. One woman said:

*In hospitals, sometimes when we go late for our appointment, sometimes we don't have bus-fare to catch bus and go. Sometimes when we have no bus-fare we used to walk. So that makes it, like, as soon as we go there, it's time up, and they want to close it [the clinic] and they get cross [angry] with us and say, “What's your time? You should come early in the morning!” and we say, “Oh, we have no bus-fare, try and understand that we have no bus-fare.” Like, they used to get cross with us. Sometimes they send us back (home) without our medication or treatment. So we used to go back and next day we used to come early to get our drugs.  
(29-year-old Papua New Guinean woman)*

In some cases health workers scolded patients for turning up late. In Papua New Guinea especially, many health workers are under-equipped, under-paid and over-worked, adding to the stresses under which they work.



Some women were also discriminated against by health workers.<sup>22</sup> Breaching confidentiality is a common form of discrimination. For example, one Fijian woman described how a nurse breached confidentiality and actively took steps to ensure that people from her community were aware that she was HIV-positive. In other cases, doctors informed the women's families without first obtaining their consent. One woman from Papua New Guinea spoke to her doctor about having children and she said:

*My doctor when he first advised me not to think about children or a relationship. I started thinking about having an operation [to be sterilized] so I spoke to him about it and he referred me to the gynaecologist ... And so when I went to see her, she looked at my referral and she threw it out. She threw it in the bin. And she told me it doesn't matter if you're HIV-positive or not. So she told me something different. And when I was admitted, when I had the miscarriage and I went into hospital she was there ... and she treated me just like any other patient. I was in the same ward as everyone else.*

*Nobody knew. Even I didn't even realize it, I totally forgot about my status at the time.*

(30-year-old Papua New Guinean woman)

This woman's story reflects negative and positive experiences with health workers. Initially the doctor told her that she could not have children despite the fact that treatment to prevent parent to child transmission is available where she lives. However, the doctor that she was referred to

did not discriminate against her, treating her in the same way as other patients.

### **Women's Perceptions of Health Services**

While the women relayed their experiences of using health services they also conveyed their perceptions of health services. Two issues that were commonly raised were counselling and access to treatment.

Several of the women expressed their views about counselling. Overall, many felt that counselling services could be improved. Many of the women in both countries felt that they would like more counselling, including adherence counselling, and that counselling services should be accessible and promoted. For example, some of the women who had lost their husbands or children to HIV felt that they needed counselling to help deal with the emotions of losing a loved one.

Many women also expressed their views on access to treatment. One woman who lived in Port Moresby felt reassured by the fact that she knew that ART was now available in her hometown of Goroka. Another woman who lived in Alotau, Milne Bay Province, said, "It's easy. Well, for me in town it's easy. I don't know about (other people)... half of the population of Milne Bay live on an island, so it's very hard to get a boat and come here or coming by road... it's very hard." Another woman expressed her concerns about access. She said:

*Like, services (are) not reaching out to the rural areas. We have a very rich country full of resources, but why is it that these services are not reaching out to the rural areas? You know, we*

<sup>22</sup> A study of the experiences of HIV-positive women in Asia found that 47% of the 1,306 women interviewed experienced discrimination from health workers (APN+, 2009).

*have a huge number of people who are affected by the virus. My husband is also one of them who did not have access to these services and treatment, so he passed away. I couldn't stay there because no services there. It's very expensive travelling here, just to have access to these services and treatment. While the other ones, unfortunately, are suffering there. So what can we do?*  
(32-year-old Papua New Guinean woman)

These women noted issues with access to treatment and other women noted their concerns with the quality and supply of treatment. For example, several women in different areas of Papua New Guinea were concerned that the treatment may run out one day or that they would be given ART that was expired – as reportedly happened

to one woman. They said:

*I see, for now, the people living with HIV, especially the ones that are already on the treatment, there will come a time when we'll be running short of supply. Like, that time I had to drink the expired one. So already, the hospital they're already keeping watch of what's going to happen ... so, like, even I heard from the Sister-in-Charge told me that – I mean it's already coming – like next year or the other year we'll face a lot of problems with how the medicine is going to be in shortage.*  
(29-year-old Papua New Guinean woman)

*The thing I really want for the future is I want the treatment for HIV. I know the ART is around, but that's only to help boost the immune system. But I want the real treatment for HIV. That's one of the things that I always question – if HIV is one of the STIs, and if all the STIs are treatable and curable, what about HIV?*  
(32-year-old Papua New Guinean woman)

Uncertainty about the future of HIV treatment in Papua New Guinea is something that people working in the field of HIV and PLHIV are well aware of. In March 2011 Maura Elaripe, an HIV-positive woman from Papua New Guinea who is an advocate for PLHIV, went to the media and described how she ran out of her supply of ART (Anon., 2011). If a vocal woman in Port Moresby has had her supply interrupted, the fears of other women who live in the Provinces are well founded. In Fiji, ART supply is less of an issue due to the comparatively



small number of people on treatment, yet they may someday face similar problems.

The women also noted issues they faced while using HIV-related health services. Breaches of confidentiality and discrimination by health workers have already been mentioned. Other issues included that many of the clinics that women used, particularly in Papua New Guinea were specifically for PLHIV or those who were getting tested. Some women felt ashamed to go to these clinics. One woman said:

*I was getting embarrassed to go into the clinic. Because most people know that this clinic is for this type of people, for the HIV-positive people, so the first time when I went in there I was really feeling out of place, like, what will this people think of me? But then as time went by, I began to get used to it and, like, it's nothing now.*

(35-year-old Papua New Guinean woman)

This woman managed to overcome her fears and sense of shame about going to an HIV clinic, but other PLHIV may not be able to overcome these feelings.

A woman from Port Moresby suggested changes to the system. She felt that the clinic is too public, which deters some people, and lamented that people can only receive treatment from the clinic where they registered. She felt that people should be given a card to identify themselves, a card that could be used at all the clinics through a computer system. This woman also felt that the support networks should be better promoted at places where people access HIV services. She suggested that leaflets and posters could be used to promote the support organizations. It is important that these insights from HIV-positive women are taken into account in order to help improve the quality of health services available to others.

### **Box 3. Sala's Story**

Sala's story demonstrates how HIV-positive women are vulnerable to discrimination in health care settings. Sala is a shy young woman who is slowly coming to terms with her HIV status, yet she has faced obstacles. She works at home taking care of the kids, cleaning her house and tending to her crops. She discovered that she was HIV-positive during her third pregnancy. She was shocked and contemplated suicide, but then she thought, "Who will look after my children?" and resigned herself to carrying on.

When it was time for Sala to give birth she had to go to the hospital to have a caesarean section instead of using a birth attendant as most women do in her village. She told her family that the baby was breach and that is why she had to go to the hospital to give birth as she had not shared her status with them. She was mistreated in the hospital. She

was put in a separate room and the nurses instructed her to use separate toilet facilities which isolated her from the other mothers. Sala sensed the nurses' discomfort in looking after her. The nurses' treatment led her mother to suspect that there was a reason why she was being treated differently.

She then said to the doctors, "*They [the nurses] know how HIV is spread and not spread. So why are they treating me like this?*" Then the doctor talked to the nurses and the next day they were kind to her, yet she still felt that they were afraid of her. After she was discharged from the hospital she was given a six-month supply of milk formula to feed her baby. Once that milk was gone, she bought cheap milk to feed the baby and sometimes gave her baby tea.

Sala suffered further discrimination when her status was leaked through a health worker and eventually people in the village learned that there was an HIV-positive woman in the village who has three children. Her family and community all found out her HIV status. She feels that people in the village judge her and say it is her fault because she used to drink and go out. Now she feels that she has to act differently and always behave properly. She is no longer outgoing, because she feels that people will judge her for not being modest enough.

### Summary of Key Findings

Participants' accounts illustrated how treatment, especially ART, has had an immense impact on the quality of life of HIV-positive women. However, there are many ways in which access and treatment support could be improved. The main problems they found with health services were: the lack of money to travel to clinics in urban and rural areas; limited access to ART in rural and remote areas; limited availability and promotion of counselling services; limited knowledge of

required adherence; side-effects from ART; use of traditional medicines; breaches of confidentiality; discrimination by health workers; support provided by health workers; social barriers to using clinics; uncoordinated ART access systems; and limited awareness of positive people's support networks. An ongoing concern, particularly in PNG, was the likelihood of enjoying continued access to ART without interruption in supply and distribution.

**Recommendations**

- Investigate the use of voucher schemes (or other demand-responsive ways of delivering health services) to facilitate individuals' access to testing and ART treatment and to help ensure maintenance of high-quality standards in testing and in the delivery of treatment, counselling, support and assistance to PLHIV, including the keeping of patient confidentiality.<sup>23</sup>
- Where relevant, develop a registration system where PLHIV can register and receive treatment from different clinics – to avoid the difficulties associated with the need to return to the same clinic each time. A voucher scheme linked to national registration could allow people on treatment to access treatment from any approved clinic. Rigorous procedures would be required to guarantee the privacy of PLHIV.
- In the short term, where travel costs and out-of-pocket expenses are a barrier to access, provide travel subsidies for PLHIV to attend clinics and counselling services to help ensure adherence.
- Within treatment centres, ensure that counselling services and educational materials cover the complicated issues of adherence and how to deal with side effects.
- Promote research into the medical and social benefits of traditional medicines and the interactions between traditional medicines and allopathic medicine. As evidence is assembled, prepare and disseminate culturally relevant explanations as to whether and how traditional medicines should be used in conjunction with ART.
- Government agencies and NGOs that are involved in the procurement and distribution of ART must be enabled to ensure continued supply to all PLHIV who begin treatment.

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<sup>23</sup> The Lowy Institute commissioned McKay and Lepani (2010) to produce a policy brief *Revitalizing Papua New Guinea's Health System: The Need for Creative Approaches* which outlines the use of demand responsive mechanisms.

## CHAPTER 4.4

# Experiences of Stigma and Discrimination among Women Living with HIV

This section explores the various ways in which the participants experience stigma and discrimination in the form of self-stigma and discrimination from family and within their communities. It also describes how they cope with HIV through support from family, friends, their partners and NGOs. Throughout the section the impact of gender inequality and gender norms are discussed alongside the women's narratives.

Stigma can be defined as "an attribute that is significantly discrediting" (Goffman, 1963). More specifically stigma consists of "devalued differences that are seen as socially discrediting, and that are linked to negative stereotypes" (Butt, Morin, Numbery, Peyon & Goo, 2010, p. 14). Discrimination refers to "specific acts that build upon these negative stereotypes, actions that are meant to discredit and disadvantage people" (Butt, Morin, Numbery, Peyon & Goo, 2010, p. 14). As Parker and Aggleton (2003) have noted, "stigma feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality" (p. 13). For example, gender norms and gender inequality affect experiences of stigma and discrimination, and sexual double standards lead women to suffer HIV-related stigma and discrimination more intensely than men (BRIDGE, 2007; UNDP, 2008).

A study of the experiences of HIV-positive women in Asia states that "women are judged as contracting HIV as a conse-

quence of bad behaviour but men are far less likely to face the same condemnation" (APN+, 2009, p. 25). *The art of living* (2009) study found that women were more likely than men to experience verbal and physical abuse, and 17.7% of females and 9.7% of men had experienced abuse as a result of their HIV status (Kelly et al.). Butt et al.'s (2010) study of *Stigma and HIV/AIDS in Highlands Papua* supports this notion and has shown that HIV-positive women are likely to feel dirty, unworthy and disrespected in their communities, whereas HIV-positive men continued to feel respected and needed. This study found that participants had limited control over the negative effects of stigma and when they experienced discrimination, it was intense.

### Stigma and Discrimination

HIV-related stigma and discrimination affects the way that PLHIV go about their lives. All of the women interviewed were affected by stigma and discrimination in different ways, depending on their situation; for example whether or not they had been severely ill due to HIV; to whom they had disclosed their status; and their overall understanding of HIV. Stigma affected their self-perceptions as well as the way that the women were viewed by others – their partners, families, health workers and their wider communities.

### Self-Stigma

Self-stigma is "the process whereby PLHIV impose feelings of difference, inferiority



and unworthiness on themselves" (Health & Development Networks, 2004, p. 3). Self-stigmatization affects people's "feelings of self-worth and personal well-being" (Butt, Morin, Numbery, Peyon and Goo, 2010, p. 26). Self-stigma also affects women's confidence to leave or confront an abusive partner and can act as a deterrent for accessing treatment and care (Esplen, 2007). A study that examined the experiences of women living with HIV in Australia found that stigmatizing messages about HIV "are so powerful and insidious that it is difficult for women not to appropriate them" (Lawless, Kippax, and Crawford, 1996, p. 1374).

Gender norms promote the idea that women ought to be good, kind and honourable towards their male partners and their families. These norms tend to intensify the blame put upon women, their own feelings of self-blame, and their engagement in self-stigma. Some participants noted that they had to be conscious of the way they conducted themselves because they would easily be judged and blamed for being HIV-positive by family and com-

munity members. As one woman stated:

*Women have to be nice to their families, you know? They have to be good to them. They have to be good by being there and staying around the house and not going out. Women should be faithful and tell the truth ... When it comes to HIV, well the thing is that men can stand up and fight back. But women are supposed to be humble and stay at home and be good to their family. They [women] have to be there for their family ... Women with HIV should listen, but men with HIV people will not say anything when they speak. (29-year-old Fijian woman)*

She added that because she lives in her village she felt especially compelled to adhere to gender norms and expectations. Another participant said she felt that people in the community would blame her if they knew she was HIV-positive. She says about her husband, "*His village, his family and people in the community (they love him) so they would say I brought it to the house.*"

Another woman had recently completed an NGO workshop that was designed to support PLHIV to conduct HIV awareness. She said, *"I want to share my story. But my Mom says, 'no' because it will spoil the family name."* Another woman from Papua New Guinea also stated that HIV would bring shame upon her family. She said, *"I don't want to bring shame into my family. Like in PNG, stigma and discrimination is in our country. So I don't want my people to stigmatize ... and say 'this girl is HIV-positive and they're looking after her'."*

In many cases, women experienced self-stigma regardless of whether their HIV status was known. One woman said, *"When I see people, I usually feel ashamed. They don't know my status, but I usually feel isolated (and) by myself."* When she was asked how HIV affected her life, she said, *"HIV affects me when I want to be somebody [go out and do things], like I want to entertain, like, look for jobs or be with other friends to do some activities ..."* Feelings of inferiority hindered this woman from living her life as she pleased. Similarly, another young woman wanted to take up nursing but was unsure if she could be a health worker because she is HIV-positive. She said:

*I'm not sure if it's safe for me to go to school. And if it's not, then how can I be keeping on with my drugs and all these things? These are questions that come in my mind you know. And if it's possible a person like me, a sick person like me, trying to help another person?*  
(27-year-old Papua New Guinean woman)

This young woman's sense of self-worth has

been diminished. Another woman described the way in which HIV had affected her life:

*I used to be very well, nice, fat. I was a good woman before. But after I got this sick, all my weight has been gone lost and I have become nobody. I went and asked (the) Sisters to give me advice. They said, "You don't have to worry, think a lot, you have to be normal, walk around as normal."*  
(45-year-old Papua New Guinean woman)

In stating that she had *"become nobody"* she reflects the loss of self worth that she felt as a result of being HIV-positive.

Another woman described how she assumed that she would be discriminated against, if she looked for a job in her community where her HIV status was known, *"Cuz, if I go look for job, sometimes some people can discriminate (against) us ... Some bosses, they don't understand ... They think that we [PLHIV] are useless to them."* This woman perceived that potential employers would discriminate against her. A Fijian woman said on this point, *"I thought that it [discrimination] would happen more. But sometimes I expected it to happen and it didn't."* Similarly, another Fijian woman described how self-stigma led her to feel conflicted. She said, *"These negative thoughts are only in my mind, but people don't do that. They come to my house to visit and ask for food."*

Some of the women interviewed chose to isolate themselves from their family, friends and community, and from the activities that they used to take part in. One woman



who had lost a significant amount of weight and was ashamed of her appearance described the emotional impact of HIV:

*I always feel lonely. I don't go out and visit my neighbours' house because they will talk too much. They will ask me many questions. They always come to my house and ask how I am and if I need anything. But I don't like to go and talk to them.*

(35-year-old Fijian woman)

Several of the women interviewed described how they isolated themselves. Self-isolation is a response to emotional impact of HIV.<sup>24</sup> Many women chose to isolate themselves as they have experienced self-stigma or fear HIV-related stigma and discrimination.

#### **Discrimination from Family**

The majority of the women who had disclosed their status to their families experienced some form of discrimination from them. In some cases it was extended family members or in-laws who discriminated against them, while in other cases it was immediate family members. Sometimes the families initially reacted in a discriminatory way but later became supportive. Experiences of discrimination ranged from outright rejection to more subtle forms, including gossip. Often, once their families came to know about their status they were scared of them and did not want to be close to them, for example, giving them separate eating utensils. In a study of the experiences of PLHIV in Fiji it was noted that women especially were subjected to criticism from their families (Labbé, 2011).

One Fijian participant described how she was shunned by her in-laws who said to her, "Go home and stay out of sight you don't have any right to be talking." Some women were told they could no longer live with their family or were forced to live in a separate area. A woman from Port Moresby said, "When my husband was sick – some of my family members, they discriminated me. They were say(ing) that 'your husband got this sick and we don't want you to live in our house'." Another woman from Southern Highlands Province said this about her family:

*They are scared of going close to me. They say, "You have sickness." Yeah, (my) family, mother, cousins, and sisters, niece. They don't accept me in the family because I got this type of sick. They used to give me good clothes, (and) good money. All my family looked after me well, (especially) my parents. I was a very smart girl – everybody likes me, giving me good food, clothes, money and everything. But after getting this sick, nobody likes me. I go around house to house, (and) wait for people to give me money and feed me. Now I am selling chicken (at the market). But at home, they reject me.*

(25-year-old Papua New Guinean woman)

One woman from Tari had her son taken away by her family because they said, "Now you have this sickness, so the kid will be affected, so we are taking it (away from you)." This woman's family were misinformed about HIV as they felt that because she was HIV-positive she was a risk to her child. This discrimination reflects the

<sup>24</sup> Labbé (2011) similarly found that many Fijian PLHIV chose to isolate themselves from people.

type of existing attitude that many PLHIV face from within their families and communities.

In some cases the lack of understanding about HIV results in severe isolation of PLHIV. Lucy from Port Moresby described how, when she was sick, her step-father instructed her mother to keep her confined to a room by herself to avoid the shame associated with her visible HIV symptoms. Then one day she was discovered by her uncle who asked why she was there and crossly told her parents, "She's not an animal. All of you must treat her like a human being and bring her to the hospital!"

### **Discrimination from the Community**

Most of the women who voluntarily or involuntarily disclosed their status to people in the communities in which they live experienced discrimination although two women felt that they did not experience discrimination in their communities and were not blamed for being HIV-positive.

The discrimination that the women experienced in their communities ranged from being the butt of gossip and other subtle forms of social exclusion to physical isolation. One woman from Tari described how she was singled out in public:

*I don't want to come out on the road in public and walk around because they used to say that I have AIDS. It used to go into my ear [she used to hear], when I was walking around not feeling good, on the roads, streets and all these. That's why I used to hide away, selling chicken at the market, covering myself with the umbrella and sitting. When I would walk up on the*

*airport or market stores, it's very big (thing for me to do), I just sit down and cover myself with an umbrella and go back home. (The) men walking on the road, (are always) talking about me, (sometimes) screaming at me and my family too ... I used to feel so embarrassed, very bad, making me sick coming close [more often].*  
(25-year-old Papua New Guinean woman)

A Fijian woman said, "People don't want to visit me anymore or use my stuff. In the village, people don't like to talk or walk (with) me." Another woman from Port Moresby was asked if she faced discrimination in her community. She said:

*In my community, yes, from all my neighbours, because they don't want me to stay with them or tell stories with them ... They are scared of me, I might give them HIV. So they don't want to story [socialize] with me or hold my hands or shake hands with me. They don't want to get my half-food. Because they're scared the HIV might be in there and I might pass it to them. They are thinking of that so that makes me just want to stay by myself in the house. I'm not free in that community.*  
(25-year-old Papua New Guinean woman)

For this woman the impact of many forms of discrimination from her neighbours was so severe that she felt restricted in her own community.

Of the women who were employed, some experienced forms and intensities of discrimination that had an impact on their

livelihoods. One woman living in Port Moresby was a teacher in her home province, but once her status was disclosed to the community she felt forced to resign. Two other Papua New Guinean women who sold goods at the market said that people did not want to buy goods from them because it was known that they were HIV-positive. Another woman living in Port Moresby described how her husband worked for a prominent company for many years but when he died they discriminated against her by not providing the customary feast and compensation because he was suspected of having died from AIDS.

### **Coping with HIV**

Although all of the women interviewed encountered stigma and discrimination, many of them also found ways to cope with their HIV status, especially when provided with support. As was described above many of the women chose at some point to deal with HIV through isolating themselves from other people. Only one woman from Fiji coped with HIV through “*drinking grog [kava], booze and smoking.*” Other women coped through prayer. One Fijian woman said, “*I pray every day so that God will help me in my life – me and my husband.*” Another woman said:

*Spiritual encouragement (which) I got from my pastors and elders also encouraged me. So, whatever situations you are in, lonely or down, you always pray and put into the Lord's hands. From there, I started to think positive and move on.*

*(29-year-old Papua New Guinean woman)*

The women said that they best coped with HIV by being provided with support from families, friends, communities, religious leaders and NGOs.

### **Support from Family, Friends and Partners**

Of the 21 women who had disclosed their status to their families, only 1 did not receive some form of support from them. The other 20 received various degrees of support. A few women received full and unconditional support, but most of these women were sometimes discriminated against and at other times supported by their families.

One Fijian woman described the reaction of her family when she disclosed her status. She said that her family said, “*If you have this sickness, then people will talk ... but we will be there for you, but you must stop living like this,*” because she used to drink, smoke, and go out to clubs. Another Fijian woman received unconditional support from her parents when she first disclosed her status to them. Her father was especially supportive, and he said, “*Those who discriminate, they are not worth it.*”



A 25 year-old woman from Port Moresby described how her mother was the only family member who provided support:

*In my family, they never supported me, only my mother. I disclosed my status (to her) and only she would comfort me. Like, she was like my counsellor, too. She told me what is good and bad and ... told me to go and worship, to stay positive-living, because in my community they used to stigmatize and discriminate (against) me.*  
(25-year-old Papua New Guinean woman)

This young woman's mother supported her when she was first diagnosed and later played an important role in aiding her to adhere to ART.

Another woman from Milne Bay Province described how her family and friends treated her poorly, saying that she "just wanted to die". It was only her father who washed her and made sure she had food. At this point she felt like giving up so her father called a family meeting and invited them to pray for her. She said:

*And that morning was, when he said "Amen," he looked at me and I looked at him, and already I was trying to close my eyes. And my little one [her son], he said, "No, mummy you can't do that, you can't do that. You're gonna leave me and who's going to look after me?" Like, when he said that, it made my thought ... my mind started to come back again. I saw my mum and my sisters. They had tears in their eyes and, like, they all came close to me, that day. And that's the first, like,*

*positive reaction from there. Came towards me and I could feel that they care, like they really care for me.*  
(29-year-old Papua New Guinean woman)

She then described how her family's care and support helped to become healthy again.

In addition to family, some women also noted the role that their friends and partners played in providing support. One woman from Milne Bay described the support that she received from a friend. She said:

*I think it helped a lot that I had a friend. She did what nobody else did pretty much for me ... she just, despite the fact that I might be HIV-positive, said, "It doesn't matter. Probably, like you'll have the flu once in a while..." I think it was just her attitude. She didn't give me any sympathy.*  
30-year-old Papua New Guinean woman

Importantly this friend did not pity her but instead gave her unconditional support. Other women described the support that their partners provided. One Fijian woman said, "When my husband came to the hospital he found out. He said he would still accept me. After that I felt at peace inside and I was able to begin to accept my status." She felt that she had contracted HIV several years ago before she met her husband and his HIV status was unknown. Other women stated that being HIV-positive was a secret that they shared with their husbands which allowed them to support each other and decreased their feel-

ings of isolation.

### **Support from NGOs**

NGOs were noted to provide a range of services including provision of information, testing, counselling, treatment, training and facilitation of PLHIV support groups. In addition NGOs sometimes provided emergency financial support that some of the participants said helped them in times of need. A few of the Papua New Guinean and Fijian women were also able to get work that was either paid or voluntary, doing peer education, prevention awareness programs for the public, and providing home-based care to other PLHIV.

Many of the women noted that NGO support had had a positive impact on their lives. One Fijian woman said, *“When I was really in need they provided (financial) support, and it really helped me to get by.”* Other women similarly stated:

*I go to church and (to) Anglicare (where the) health workers give me good counselling, (and) they help me sometimes with money. They give me things, they come and talk to me and say, “Are you sick?” when I go to Anglicare. So they treat me like their family, so I feel open. So when I feel sick or need anything, I just go there. So that makes me normal, like a normal person.*  
(22-year-old Papua New Guinean woman)

*And me – I’m alive because I started to get treatment early. I came to Igat Hope and (was) trained to look after myself. They taught us how to study about nutrition and all of that. All the*

*things (so) that we keep living.*  
(37-year-old Papua New Guinean woman)

Other women noted how NGO programs that are often referred to as “Positive Living” helped to promote a healthy and balanced diet, exercise, hygiene and ART adherence. NGOs also provided training in life skills, advocacy and public speaking. Those women who had participated in this training felt it had as they were relieved to learn that they were not alone. It made them feel more open about being HIV-positive and they felt less afraid of interacting with people.

Peer support that is offered through training, and PLHIV networks or support groups that are part of NGO programs had an immensely beneficial impact on the women interviewed. One woman from Fiji said, *“They [the members of FJN+] are so kind, we meet together and share our problems.”* Other women said:

*For me, it was like a challenge for me. I just wanted to kill myself and just die, because my baby died, and it’s no use for me to stay (alive). And then after, they referred me to Anglicare, and then I started seeing my friends. I found that there were others like me who were HIV-positive here. It gave me strength, that I can stay (alive) for many years.*  
(25-year-old Papua New Guinean woman)

*I used to be so shy and just wanted to hide away, but after I met my friends, my peers from Igat Hope and people like Helen (Samilo) and Peter (Momo)<sup>25</sup>*

*and they kind of like helped me to be strong and to come out and be positive about who I am ... I mean, if my friend did not introduce me to Igat Hope, I'd probably be dead already. (35-year-old Papua New Guinean woman)*

This woman felt that peer support networks ought to be promoted more widely to diminish the sense of isolation that PLHIV feel.

Peer support networks often foster an attitude whereby people want to help others who are also HIV-positive. Some of the women described the ways in which they supported other PLHIV:

*I've also visited other PLHIVs to give them support, to encourage them, or when they come into the office I also talk to them, encourage them, give them hope, encourage them with positive words. With their diet, too, is also important, what they eat and what they shouldn't eat that will make them look healthy. Live a normal life and stay (healthy). (I) also encourage them to take condom for their safety, especially. I do that as a trained counsellor, I went to the HIV training and (I) also encourage them to practice safe sex, too. (29-year-old Papua New Guinean woman)*

This woman raised the topic of safe sex which is further discussed in section 4.6. Other women were involved in providing home-based care to PLHIV through programs and some provided home-based care independently. These women took

pride in providing support and encouragement for PLHIV.

NGOs sponsored and oversaw many important programs, but some of the women criticised some of these programs. These women wanted help in gaining economic independence so that they could take care of themselves and their children.

One woman from Port Moresby spoke of the lack of continuation of NGO livelihood-support programs. *"Sometimes they sponsor us to go for this training, like tie-dye and baking ... but they trained us and they dropped us. They never supported us to do what we're learning so (that) we can survive."* Another woman who had publicly disclosed her HIV status also had criticisms of some of the specifics of NGO programs. She said:

*Like so many times, we, especially PLHIV, are used and they don't benefit from this type of public awareness - especially giving life testimony. And that's one thing; I decided to cut down on that, because of how I have been used.<sup>26</sup>*



<sup>25</sup> Helen Samilo and Peter Momo are two well-known Papua New Guinean HIV advocates who were among the first to public declare their HIV-positive status.

(29-year-old Papua New Guinean woman)

Overall, NGO support greatly assisted many of the women in getting on with their lives but the criticisms noted are important and should be considered in future NGO program development.

### **Living with HIV**

Some of the women said that they had reached a point where they were able to get on with their lives. One, who had been very ill, had regained her health and moved on with her life despite experiencing discrimination from her family. She had advice for other PLHIV. She said:

*I want to encourage those others, those who have HIV who are having doubt, be free, ah, we must be always happy ... We are here to live (with the) Lord only. So we must not worry about the sickness. We must ignore the sickness and say "I'm normal".*

(37-year-old Papua New Guinean woman)

A number of the women who faced adversity as a result of being HIV-positive still did their best not to let stigma and discrimination get them down. Some of them reached a point where they wanted to overcome the effect that HIV was having on their lives. Two women said:

*I decided to overcome all those feelings and I decided to live positive; to think positive and live normal like everyone. And that's how I got out of it. When people look at me and say, "Oh, you're like this and like that," I just forget about what people say and just*

*continue my everyday work and what I'm doing. So I don't look down on myself, I just stay positive.*

(29-year-old Papua New Guinean woman)

*I guess it was some unconscious decision that I can't be bothered by all of that. I'm going to just go on, continue doing what I was doing (before)... If I'm not dying tomorrow, then I might as well live my life.*

(31-year-old Papua New Guinean woman)

The women who reached this point had strong support systems that aided them to overcome HIV and its related stigma and discrimination. As well, they found the inner strength to begin to disregard and get over the tendency to self-stigmatization. There were many women who continued to struggle, however, and HIV still seemed to define their lives.

<sup>26</sup> Taking advantage of PLHIV by NGOs has also been noted to occur in Asia too (see Paxton & Stephens, 2007).

**Box 4. Helalo's Story**

Helalo has not been able to reconcile her HIV status and she suffers from the effects of self-stigmatization. Helalo lives in relative isolation. She is often depressed, but has her reasons for carrying on with life. She is 27 years old, and from a remote village. She is the first in her family to have graduated from high school. She moved to town a few years ago and lives with her extended family members. She has a job and earns about K200 a fortnight. She works hard to send money home to her family in the village and feels it is her obligation to support them. In the past she has had a couple of boyfriends, but she is single now. Helalo describes how she came to be tested for HIV:

*Before, I was very fat. (At) first I realized I was losing weight, my clothes couldn't fit into me anymore. People asked, why you not gaining weight? I began to have this dandruff or something ... Yeah, like on my face. And then my general body, sometimes tired, sometimes I feel inflamed, I feel hot. It came on and then, when it was coming closer, I began to realize sometimes I had diarrhoea.*

After going to the hospital several times, she was put on malaria treatment. Eventually she was referred for an HIV test. She did the test with the nurse and when it was reactive Helalo was shocked. She says, *"I felt down in my heart, I was in tears."* At the end of that appointment the nurse asked her, *"Are you going to tell anyone or what?"* and she said, *"No, I will keep it to myself."* She has stuck to that decision and has not disclosed her status to her family members, friends or work colleagues.

Helalo struggles to live with the impact that HIV has had on her life. She is up and down, and finds it difficult to be strong with limited support. HIV is a source of stress and she has difficulty sleeping. She says *"I just feel sleepless. During work I feel happy, I feel strong. But there's sometimes (when) I feel down, I just feel a bit lazy, I feel pains ... and I feel tired."* She also expressed other ways in which HIV has affected her life. She said:

*HIV, the first thing it did, it changed my good appearance, changed my good appearance, it made me suffer a lot of pain. And one thing, the important thing, I realized that I sometimes, I always feel down. It made me, my family, my relatives, my good friends, to stand away from me. I sometimes feel really emotionally down. And a person like an aunty or uncle who comes and says, "You look sick, you're supposed to be in the village, just stop work and go home," and I feel really down. Really, really down.*

Being HIV-positive has led to negative health issues such as fatigue, weakness, loss of appetite, weight loss and a change in her appearance. She feels depressed. Although people do not know that she is HIV-positive, she has become socially isolated because people



view her as a sick person. Helalo's extended family members who she lives with have not provided the support that she had hoped for. She does not want to face the shame, stigma and discrimination associated with HIV, which she feels she would have to face if she revealed her status.

Despite keeping her HIV status relatively hidden, Helalo is receiving treatment. When she was asked how she felt about the people who provide health services, she said:

*I feel I'm comforted. They talk to me, they smile at me, they share experiences. And they become more close (to me). They just feel free to come to me, come talk to me ... So I feel good and I feel comforted.*

The health workers that she interacts with do not treat her in the same discriminatory manner as her family. Helalo has chosen not to reveal her status, and only receives support from a few health workers.

Helalo's situation is likely to be similar to hundreds, perhaps thousands, of people in the Pacific who are HIV-positive and who only have health workers to support them. It is highly likely that there are many others who are diagnosed HIV-positive but who do not return to clinics for treatment and do not seek compassion and support from their families or health workers because of their fear of stigma and discrimination. These are the people who are categorized as "lost to follow-up." In reality, these people are lost to stigma, discrimination, ignorance and misunderstanding about HIV and AIDS, the same misunderstanding that has led Helalo to live in relative isolation.

### **Summary of Key Findings**

All participants reported experiencing self-stigmatization to varying degrees. Self-stigma diminished the women's sense of self-worth and in many cases prevented them from going about their daily lives as they wished. Some participants experienced discrimination, mainly from family and community but sometimes from employers. However, others received support from within their families and from friends, partners, NGOs and peers. The beneficial

impacts of peer support networks were cited as important sources of assistance, particularly in diminishing their sense of isolation. Some of the women had reached a point where they chose to disregard self-stigma and discrimination and simply get on with their lives.

Overall, the women's experiences indicated that for most, at different times since being diagnosed HIV positive, the negative social impacts of HIV were far worse than the physical impact, especially for those

whose negative physical effects had been minimized with treatment.

The role and value of NGO programs elicited some interesting – and important – information. Some women noted that while NGOs provide many programs, often these programs did not meet their needs for

training that would allow them to develop economic independence. This was the greatest need of many participants.

Where NGOs did provide livelihood training, a common feature was only a short period of training with no follow-up and no support to apply newfound skills in earning an income.

### **Recommendations**

- Provide training for counsellors to ensure that self-stigma is understood and addressed – and that counsellors can recognise the signs and consequences of self-stigma in their counselling, and its potentially different impacts on men and women living with HIV.
  - Promote peer support networks for PLHIV. Provide training in the establishment and running of independent peer support networks, that is, networks that do not require the ongoing involvement of NGOs.
  - NGOs need to reassess programs to ensure that, in each location and for each target group, programs provided meet the real needs of participants and do not simply reflect the preferences and priorities of the NGO and/or donors. NGOs also need to ensure the continuation of livelihood support programs, with follow-up training and support to apply newfound skills to earning an income. Where appropriate, NGOs could consider linking with micro-finance organisations to provide people with access to the funds necessary to start their own businesses.
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## CHAPTER 4.5

### Motherhood and HIV

In the Pacific, as in most of the world, motherhood is viewed as an integral social and cultural role for women (Lepani, 2008; Luker, 2002). HIV-positive women are not exempt from this role. Childlessness can lead to feelings of shame and inadequacy. Yet child-bearing amongst HIV-positive women is socially contested. This section explores the participants' views and desires related to motherhood and HIV, including their experiences as caregivers.

Of the 25 women interviewed for this study, 18 already had living children while 7 did not have any children. Table 5 below describes the women's desires when it came to having children in the future.

#### **Having Children: Desires and Apprehensions**

As is conveyed in table 5 approximately half of the women wanted children or more children and half did not. The women's descriptions of their experiences relating to motherhood and having children reflect many of the dilemmas surrounding motherhood and living with HIV. The main reasons the women wanted to have children was to fulfil their social obligations, to ease feelings of loneliness and to support them when they are

older. As one young woman commented:

*That's another thing that I think HIV affects ... I'm the second born, I have to have children before my smaller ones. And just because of this case [HIV], my smaller ones went ahead, I feel dumb. (27-year-old Papua New Guinean woman)*

This woman felt that HIV stopped her from finding a partner and having children and consequently she felt inadequate for not having met her social obligations. Another woman who wanted to have children to take care of her in old age said, *"I'd love to have (more) children. Because, now, I'm a single mother, now, I wish ... If I have another child it would be nice, like, he can look after me and make my grave later on."*

Although children were viewed as a source of security, the women were also apprehensive about having (more) children they felt that they must have the financial means to take care of them. One Fijian woman expressed her concern about this. *"I would maybe want to have more children, once I am settled and I know that I can feed*

**Table 5: Participants' desire to have or not have children**

	Did not want children	Wanted children	Unsure
Women who had children	9	7	2
Women with no children	2	4	1

them." Some of the women who were already mothers felt that having HIV burdened them as mothers. One Fijian woman stated, "It is hard having this sickness and having kids. I wonder what will happen to them when I die? I also feel more stress because I (am HIV-positive and) also have to take care of them." Yet, these were not their main concerns.

Overwhelmingly, the women were most apprehensive about having children because of their concerns about transmitting HIV to their babies or partners. Many of the women felt that they simply should not have children as HIV-positive women or that they could not have an HIV-negative child. As one woman said:

*I have no children, but I want to have (children). I feel very alone at home, it is just me and my husband ... In the future I would like to try and have children, but I have not discussed any of this with my doctor. But sometimes I think of having a baby, but that [HIV] stops me from wanting a baby 'cause I feel sorry for the baby because it might get HIV (too).*

(35-year-old Fijian woman)

As noted earlier, when one woman consulted her doctor about having children she was first told that she should be sterilized but later another doctor told her that she could have children as any other woman could. The quote below describes the experience of a woman who lost a child to HIV and was later able to have an HIV-negative child.

*Because of that first one [baby who passed away], I don't want to have*

*children. Because she was HIV-positive, I have that kind of thinking that if I have a child, my child might have HIV again. So I don't want to have children again. But ... I don't know ... everything is God's plan, so I have that second one. I have that second one and I was on drugs, so my baby was okay. First one, I was not on drugs and my baby was infected and I was breastfeeding and like that, so when I brought my baby to VCCT and she was tested HIV-negative, then I want to have some (more) babies....*

(25-year-old Papua New Guinean woman)

Overall, many of the women were unaware of how effective ART can be in preventing parent to child transmission.

Several studies in other resource-limited settings have also found that HIV-positive women face the predicament of wanting to fulfil the role of mother but are HIV-positive (Chi, Hnh, Rasch & Gammeloft, 2009; Kanniappan, Jeyapaul & Kalyanwala, 2008; Kisakye, Akena, Kaye, 2010). On the one hand, there is potential for the spread of HIV to the fetus (in the uterus or during



delivery) and to babies (while breastfeeding) and partners (through sexual intercourse) if women do not have access to or follow treatment. On the other hand, when treatment to prevent parent to child transmission is promoted only as a means of stopping the spread of HIV, then HIV-positive women are denied the right to bear children.

### **Being an HIV-positive Mother**

Self-stigma also affected the women's perceptions of themselves as mothers. As one woman said:

*As a mother I feel afraid of telling my kids the truth. I am afraid that they will get it so I don't want to get [physically] close to them. So I can't be a mother the same way that I was before. I think that I need some counselling about this, about (how) I can be a good mother because I am HIV-positive.*  
(32-year-old Fijian woman)

Other women also thought that they could transmit HIV to their children through casual contact and that they could not be a mother in the same way they had previously been. While many of these thoughts are based on self-stigma, the reality of being a single mother is something that a number of the women experienced.

Of the 18 women who had children, 16 were single mothers because their husbands had passed away due to AIDS. The women noted the challenges they faced as single HIV-positive mothers. For example one woman stated:

*It's really very challenging. Like, I'm carrying the burden, struggling alone as a*

*single mother. It's very disappointing. Sometimes I sit back and think the father should be here to help me. You know, it's very hard trying to, you know, manage life alone.*  
(32-year-old Papua New Guinean woman)

Generally the women also emphasized the financial instability they faced as single mothers. Many women, regardless of their HIV status, face this situation, but for most of the participants living with HIV was an additional burden they faced on top of being single mothers.

Despite the struggles that the women faced as mothers, many of them talked about how their children were a source of hope and support. Two of the women said they actively took steps to commit suicide after learning about their diagnosis, but when they thought of their children they decided that they could not go through with it. Their main concern was who would look after their children if they were not around. One woman stated:

*It's made me to really love my kids. Like, every morning that I wake up, I always thank God that I'm alive, that my kids are there ... are there to help me, support me, and there to also make me angry, and I'm screaming at them at times, but at the end of the day – I'm just happy that they're there.*  
(35-year-old Papua New Guinean woman)

The *art of living* (2009) study which was conducted among PLHIV in Papua New Guinea reported that the feeling that children were a source of support was particu-

larly strong amongst the female participants (Kelly, et al.).

### **HIV-Positive Children**

Learning that you have a child who is HIV-positive is a devastating experience - seven of the participants had HIV-positive children. A number of women described how they began to notice that their baby was getting sick. For some women this resulted in frequent trips to the hospital, an HIV-positive diagnosis (for both mother and child), and eventually being put on treatment.

In some cases, the child died and the mother later learned of her HIV status. One woman from Milne Bay Province described how she lost her child:

*I think (about) when my baby died, I was feeling really sad because he was a part of me. And when my husband died I was sad, too, because they are my family members, too. So, at first we were staying together, eat our food together and live together and now, somehow I see that they are missing. I have a heart for them and, like, every time I'm, like, happy, like, I think of them. I think of my child and the daddy ... I still have a heart for him, the baby who passed away.*

(31-year-old Papua New Guinean woman)

Other women living in isolated areas in which the health care infrastructure to support treatment to prevent parent to child transmission is missing may well face a similar situation. Some women talked about the pain of losing a child and the ongoing sense of loss that they felt.

As described above in section 4.3, treatment to prevent parent to child transmission can enable HIV-positive women to avoid having HIV-positive babies and suffering their early deaths. The availability of HIV testing during pregnancy is the key to this form of prevention, but it must be done with the women's consent.

### **Caregiving**

Gender roles and expectations in both Fiji and Papua New Guinea mean that in most cases it is women who take on the role of providing care for their children or husbands when they become ill. One woman said:

*My small girl had pneumonia with HIV infecting her, and (for the) nine months I spent my time in the hospital I never go home for nine months. What pain she went through, I went through, too, with my baby. I want my baby to come back to life, so I spent all my time with her. When she didn't eat, I never ate, too. And when she died, I just want to kill myself because, what was the use for me to stay here? Because, me, too, I'm infected, so why should I stay? So I must kill myself with my baby and go ... that's what I thought.*

(25-year-old Papua New Guinean woman)

One woman poignantly recounted the emotional impact of the issues she faced by having an HIV-positive child:

*Sometimes I just sit and watch kids playing around, and my little girl there also goes in to play, and I compare my child with the rest of the children. My child is a positive child playing around with*



*negative child(ren) and you know, I feel sorry, I feel very emotional. Sometimes, I just think, "Why has this affected my child?"*

*(32-year-old Papua New Guinean woman)*

When this woman was asked how she felt about doing this sort of care giving work, she stated that:

*It's very tough. You know, living in the city, with money and all those things – it's very tough. But, you know, when you have all the family there, the family can also come in to support you. I don't know about the others who have more than three or four children, how they feel. I have only one.*

Having an HIV-positive child appears to increase stress for HIV-positive women insofar as the burden of providing care for them also increases.

Some of the women also noted how they cared for their husbands when they suffered from AIDS-related illnesses.

*Like, it was so much for me, and even I went through the worse part of it,*

*where I had to clean him. Clean all his rubbish. In that situation that he was in, he was losing weight, (he had) diarrhoea, sores and all that. I had to be there for him, hold him on the hand and pull him (up), and just imagine, he's bigger than me and sometimes I find it hard. But then again, I had to cope with it.*

*(29-year-old Papua New Guinean woman)*

*Yes ... with my baby, he was, he was just a baby so it was easier. I could just carry him and when I was tired, I would give him to my husband to hold him for a while but husbands, they don't usually carry the babies for a long time, so he gives it back to me. For my husband, it was a struggle. Because he was hospitalized at some stage and we had to bring him to the toilet. I had to wash him and bath him and shave him. Probably my sisters would've come and taken care of me. PNG customs, if your husband has that status, he can't take care of his wife. He only takes care of me financially. But physically helping with me, sleeping with me in the hospital like that, he won't do that. It is different (for men).*

*(35-year-old Papua New Guinean woman)*

This woman highlighted the gendered aspects of caregiving in Papua New Guinea. Generally, it is women who are expected to care for both men, women and children. She noted the intense physical and emotional work that is involved in caring for both a child and husband who are suffering due to HIV related illnesses.

**Box 5. Mary's Story**

Mary's story provides insight into how gender norms increase women's vulnerability to HIV and also shape the experiences of HIV-positive women. Mary is 35 years old and describes herself as a widow but feels that she is too young to be one. She is a calm and well-spoken woman and has three children. She attended college and has a diploma.

When she was in her early twenties she met her husband, a successful and well-respected man who was nearly 20 years older than her. Shortly after they met, they got married and began having children. During her first pregnancy she learned that her husband had other wives. She said, *"I married a man from the Highlands so the Highlands people's custom is like, as long as you are a leader and have a (high) status, then you can get married to so many wives and stuff like that."* Over the span of eight years she had four children with her husband. She describes what happened after she gave birth to her last child:

*After I gave birth to him, he was really healthy, chubby, and nice. And then he started getting sick, like, frequently, and I didn't know what was happening. And the whole family, we blamed it on witchcraft. So every time he got sick we would bring him to the hospital but he never got better. We'd take medication and come back and he would fall sick again. And then it went on until in 2004, July, he died. I was admitted in the hospital and he died.*

Mary was very upset at the loss of her baby and was unaware of the cause of her baby's death.

Mary tried to get on with her life but then she kept getting sick. Eventually, her husband asked her to go to a clinic to be tested for HIV. This angered Mary as she thought that her husband was accusing her *"going out and doing stuff outside of the house [having extra-marital affairs]."* Then he admitted that he was the one who had been unfaithful and engaged in risky sexual behaviour but he was too embarrassed to get tested. She eventually decided to go for VCCT. She received both pre and post-test counselling and soon after she followed-up with them. She was shocked to learn of her status and very angry with her husband because she had *"lived with him for so long and I had so many kids from him I took care of all his other kids as well from the other women"*. Mary felt intensely angry at her husband. Yet, she did not want to abandon him. She said, *"I wanted to kill him and I wanted to die at the same time, but after that he just held me and he said, 'It's ok, both of us are in this together.'"*

Upon hearing the counsellor's advice that she register at one of the main clinics in Port Moresby that distribute ART, she began taking ART and regained her health. Later on her husband was tested and he soon started ART too, but shortly after he started treatment he passed away. Mary says that self-denial was the reason why he passed away. Although



she was angry with her husband, she chose not to abandon him as they were both HIV-positive; somehow, it brought them closer together and changed their relationship. She says:

*It made me feel so close to him, because before that we were always fighting. He was always jealous. After we found out what we had in common, even though we had kids and that brought us together, we always had problems. After that, I saw him change from a much aggressive person to a much calmer person. And that's why I couldn't leave him because I loved him so much. I felt so close (to him).*

It has been a couple of years since Mary lost her husband. But she feels that she has not really got over the death of her husband and baby.

*Most (of the) time I just sit and cry because he was always there helping me and now I'm just stuck. And sometimes I'm angry with him and say it's because of you I'm stuck in this situation and all. But now I think I'm a much stronger person. I can talk. I've met a lot of friends. And my family helps me a lot; they don't pressure me or anything.*

There are key sources of support in Mary's life that have helped her to cope with living with HIV.

After her husband passed away, Mary began to attend training and PLHIV support network meetings offered through NGOs. From training and workshops she learned how to look after herself, eat properly, take her medication properly, and overall she gained a much better understanding of HIV. Mary feels that she would like to share her experience of being HIV-positive and the strong impact that NGO support has had on her life, but still fears the repercussions of going public with her status.

### **Summary of Key Findings**

Many of the women wanted to have children or more children for security in old age, because they were lonely, and especially because they wanted to fulfil the social expectation of motherhood. Yet most of them were confused as to whether an HIV -positive woman could have an HIV-negative child. Self-stigma affected many of the women as mothers. For example,

some were concerned about transmitting HIV to their children through casual contact and felt that they could not be as good a mother as they had been in the past. Many of the women struggled as HIV-positive mothers and many of them were single mothers (16 of the 18 women who were mothers), having lost their husbands to AIDS-related illnesses. Although the women were concerned about having the

economic means to care for their children, many of them also described their children as a source of hope. Many of the women were burdened with caregiving for their children as well as their husbands who become ill.

As access to treatment continues to improve in the Pacific and HIV-positive women live longer, it is essential that HIV-positive women are given the freedom to make their own informed choices surrounding reproduction. The experiences of participants indicate that HIV-positive women

need to receive more counselling about the misconceptions surrounding HIV, for example that an HIV-positive woman cannot have an HIV-negative child or that HIV can be transmitted through casual contact with their children. As well, they need to understand that HIV does not affect their ability to be good mothers. As treatment to prevent parent to child transmission expands and improves throughout the Pacific, there is a strong need to integrate the reproductive rights of HIV-positive women into health services for PLHIV.

### **Recommendations**

- Promote a human rights-based approach to HIV. This supports the idea that HIV-positive women ought to have the right to have relationships and children just as are HIV-negative people. ART should be promoted as a means of broadening the reproductive options of women living with HIV.
  - Support family planning agencies in training medical staff and counsellors to provide HIV-positive women with accurate information on their ability to bear HIV-negative children – consistent with sound family planning advice (including, for example, mother's age at birth of first child, spacing of children and number of children).
  - Through the design and implementation of counselling and peer support networks, recognise and address the self-stigma that many HIV-positive women feel in relation to their role as a mother.
  - Governments and donors should examine ways in which direct support – financial or non-financial - could be provided to caregivers, particularly given the large contribution to public health resources represented by caregivers.
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## CHAPTER 4.6

# HIV-positive Women's Experiences of Relationships, Violence, Sex and Condoms

The women faced many complex issues in terms of their relationships, violence and sex which are often not discussed in detail when it comes to HIV. This section focuses on how the women described their relationships with their male partners. In particular, there is discussion of dealing with HIV in relationships and how women experience blame. The women's experiences and perceptions of violence in relationships are also discussed. The women's perceptions of the topics of sex and condom use are also discussed including the factors that inhibit condom use. Lastly, the women's views on having future relationships are discussed as is the issue of rights and responsibilities of PLHIV.

HIV can change the dynamics between spouses and other kinds of intimate partners and often provokes new kinds of crisis within a relationship. As one study that was focused on the lives of HIV-positive women in Zimbabwe found, "The continuation of marriages after an HIV diagnosis conceals the initial anger, pain and emotional turmoil that the women experienced" (ICW, 2002, p. 36). That study also noted that the women felt married life deteriorated after HIV, but over time couples tended to come to terms with their diagnoses especially through help from counselling or support groups (ICW, 2002).

At the time of diagnosis, the majority of participants (20 women) were in a relation-

ship – 17 women were married and 3 women were in steady relationships. A few of the women said that they had been forced to marry older men, even when they were as young as 14 years old. Two women were in polygynous marriages, two women were single, two were separated and one was widowed. Of the 17 women who were married at the time of diagnosis, 15 of them felt that they were infected by their husbands. The other two women were unsure of their husbands' HIV status.

Between diagnosis and when they were interviewed for this study, many women said their relationship status changed. Of the 20 women who had steady partners, 10 lost their husbands to HIV-related illnesses, five women separated from their partners, three remained married and two had new partners. Of the women who separated it was most often due to HIV. Of the women who were already single, separated or widowed when they were diagnosed most of them remained that way up until the time of the interview. Hence, for the majority of women, HIV led them to become "single". Some of the women noted that losing their husbands resulted in feelings of loneliness and isolation. Many women also noted that losing their husbands meant loss of financial support and as a result it became more difficult to get by – especially for women with children.

Nearly all of the women (19 out of 20) reported infidelity in their past relationships, and two of the 19 reported their own infidelity. Wardlow (2009) notes the risk of HIV for wives who live in rural areas of Papua New Guinea as male mobility “whether for work or some other purpose, seemed to all but guarantee that men would have extra-marital relations” (p. 149). Some of the women stated that when their husbands travelled for work or worked away from home, they had been unfaithful. Mobility may make infidelity more likely, yet many women who lived with husbands who did not frequently travel also had unfaithful husbands.

### Dealing with HIV in Relationships

HIV has an impact upon relationships with husbands, boyfriends and other kinds of intimate partners in many ways. An HIV diagnosis often brings about feelings of anger and blame between partners. In several cases, women felt angry with the husbands who they felt had infected them with HIV. Some couples were able to resolve their HIV diagnosis, but in other cases women chose to leave their partners after discovering that they were HIV-positive, which led them to learn that their male partners had been unfaithful.

As noted in section 4.4, many of the women said that when it came to HIV in relationships, women tend to be blamed and punished. The women said that they were blamed by their husbands whether or not they themselves had been unfaithful. As one woman said, *“Sometimes, if they’re [male partners] angry, and then they’ll blame. Like, we ladies, we got it and passed it to them [the virus] and then they start mentioning things like that and then*

*they start hitting the women.”*

Some of the women had also internalized this blame. For example, one woman blamed herself as she had “*allowed him to live the lifestyle*” that led to her husband’s infidelity and ultimately she felt responsible for both of them contracting HIV. A 2010 article in the Fiji Times titled “*Bedroom roles vital, wives told*” demonstrates a similar sentiment. The article reported discussions at a church women’s conference where it was stated that women must fulfil their husbands’ needs or their husbands would be unfaithful – the underlying message being that women are to blame for their husbands’ infidelity (Silaitoga, 2010). The idea that women are to blame for their husbands’ infidelity is often true in contexts in Papua New Guinea (see Hinton & Earnest, 2010). The ways in which women were blamed, or blamed themselves are fixed in popular ideas about HIV whereby women tend to be viewed as responsible for HIV transmission.

### HIV and Violence in Relationships

As Lepani notes, “Violence not only exposes people to possible HIV infection but



is often the consequence of living with the virus" (Lepani, 2008, p. 151). Violence in the form of husbands beating and abusing their wives was a common experience among most of the participants. Overall, 18 of the 20 participants in relationships said their partners had been physically violent towards them including slapping, hair pulling, punching, pushing, kicking and cutting with a knife. Sexual violence included the women being forced to have sex. The main issues that led to violence inflicted by husbands upon their wives included jealousy, men's infidelity, men wanting sex against their partner's wishes, and anger associated with an HIV-positive diagnosis.

Several women noted that their partners had been jealous. One woman said:

*I was 16 and he was twenty-something ... 27 (when we got married). Sometimes, when I go out with my friends, my girlfriends, he usually blames me for going out with some other men. He gets jealous. And he doesn't want me to tell stories [hang out] with some of my street mates. That's why sometimes he usually beats me up and he locks me up. I don't go out with my friends or play sports or anything.*  
(29-year-old woman Papua New Guinean woman)

As shown by this quote and other narratives of the women, violence is a means used to control and enforce the dominance of male partners.

The women stated that disagreements about extra-marital affairs often led to violence. Labbé (2011) noted that in Fiji the

dominant gender ideology assigns women a subordinate position and women fear violence which prevented some of the HIV-positive women that she interviewed from questioning their partners' suspected infidelity. As well Hammar (2010) noted the significant role that Christian teachings play in reinforcing traditional submission of women within marriage.

Several women said that when they refused to have sex, their partners became angry and they argued which lead to violence and marital rape.<sup>27</sup> One woman described her situation, which she felt was similar for other women:

*Also, if the husband asks the lady for sex, and she refuses, then the husband (will) bash her up. Just for sex only. So, like, I went through that situation, that's how I knew. I mean, I've been through it and I know. Sometimes when we're not in the mood of having sex, we're forced into it. I mean he comes and forces and tells (me) what to do – which is against – I mean, we have our rights, whether to say "no", but some men, they don't really understand. Especially in our PNG culture, we have those type of people who don't care – [they have a] don't care attitude. And if the woman disagrees, then he gets up and bashes the woman or sometimes throws her out of the house or she gets really badly affected by bashing.*  
(29-year-old Papua New Guinean woman)

This woman's perspective is telling in many ways. First, she noted the disconnect between her rights and her culture. Second, she said that she had been forced to have

<sup>27</sup> Other studies affirm that refusal of sex is the main reason for violence from male partners (see Gibbs & Mondu, 2010; Lepani, 2008; Salomon & Hamelin, 2008).

sex with her husband, but disassociated herself from it by using the term “we.” By saying “we” she also acknowledged that she perceived marital rape to be common. Another woman faced a similar situation:

*I don't like my husband, because he likes to have sex a lot. Sometimes, if we say “no”, he just comes and smacks us and says “hey, you must hear what I say” and if we don't give any, he just got angry and he just bash (me) up. And you know, we are human beings; we have our rights, ah? If we say “no,” then they don't like it. “We didn't feel like going out with you,” so we just say “no.” Or “we have sick” or “we don't feel good in our bodies, so you don't know our problems, how we feel, our personal (issues),” but they don't understand us. Sometimes, in my own experience, if I say “no”, my husband will bash me up. (With) my first daughter ... that's why I carry one after the other because he wants to stay [have sex] with me many times. But I said, “Oh, please, I don't like it,” but he force me. Like, he's a man, so if I don't hear what he's saying now, then he's going to go and find another lady, so I don't want him to go and bring back sick, so I have to give it [sex] to him all the time. So these men don't respect their wife, and they get angry because they just want sex - that's all they want.  
(22-year-old Papua New Guinean woman)*

These women's comments showed how they experienced sexual inequality and a lack of sexual citizenship and support the idea that violence and threats of violence limit women's abilities to negotiate sex with

their partners. Gender inequality obligated them to please their husbands. If they disobeyed they faced the consequences. In the end they experienced limited control in sexual relations; physical and sexual violence; and infidelity. It is important to note that both women said that they have rights and that the bashing they experienced was wrong. Yet, they did not seek help from a health worker, counsellor, family member or friend when they experienced violence from their husbands.

The issue of HIV, particularly regarding disclosure and conflict related to the women's HIV status, was another source of violence of men towards women. One woman described what she felt was a common occurrence:

*Yes, in some communities, women who didn't disclose their status, for example me, when my husband knew that I was this and that, he started hitting me. Some of our women, they experienced that, too. When they didn't disclose their status to their husbands, they started hitting them. The husband started bashing them and just throw them out of the house and tell them to find their own house to live in and they sleep outside (on) the road and they used to come to the Centre.  
(25-year-old Papua New Guinean woman)*

This woman's insights highlighted the idea that abuse and abandonment can be a consequence of women revealing their HIV status to their partners. Similarly, AusAID reported that social workers at Port Moresby Hospital's Family Support Centre

found that:

Now that [antiretroviral therapy] has become available, women who kept quiet about their status when they were tested in pregnancy are coming to get the treatment. Some of them get bashed up when their husbands find out, even if they [the husbands] know they are responsible. We see them come in now with broken bones and quite bad injuries (AusAID, 2008, p. 20).

Most of the women reported that they experienced violence in their relationships. They mentioned issues of mistrust, the pitfalls of a lack of mutual respect, the stigmas brought on by HIV infection, and the tacit social acceptance that led men to violently abuse their wives with few if any consequences. There were differences in the women's experiences of violence in Fiji and Papua New Guinea. Among the Papua New Guinean participants violence appeared to be so common that the women spoke of it in a matter-of-fact tone and it seemed to be part of everyday life for many of them. Among the Fijian participants violence was mentioned but seemed to be less pervasive and they were less open to discussing their experiences of it.

### **Sex and Condoms in Relationships**

Gender norms determine that men normally have more control within relationships, especially sexual ones (Hammar, 2010; Reid, 2009). As one Fijian woman stated, "*In Fiji, the man is the boss and [they] have to take the lead in everything.*" Women from Papua New Guinea expressed similar opinions. In discussing gen-

der relations and safer sex Reid (2009) states that:

For most women, the only way to protect themselves, when having sex with a man who is not protecting himself, is by confronting, resisting, negotiating, cajoling, battling in each encounter with such a man. This holds whether the woman is married to the man, having consensual sex with the man, being raped by the man or men, or involved in various other forms of transactional or commercial sex (p. 46).

When the issue of condom use was brought up, the overwhelming response was that husbands and boyfriends did not want to use condoms.<sup>28</sup> Consequently, the women said that condoms were rarely used in marriage and only sometimes in casual relationships – depending on whether the man wanted to or not. Women who had boyfriends also agreed that men do not like to use condoms. The women involved in sex work stated that clients sometimes decided to use condoms but not always. The women did not carry condoms themselves and only used them when supplied by the client.

Based on her experiences with past boyfriends a young single Papua New Guinean woman stated, "*When asked to use safety [a condom], they refuse. They say like 'You don't like me, you don't love me, you know all these.'*"

One woman summed up the general view on using condoms:

<sup>28</sup> Kaitani who studied sexual expectations of young Fijian men noted that the main reasons they do not want to use condoms are because: "they prefer skin to skin"; "the condom is not reliable"; "I trust my girlfriend so there is no point in using it"; "I was too drunk". Some men stated that using condoms does not give the feeling of sexual satisfaction to both partners.



*Many men, most men, they never like the idea of using condoms, because what they say is (that) they don't enjoy sex using condoms. They don't like the idea of using condoms. Like, my husband, when I ask him to use condoms he said, "You are my wife, you are not my girlfriend so I'm not using a condom (with you)." (32-year-old Papua New Guinean woman)*

Other women from both countries expressed nearly identical statements. One young woman said, "I did not use condom with my husband, when we got married. Before, I did not understand (about) condom(s). I thought it was for prostitute people (only)." The assumption that condoms are for "prostitute people" is common and reinforces the idea that husbands do not need to use condoms with their wives. Some of the women also noted that asking their partners to use condoms was another potential issue

of conflict between the women and their partners.<sup>29</sup>

Other women shared their thoughts and experiences related to condoms. A woman from Southern Highlands Province said:

*Condoms are ... especially the women, (in) the ministry in the churches ... they feel scared of condoms. They say, "You are bringing the hidden thing into the church." But, it's much better that we go for one awareness about condoms. Especially (in) Tari, they don't know it [about condoms] yet. They heard (about) condom(s). But how to use it, how to see the expiring date – they don't know it. (It would be) much better, if we told them how to use women's condom too, and demonstrate how to use women's condom. (33-year-old Papua New Guinean woman)*

Fear of the church and a lack of practical understanding illustrated the key issues relating to condoms and condom use. Later this woman went on to say:

*"Condom has no feeling." People talk like that, they say that. We're going to kill (a) pig for condom?' (In) our tokples [language] we say that condom, no feelings. (Men say) "We don't have happiness in having sex with women; we don't have the taste so we are just doing it for condom."*  
33-year-old Papua New Guinean woman

When she uttered the phrase, "We're going to kill [a] pig for a condom?" she was referring to the custom of paying bride wealth.

<sup>29</sup> Among 374 PLHIV surveyed in Papua New Guinea less than half (46.2%) reported that they had always used a condom in the previous six months (Kelly et al., 2009).



The word-play is meant to be humorous and alludes to the idea that it would not make sense for a man to give bride wealth (by killing a pig) and then use a condom with his wife.

Condom non-use in marriage is where the predicament of HIV risk and gender inequality is made visible. Condom use needs to be vigorously promoted in a strategic manner that acknowledges cultural and gender issues.

### Future Relationships

The women had different views and experiences about having new relationships post-diagnosis – generally there was a lot of confusion. Some women decided that they wanted to stay single after being diagnosed HIV-positive and separating from their partners. Two women said:

*I feel like looking at men, laughing [flirting] at men, but (that was) before. Now after this sick, I don't have this desire of men and loving but (only) for the kids. I want somebody [a child] to look after me, stay close to me, but I want to bear my own kid.*

(25-year-old Papua New Guinean woman)

*But how can I find my partner? Because I know that I have that virus. So how can I find a husband – like, he's negative? How can I spoil that man? You know ... I must find a man where he is positive, you know, because we are positive people. We must marry the positive man, because I don't want to spoil innocent people. You see in the bible, it's like I'm murdering a person, if I spread this thing. So I don't want to*

*make sin. So I must be faithful to God, so that God will be faithful to me. God can heal my sick too, like, I believe. So I don't like to spread this sick to normal people. So sometimes men come and ask me can we just "friend" [date], so I say that's okay, that's fine. But I don't want to hurt that man. So I say, "Yeah, we can 'friend' but I don't like, I don't think that we'll go and have sex." No, I don't, because I'm a positive person, so I want to live on my own, but I wish to have kids, but how can I have, because I have this sick, so how can I find my partner?*

(22-year-old Papua New Guinean woman)

This woman expressed many of the dilemmas that PLHIV, especially HIV-positive women, face when it comes to having children and relationships. *The art of living* (2009) study found that many HIV-positive people had been counselled that continuing to have sexual relations post-diagnosis is sinful (Kelly et al.).

Other women had started new relationships. For example, one woman from Papua New Guinea had married an HIV-positive man that she had met through a support network. An HIV-positive woman having a relationship with an HIV-positive man is more readily socially accepted. Other women were in new sero-discordant relationships and only some of them had disclosed their status to their new partners.

Many of the women interviewed were confused about whether or not they should have a relationship in the future and had concerns about moral, ethical and legal issues. A woman describing an

area of confusion said:

*If an infected person finds somebody, and tells them their status ... and this other person, he is negative, but he accepts it, most probably, people will look and say, "She is this and he is that and why are they hanging out together?" But what I am wondering is, if there is a law or something that says that, you know, that (they can not be together)?*  
(35-year-old Papua New Guinean woman)

This woman was connected with a PLHIV support network, yet she did not know whether she could legally have a relationship with an HIV-negative man or if it would be socially acceptable. According to the HAMP Act, an HIV-positive person "should inform any intended sexual partner" of their HIV status; however, legally, there is no provision which states that PLHIV cannot have relationships, get married, and have children even if their partner is HIV-negative. Nevertheless, the woman is right to be concerned as the notion of PLHIV developing new relationships with HIV-negative persons is not widely accepted. One woman from Papua New Guinea was considering developing a relationship with a man who was interested in her, so she consulted a nurse at the clinic for advice. The clinic nurse provided sound advice and told her to first try to get to know him. "When you are comfortable you can reveal your status, but ask him to keep it to himself." She also advised her to have her potential partner tested. The nurse also said that if they decided to have sexual intercourse they should be sure to use a condom. This woman was pleased with this advice, but in the end decided not to pur-

sue the relationship as she did not want to reveal her status to anyone.

In addition to the moral and ethical issue of disclosure, there is also the issue of condom use in relationships. One Fijian woman said:

*What if I go out with a guy and we are together [have sex] and then the condom breaks? I feel shy to tell him (about my HIV status) and I am afraid. So I feel that it is better to just keep it [her HIV status] to myself.*  
(28-year-old Fijian woman)

Another woman stated that she had sex after learning about her status, but was not sure if she used protection because she was drunk at the time. She feared disclosing her status later, and so she just kept quiet. Disclosure of one's HIV status to current and potential partners is something that some of the women feared and were confused about what to do.

*The art of living* (2009) study found that because many PLHIV were on ART and felt happier and healthier, they wanted to have a sexual life and did not want to abstain from sex (Kelly et al.). This study also



reported that the respondents were provided with inconsistent advice about having sex and that some respondents were fearful of having sex as a result of health workers' advice (Kelly et al.).

When it comes to having future relationships, there are issues of both rights and responsibilities that women and men living

with HIV and people in general could better understand. PLHIV ought to have the same rights to have relationships as HIV-negative people. At the same time, they also have ethical if not legal responsibilities to disclose their status to their future partners and especially to practice safer sex by using condoms.

### **Box 6. Raka's Story**

Raka's story highlights important issues related to preventing parent to child transmission, treatment, stigma, gender norms, and relations between husband and wife. Raka is a bright and cheerful 22-year-old woman from a town in the Highlands. She moved to Port Moresby less than a year ago and is staying with her sister's family. She got married when she was 16 years old while she was still in school. Her husband is from the same town as her and attends university in a city, but comes back to visit during holidays.

Raka has had two children. When she first became pregnant, she and her husband were tested for HIV and the test results were non-reactive. Her first child was born two years ago, but she passed away at nine months of age. Her second child is almost one year old. During her second pregnancy she was advised to get tested. She said:

*So when they told me that I was positive, I couldn't believe that. I was crying and I just can't believe. I just want to leave my baby on the floor and try to make something else. So they told me, "That's okay, you'll live long and there's nothing you can do, so you must accept that virus in your blood." So I accept that sick.*

In the hospital Raka was given treatment to prevent transmission to her baby. She said:

*The doctor – the women's doctor told me that – when you want to deliver, we'll help your baby. So they helped me. When I went to deliver, I was on the labour bed, they give me a pill. I drank [the pill] and they told me "no breast feeding". And I told them, "I'm not a work-lady, I'm a house-wife. I have no money to buy milk ... to feed that baby. So how can I give milk?" So I said, "Just give me 3 months to breast feed." But they told me, "You won't breast feed that baby. We'll help you and provide your milk." So they helped me.*

Raka's husband was away at university during the time when she was diagnosed, when she gave birth to their second child. She did not feel comfortable disclosing her status to her husband. She explained:

*So he, like, he rang me ... he asked me, "Did you deliver a boy or a girl?" I said "girl". (Then) he got angry with me. He said, "Oh, first born was a girl, and now second girl." He got mad on the phone and he got angry with me. And I said, "I won't give breast-feed." He asked me "Why?" That time, I got a little problem on my nipple ... my nipples got sore ... so I give the reason that my breast is so sore ... so I won't give that child breast-feed. So, he agreed. So he said, "Okay – we have no money, that's up to you. How you feed that baby is you."*

Later, Raka heard from a woman in town that her husband was going around with another lady in the city. This made her angry and she decided that she wanted to leave her husband. She blamed him for being unfaithful and did not want to admit to him that she is HIV-positive:

*Like, I bring my husband to court and I want to divorce with him. But he said, "No, you are my wife. I love you and I want to live with you." So we argue and the magistrate said, "That's okay, the man is elder, the head of the family. So you have to respect your husband and that's the decision, so go back to your husband." So I kept secret – I just keep it in my mind and I go back home ... I thought, "You won't hold my leg, yeah." Then I told my brother I'm not happy because we struggle ... get by, like, four years when my husband is in university. I do hard work, like, I support in school fees, bus-fare, clothing and now ... when he is working now, we are about to enjoy and be happy have a car, house ... and we hold money. How does this thing happen? I was very, very angry. I go and I drank, I talked with my ex-boyfriend, because I was very angry. So I give my daughter to my elder brother and I got [a] ticket and I came down to Moresby.*

She ran away from her husband and has not been in touch with him since she moved to Port Moresby. She remains concerned for her baby's well-being and is unaware of the baby's HIV status. Her husband remains unaware that his wife is HIV-positive. Raka's situation with her husband also demonstrates the gendered power dynamics in relationships whereby her husband's wish to remain married was honoured by the male magistrate.

### **Summary of Key Findings**

An HIV diagnosis often brought about feelings of anger and blame between couples. Many of the women were blamed by their husbands and felt that they would be blamed by society for being HIV-positive. Violence inflicted by men upon women was the norm and most often thought to stem from issues such as jealousy, infidelity, sex, and diagnosis as HIV-positive, with the root cause being social acceptance of violence against women. Condoms were viewed as something that men, and especially husbands, refused to use. When it came to having future relationships, a number of women wanted them but they were confused and had a limited understanding of their rights and responsibilities as HIV-positive women.

**Recommendations**

- Government agencies, donors, condom social marketers and NGOs should become more closely involved in promoting condom use. Specific issues ought to be addressed including lack of practical understanding; lack of social acceptance in relationships; and opposition from some religious organizations. Different approaches to promoting condom use need to be developed that are relevant to different cultural settings, age groups and relationship types. One size does not fit all!
- NGOs should offer Rights and Responsibilities training to PLHIV, counsellors and other stakeholders to increase understanding of the notion that along with having rights PLHIV also have responsibilities.
- Continue to develop, implement, and document programs such as the "community conversations" and Stepping Stones which encourage community dialogue and consensus building at the local level as a means to address harmful gender norms, gender inequality, relationships, use of drugs and alcohol, violence and sexual health.<sup>30</sup>
- Strategies to end gender-based violence must be integrated with HIV interventions consistent with the recommendations posed by the Pacific Commission on AIDS (2009) and UNDP (2009) to strengthen laws and policies to protect women.

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<sup>30</sup> For example, the Stepping Stones program which is being implemented in the Pacific by the Foundation of the People's of the South Pacific International. Information about this program is available at <http://www.fspi.org.fj/index.php/stepping-stones.html> See Reid (2010) for discussion of the "community conversations" approach in Papua New Guinea.

## CHAPTER 5

### Conclusion

The experiences of the women from Fiji and Papua New Guinea are in many ways similar although there are several differences.<sup>31</sup> First, treatment is more accessible for the Fijian participants. This is because there are 48 people on ART in Fiji while in Papua New Guinea thousands of people are on ART and thousands more are said to be in need of it. Second, the cultural practices of bride-wealth and polygyny are common in Papua New Guinea but not in Fiji. However, in Fiji the cultural tradition of the expectation of virginity at marriage is especially strong and also disadvantages women. Third, extreme cases of violence towards HIV-positive women and accusations sorcery and witchcraft by HIV-positive women have been reported in Papua New Guinea but not in Fiji. However, in Fiji religious influences appear to be stronger and they can play a role in fostering stigma and discrimination. Fourth, as was noted previously, violence against women appears to be the norm in Papua New Guinea while it is less frequent but still common in Fiji.

This report has provided an overview of the perspectives and stories of the women who chose to share their experiences as women living with HIV. It has provided insight into how these women faced being diagnosed HIV-positive, treatment and health services, stigma and discrimination, the challenges they face as HIV-positive women and the many ways they are coping with HIV. Their experiences also demonstrate the pervasiveness of conservative ideas about HIV and the profound and often negative effects these ideas have had on their lives. The negative impact of these ideas serves to remind us of the responsibility of those who provide information about HIV to promote care and compassion towards all PLHIV and make efforts not to reinforce gender inequalities.

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