

**A Qualitative Study of Attitudes and Risk Reduction Behaviors of Non-
sex worker Women living with HIV or HIV-Positive Partners**

Technical Report

Prepared for AWARE

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ACRONYMS & DEFINITIONS¹

ART: antiretroviral therapy or treatment (ART) slows down replication of the virus and can greatly enhance quality of life, but the treatment does not eliminate HIV infection.

CDC: Communicable Disease Centre is a centre within the Tan Tock Seng Hospital. The centre provides a consolation and treatment for a variety of infectious diseases.

HIV/AIDS: Human Immunodeficiency Virus (HIV) is a virus that weakens the immune system preventing the body's ability to fight off infection and disease, ultimately leading to Acquired Immunodeficiency Syndrome (AIDS), which is a fatal disease.

Sero- Concordant: often refers to couples that have the same HIV status, either both negative or both positive.

Sero-Discordant: often refers to couples that have different HIV status, one positive and the other negative.

STI: Sexually Transmitted Infections (STIs) are spread by the transmission of organisms from person to person during sexual contact, more than 20 diseases including HIV are categorized as STIs.

EXECUTIVE SUMMARY

Background:

As of December 2012,² 5,775 Singaporeans were diagnosed with HIV/AIDS, of which 549 (9.5%) were females. More than half (57.4%) of the women were married. Presently, little is known about HIV/AIDS-related knowledge and AIDS risk reduction behaviours among married or single non-sex worker Singaporean women living with HIV.

Objective:

This qualitative study, funded by the Association of Women for Action and Research (AWARE), explores attitudes about HIV/AIDS, safer sexual practices and concerns of HIV-positive women and women living with HIV-positive husbands or partners.

Methods:

In-depth one-to-one interviews were conducted with four groups of women, namely women who were either: (i) HIV-positive with a HIV-positive husband; (ii) HIV-positive with a HIV-negative husband; (iii) HIV-negative with a HIV-positive husband; or (iv) HIV-positive and single. These women were recruited from the Communicable Disease Centre (CDC), Tan Tock Seng Hospital and the Department of STI Control Clinic (DSC). Women who are sex workers were excluded from the scope of this study as there have

already been studies on this population,³ whereas there is minimal local research on HIV/AIDS prevention among other married or young Singaporean women.

Results:

Between January 2007 and November 2012, 60 women were interviewed, and 55 interviews were analyzed. The interviews strongly suggest that many of the ever-married women were monogamous and had acquired the infection from their husbands. A few women (n=8) were aware of their husbands' infidelity. Yet many remained in the marriage because they were economically dependent on their husbands, felt that extramarital affairs by men were a societal "norm", or felt powerless to change the situation. Although they wanted to protect themselves from HIV, they were not able to persuade their husbands to use condoms. One woman was beaten and three were subjected to verbal abuse when they tried to avoid unprotected sex.

The main concerns experienced by the women were the high cost of medications, stigma from family members, friends and employers, and conflicted emotions related to their desire to have children.

Recommendations

Women living with HIV clearly need holistic care to help them cope with the negative impact of the illness on their physical, mental and social and sexual wellbeing.

Strategies to complement the care currently provided by the dedicated health care team at the Communicable Disease Center should include: (i) the establishment of more support groups, especially for single women living with HIV, and (ii) the delivery of marital and family counselling services to affected women.

More public education is needed to combat stigma and promote acceptance of HIV infected women in the family, workplace and the community.

The government should consider providing subsidized care and cheaper generic drugs to increase compliance with medications among these women. This will lead to better health outcomes and their employability, hence reducing dependence on the family and health and social services.

Education programs on HIV should be implemented for women to increase their HIV awareness and risk of acquiring the infection. HIV-positive married and single women should be involved in awareness building to contextualize and bring reality to the messages.

Given the low success in negotiating condom use with husbands and the non-availability of female-controlled technologies, condoms should be promoted as products to protect the family and enhance pleasure, rather than just to prevent disease or pregnancy. Public

education for men should be intensified to prevent them from getting infected with HIV before or after marriage.

1. INTRODUCTION

As of December 2012,² 5,775 Singaporeans were diagnosed with HIV/AIDS, of which 549 (9.5%) were women. More than half (57.4%) of the women were married. Sexual transmission remains a significant mode of HIV transmission among Singaporeans, with heterosexual transmission accounting for 47% of infections in 2012. About 30 to 45 women with HIV were reported yearly from 2006 to 2011. In 2012, 32 women were reported with HIV/AIDS of which 40.6% were married. The others were divorced (31.2%), single (21.9%) or widowed (6.3%).

Casual sex, including that with sex workers, is the main source of HIV/AIDS and sexually transmitted infections (STIs) among heterosexual men in Singapore. Recent studies on male Singaporean clients of sex workers found that only about half (54.4%) used condoms with sex workers overseas although the majority (87.4%) who visited sex workers in Singapore used condoms.⁴ These men likely act as a 'bridge' for transmitting HIV and STIs from female sex workers to their wives and girlfriends. Other than studies carried out on sex workers, there is minimal local research on HIV/AIDS prevention among married or young Singaporean women. Hence, little is known about their HIV-related knowledge, attitudes and sexual practices. Some remaining questions include: Do married and young women know they are vulnerable to acquiring HIV? Do they know how to protect themselves from getting infected by their partners? Do they know how to negotiate for safer sex practices? What are their lives like after diagnosis? What are the cultural and sociological effects of living with HIV for women in Singapore?

Concerns have been raised about such women in these aspects - her approach to issues related to safer sex; her knowledge on sexually transmitted infections; and her level of empowerment in condom use and in communicating about sex with her partner.

2. STUDY AIMS

This study aims to explore the attitudes about HIV/AIDS, sexual behaviour and safer sexual practices among married and non-married women, who are either HIV-positive or have an HIV positive spouse or partner.

3. METHODS

Between January 2007 and November 2012, we conducted in-depth interviews with 60 non-sex worker women (defined as women who did not engage in paid sex) from the following categories:

- i. Married women with HIV and HIV positive husbands
- ii. Single women with HIV
- iii. Married women in sero-discordant marital relationships

(i.e. HIV positive women with HIV-negative husbands or HIV negative women with HIV positive husbands)

The study was approved by the National University of Singapore Institutional Review Board (IRB) on 26 November 2006. The women were recruited from the Communicable Disease Centre (CDC), Tan Tock Seng Hospital and Department of STI Control Clinic (DSC). A maximum variation sampling strategy was used to select women of diverse socio-economic, educational and cultural backgrounds for the in-depth interviews.

Although we planned to recruit 20 women from each of the above categories, we faced difficulty in recruiting single HIV positive women because of the stigma. Additionally, it was difficult to find married women who fit the inclusion criteria of HIV sero-negativity. The final distribution of the 60 women recruited was as follows:

- i. 33 married HIV-positive women whose husbands are also HIV-positive
- ii. 5 non-married HIV-positive women who have never engaged in paid sex
- iii. 5 HIV-negative married women with HIV-positive husbands
- iv. 17 HIV-positive married women with HIV-negative husbands

Of the 60 conducted interviews, 55 were used in analysis. Five transcripts were unavailable to be used in analysis; 4 of ever-married women with HIV positive husbands and 1 of a HIV negative woman with an HIV positive husband. During analysis, the research team lost contact with the assistant who transcribed these five lost transcripts. However, exclusion of these five scripts is unlikely to bias the results because there was a large sample (n=29) of HIV positive married women. From the four HIV-negative women we did interview, we were able to obtain comprehensive information.

Table 1. Interview Numbers

	Married HIV-positive with HIV-positive husbands	Single non-sex worker HIV-positive women	Sero-discordant couples		Total
			HIV-negative women with HIV-positive husbands	HIV-positive women with HIV-negative husbands	
Target number	20	20	20		60
Numbers interviewed	33	5	5	17	60*
Numbers used in analysis	29	5	4	17	55

3.1 Questionnaire and in-depth interviews

Prior to the in-depth interviews, we explained the purpose of the qualitative study to the participants. The participant information sheet was explained and given to them and written consent was obtained. The participants were assured of confidentiality. Their names or identification card numbers were not recorded in the questionnaire or consent form. Each interview lasted two to three hours.

A semi-structured questionnaire comprising open-ended questions was used to explore the following areas sensitively and empathetically:

- i. How the women contracted HIV and their perceptions of how their husbands or partners acquired the infection
- ii. Impact of the infection on their relationships, family and work
- iii. Knowledge and attitudes about safer sex practices
- iv. Protective and safer sex behaviors adopted by the women
- v. Problems encountered in attempting to practice safer sex with their husbands
- vi. Their need and concerns, in particular, problems related to stigma

3.2 Data Analysis

The analysis in this report draws on the data collected from 55 of the completed interviews, which comprised 91.6% of the targeted sample. Qualitative analysis of the data was carried out by both narrative reconstruction of the participants' firsthand accounts and experiences, and categorization of their feelings, views, safer sex practices and concerns into themes. The transcripts were first searched for words or phrases and divided into simpler text units and coded. Using focus coding procedures, the coded text units were sorted and systematically categorized according to emerging similar issues and then into broader themes. Outlier opinions within and across marital status and ethnic groups are also reported.

4. SOCIO-DEMOGRAPHIC CHARACTERISTICS

The ages of the HIV positive women ranged from 21 to 69 years. Of these, 5 were single and 3 divorced. The majority 45% (n=25) were Chinese Singaporeans with 9% (n=5) Malay, and 5% (n=3) Indian (Table 2). Twenty of the married women were foreigners (10 Thais, 1 Filipino, 2 Chinese nationals, 1 Myanmarese, 1 Cambodian, and 5 Indonesian) all were married to Singaporean men. About 22% (n=12) of the women had attained a level of education no higher than primary school; 42% had at least some secondary schooling; 20% (n=11) had achieved their A-levels, a degree or a diploma; and one woman had a Master's qualification.

Table 2: Socio-demographic characteristics of women in the study

	Married HIV-positive* women with HIV-positive husbands n=29	Single non-sex worker HIV-positive women n=5	Married HIV-negative women with HIV-positive husbands n=4	Married HIV-positive women with HIV-negative husbands N=17
Race				
- Chinese	15	4	3	6
- Malay	5	0	0	2
- Indian	2	1	0	0
- Thai	5	0	0	6
- Filipino	1	0	1	0
- Myanmarese	1	0	0	0
- Cambodian	0	0	0	1
- Indonesian	0	0	0	2
Age				
- 20-29	0	2	0	4
- 30-39	12	1	3	7
- 40-49	11	0	0	5
- 50-59	5	1	0	1
- >=60	1	0	1	0

***1 woman who had been married for 8 years had refused testing**

5. DISCOVERY

A majority of the HIV-infected women were asymptomatic and on antiretroviral medications. About one third (n=11) of the ever married women with HIV-positive husbands found out their HIV-positive status when they got tested because their husbands were sick from AIDS. One woman found out about her HIV-positive status when she went for screening after her husband was tested by his employer. Fifteen other women came to know of their HIV status during routine antenatal testing (7 of which had HIV-positive husbands, 8 who had HIV-negative husbands). One woman found out her status as she was giving birth to her child. Three women discovered their HIV status when their children (6 months to 6 years of age) became sick (n=2) or died (n=1) from complications related to AIDS. Eleven women learned of their HIV positive status when they themselves fell ill. Of the single women, three found out after becoming sick, and one found out through a routine medical test.

5.1 Emotions upon learning of HIV status

The women (n=52) expressed a wide range of emotions and feelings related to their diagnosis. Many of the reactions were similar to what is often expected with the diagnosis of any chronic, life-threatening disease. These include denial, shock, anger and sadness. Some reactions were severe, with 12 of the women admitting to suicidal thoughts, and in one case the woman attempted suicide. Even more expressed feelings of depression. However, at least twelve of the women described feeling calm about their diagnosis. Many of these women felt compelled to handle their diagnosis positively for the sake of their families, particularly for their children. One woman had done a wealth of research on HIV/AIDS after her diagnosis, and noted that the knowledge about the disease and the treatments “empowered” her. Another participant noted that with proper treatment she could live a long and normal life, which helped her cope in a positive manner.

At least two participants found comfort and strength in religion. One woman, a self-proclaimed Buddhist, found a support system in a local church that visited the Communicable Disease Center (CDC). She had previously felt suicidal upon her diagnosis, and said that because of them (church volunteers) she did not end her life. She did not convert to Christianity, but instead was comforted by the support these individuals afforded her.

Many of the women expressed that the initial days or week after the diagnosis were the most difficult. One woman described this period as a “nightmare.” However, those who had support during this time coped much more positively, and that support took many forms. Those who either knew about HIV and treatments, or who were given this information by their doctor immediately after diagnosis, expressed more feelings of calm and a positive outlook. Additionally, women who felt supported emotionally by their husbands, children, family members or friends had a much more positive view about their diagnosis and life ahead. The women who expressed a strong feeling of responsibility towards their family also coped in a much more positive manner.

One woman said:

“I had a lot of positive thinking and that made me stronger than other people. Although I’m aware that I am positive I don’t want to become weak or become sad. It’s not a problem as long as I can take care of my son. I tell myself that I am not sick. If I die tomorrow, it’s ok. I will let God decide.”

Those who felt alone, or kept their diagnosis a secret, expressed more feelings of sadness and depression.

5.2 How their husbands or partners contracted HIV

The findings suggest that most of the 50 HIV-positive women who had ever been married were monogamous. Twenty-four, or almost half, of the married women who are HIV-positive believed that they had acquired the infection from their husbands. When asked about how their husbands had contracted HIV, fourteen of these women believed their husbands had caught it from commercial sex workers, either before or during their marriage. Eight women felt that their husbands were probably infected by their past girlfriends. Five women were unsure how their husband contracted HIV, and many of them simply did not want to know.

One of the married women had married twice and divorced five years before she tested positive for HIV and presented with symptoms of eye infection suggestive of AIDS. Her first and second husbands were both HIV-negative. She had lived with two boyfriends after her first divorce. She believed that she had acquired the infection from her boyfriend, a New Zealander and a senior director of a multinational company. She had agreed to live with her boyfriend who 'loved sex' because he was paying for her upkeep.

Two married HIV-negative women who were interviewed knew that their husbands were HIV-positive before marrying them. They loved their husbands and did not blame them. In their own words they said "It can happen to any man". One of them, who is currently working as a real estate agent, commented:

"He has a Thai girlfriend before he met me. I know that he is faithful to me after he starting dating me and he really cares for me. I do not blame him at all."

The other, a graduate working as an analyst, believed that her husband had acquired the infection from one of his girlfriends. She reported that she had many casual partners before meeting her husband.

The five single women suspected that past partners had infected them. One woman shared that her ex-boyfriend had been an intravenous drug user, and she suspected that was how he was infected with HIV. Another woman explained that after her diagnosis, her ex-boyfriend admitted to visiting other women as well as sex workers. Three women were not able to determine who specifically had infected them. One woman stated "It could be the first, the second, could also be the third boyfriend or the fourth. I was young and didn't think so much then."

Many of the men above obtained sexual services in Thailand, Vietnam, Batam and other parts of Indonesia.

6. EFFECTS OF DISCOVERY

6.1 Impact of the infection on their relationships and sexual intimacy

The majority of the women, including those who had suffered from complications of the disease, remained married and had come to terms and forgiven their husbands for spreading the infection to them. Three of the 51 married women had divorced their husbands and six were widowed.

Many women expressed negative feelings towards their husbands, including bitterness and anger. Many of these women came to forgive their husbands after time, including one woman who had divorced her husband because of HIV. She forgave him just before his death and after being persuaded by her twenty-year-old son. Some of the unemployed foreign women felt that they had no choice but to stay in their marriages because their HIV-positive husbands were still working and financially supporting them and their children. Many of the married women were also working to support themselves and to pay for the medications.

A majority of the women (60%) expressed that sex was an important part of their marriage, both before and after diagnosis, or an important part of relationships in general. 64% of the women in our study continued to have sexual intercourse with their partners post-diagnosis.

Almost all women, including older women (50+), continued to engage in sexual intercourse, albeit less frequently, because it helped to bring them closer to their husbands. A number of women continued to have satisfying sexual lives and at least five women indicated their desire to have children.

The women gave the following reasons for continuing sexual intimacy with their husbands: “Marriage without sex is not a marriage. It is just like a relationship between friends.”

A 27 year-old-married woman expressed: “I still have a sexual urge.”

Still, many of the women saw love as more important than sex within a marriage. At least 12 women expressed ambivalence towards sex, or saw a marked decrease in sex after their diagnosis (or their husband’s). This was often attributed towards not wanting to infect their partner and/or become infected. One woman stated: “Even though we do not engage in much sexual intimacy, this is because of my condition, not because we do not love each other.” Some women also felt betrayed by their husbands, and no longer desired to have sex with them. One woman explained: “Even though I love my husband, and we did have a good sex life before, I do not want to have sex with him now... I sensed he must have had some inkling about his condition for some time but he kept it a secret. I feel betrayed.”

There were also three HIV-positive women who verbalized that they had more sex with their HIV-positive partners post-diagnosis. It appeared that the three women had

developed a closer relationship with their partners after being diagnosed with HIV. A total of seven participants had reported a decline in frequency of their sexual intercourse post-diagnosis. Reasons cited for this included climbing age, a loss of interest in sex, preventing cross-infections to their spouses and reduced energy levels due to side effects of their medication. About 27% of the women (n=15) had abstained from sexual intercourse altogether because of decreased libido, fear of infecting their partner with HIV, rejection from a HIV-negative spouse or to protect oneself from a cheating partner.

6.2 Awareness and attitudes about HIV and Safer Sex

Nearly all the participants, particularly the older women aged 50 and above and those with primary education, lacked awareness about HIV/AIDS before their diagnosis. Of the 55 women, 63% (n=35) expressed having little or no knowledge about HIV prior to their diagnosis. Eight women had a fair amount of knowledge, and four felt they were very informed.

Many women reported having believed a diagnosis of HIV was an immediate death sentence. Many others used to believe that the disease only affected gay men and sex workers. A few women knew how HIV is transmitted, but in the words of one woman: "I did not apply the knowledge to myself. After all, it was not like I was sleeping around. I was only with this one guy". Even though some of the women had a basic knowledge of HIV, they did not believe that it could happen to them. Many others believed myths on HIV such as, believing that it could be contracted via touching or even by sharing bus seats. One woman thought it could only afflict white people. One woman said: "I thought that diseases like HIV would never occur in Singapore as no one spoke of it before".

It is interesting to note that the majority of those who knew a fair amount or were very informed about HIV were non-national women, five of whom were Thai. A possible explanation is that HIV education is much more prevalent in Thailand. The education level of these women was also quite high, with almost all having completed at least secondary school.

After being diagnosed with HIV, they became more informed about HIV/AIDS because of the counseling sessions with the doctors and medical social workers. Despite this awareness and the advice given by the doctors to use condoms, many women still found it difficult to adopt safer sex practices. To illustrate, one participant and her husband gave up on their first attempt at using it, despite the fact that the man was HIV-positive. He himself had never used a condom before. After that failed attempt, the couple abandoned the use of condoms entirely.

7. PROTECTIVE BEHAVIOURS AND SUCCESSFUL STRATEGIES OF CONDOM USE

7.1 Before acquiring the infection

The findings suggest that the majority of the women had never used condoms with their husbands prior to diagnosis. One woman in her fifties never thought her husband would visit a sex worker and therefore did not prioritise condom use when engaging in sexual intercourse with her husband.

One married HIV-positive woman, who currently works as a hairdresser, was often able to convince her husband to use a condom. She would buy condoms and keep them in a cupboard at home. She had been requesting her husband to use a condom for every sexual intercourse with her because she knew that her husband had been patronizing sex workers even after marriage. She recalled not using a condom only once because she had run short of condoms. Her husband had insisted on sex and she was not able to refuse him. She felt that she had been infected from that incident.

Of the five single women interviewed, two reported that they had almost never used condoms with their partners. The other three reported to only using them sometimes. One single woman would ask her partners to use a condom “in the beginning”, and this would be the case “until she trusts them.” Their reasons for not using condoms were perceived low risk of their boyfriends having HIV/STIs or partners refusing to use them. One of the single women explained that she did not understand the risks early on in her sexual experience, and this set a “pattern” of not using condoms later in life.

7.2 After acquiring the infection

Consistent condom use is important for both sero-concordant and -discordant couples. It is important for the latter group to prevent the spread of infection to the uninfected. Condom use is also important for sero-concordant couples to prevent transmission of new HIV strains or antiretroviral therapy (ART) resistant HIV strains, which may lead to rapid progression of the disease.

About 35% (n=10) of the sero-concordant couples who are still living together used condoms consistently. Four additional women in this category reported only using condoms sometimes within the marriage after diagnosis. The rest of the couples were not compliant with the doctor’s advice to use condoms consistently, and the women, particularly the older women (40+) had difficulty persuading their husbands to do so. They often leave it to the husbands to buy condoms and sometimes their husbands would forget, or choose not to. Younger women appear to be more successful in persuading their husbands to use condoms. They often used the excuse of using condoms to prevent pregnancy or would put on the condom for their husbands in a pleasurable manner.

Close to 60% (n=10) of the sero-discordant couples (HIV-positive women with HIV-negative husbands) used condoms consistently in their marriage. One HIV-positive woman was very insistent about condom use; she would buy big boxes of condoms and was able to persuade her husband to use them by buying colourful thin condoms of good quality and using her 'charm' so that her husband would enjoy sex with a condom. Another young Malay woman was also proactive in persuading her second husband who was HIV-negative, citing the reason that he must keep healthy for the sake of their young children. However, her first husband (to whom she had been married for six months) was religious, would refuse to use condoms or go for HIV testing.

There were four HIV-negative women interviewed with HIV-positive husbands. All four reported either abstaining from sex with their husbands, for fear of being infected, or else using condoms every single time when they do decide to engage in sex. One woman, however, intends to try for a baby in the near future, and expressed a willingness to risk her health and her future child's, because she "wished to have a normal family life even if bad things happen...life must go on."

In contrast, a 30 year-old-woman graduate who has been married for three years has not engaged in sex with her healthy asymptomatic husband for the last one year because she was not prepared to take "the 5% risk even" from protected intercourse. This has resulted in a strain in her marriage. She is contemplating divorce so that she can meet another man one day and have a child who has no risk of contracting HIV. She knew her husband was positive before marrying him but she did not mind then, because she loved him. She had unprotected intercourse with him for about one year before their marriage. In the early part of their marriage, they were having sex about once a week and always used condoms. Lately, she did not even want him to touch her or kiss her because of her fear that it may lead to him demanding sexual intercourse. She has also faced pressure to conceive from her mother-in-law, who is unaware about her son's HIV status.

7.3 Reasons for not using condoms before and after HIV diagnosis

There are many reasons why the women in the study did not use condoms with their husbands or partners before they were diagnosed with HIV. The five single women all reported using condoms only rarely, because they felt that they did not need to, or else their partner refused. When they were having sex with their boyfriends, they were in love and it felt great for them that they were 'needed' by their boyfriends. Married women also gave the above reasons. Additionally, married monogamous women faced many barriers in negotiating for safer sex with their husbands. The reasons could be broadly categorized into the following:

Lack of awareness about HIV: An alarmingly large number of women in the study believed HIV infection only affected "gays, prostitutes and drug abusers." In addition, they believed that their husbands did not have HIV because they looked well.

Self-perceived low vulnerability to HIV/ AIDS: Other women felt themselves to be at low risk because they did not think that their husbands had been unfaithful to them. This was true for a few women whose husbands appear to have acquired the infection before their marriage to them.

Difficulty in assessing husband's infidelity: Some women were not aware that their husbands were having extra-marital affairs. They were exposed to the risk of HIV without warning.

Inability to change their husbands' extramarital sexual behavior: Fourteen of the 50 married women either suspected or had confirmed that their husbands had contracted HIV from commercial sex workers. Eight of these women were previously aware that their husbands were seeing sex workers. However, they could not ensure their husbands used protection outside marriage. Some of these married women reminded their husbands to practice safer sex should they visit sex workers.

One 60-year old woman was aware that her salesman husband made frequent weekend trips to Haadyai. When she tried to persuade him to stop seeing sex workers, he would frequently become physically abusive towards her.

Difficulty in persuading husbands to use condoms: A majority of the married women reported that their husbands would not agree to condom use even if both parties knew of the man's infidelity. The men often complained that condoms are "uncomfortable" and refused to use them.

One woman in her late forties elaborated on her husband's belief that condoms interrupt the natural flow of his seminal fluids and would lead to 'heatiness' and illnesses in him.

In one instance where her husband was known to visit sex workers, a woman was physically abused and sustained a skull fracture when she refused unprotected sex.

Many of the women expressed that they felt they could not even discuss using condoms, fearing that their husband would suspect them of cheating, or suspect them of suspecting him of cheating. One 54-year-old woman explained:

"People who are married and still use condoms are crazy as it shows they do not trust each other."

Another 41-year-old Thai woman explained a sense of fate:

"If the women are really in love, they would do anything to please their husbands. Love is very strong, if a couple has to die (from HIV/AIDS), they'd die together."

This sense of fatalism appeared several times throughout the interviews, where either the women or their husbands resigned themselves to acquiring the infection if they were fated to, and thus would not bother to use condoms.

7.4 Successful strategies adopted by women for condom use

Despite the many barriers faced by a majority of the women, two women were very successful in persuading their husbands to use condoms almost all the time. One had received the infection from her boyfriend and wanted to protect her HIV-negative husband. One sero-concordant couple was highly motivated to use condoms to prevent transmission of other HIV strains, which can cause the condition to progress further. The wife said that she takes control by buying the condoms herself. She chooses thin condoms of different types to give variety to her husband. She also puts the condom on her husband and reminds him that they have to remain well for the sake of their children.

One HIV-positive woman with a HIV-negative husband who is very motivated to use condoms said this:

“I’ll talk nicely to him and sometimes just put it on in a nice way without asking him. Other times I’ll tell him I know that you love our children and want to see them grow up. I am already positive. It is important that you keep yourself healthy and well so that you can take care of them should anything happen to me.”

8. LIFE AFTER DISEASE

8.1 Negative intrapersonal changes (individual attitudes and beliefs)

Common negative experiences at an individual level were reported by more than half of the participants (n=34). All but one of them was HIV positive. Some of the negative experiences that the women described were: a change in temperament (being easily irritated), low self-esteem, concerns about changes to their appearances, decreased energy levels, guilt, higher stress levels, feeling low or depressed, a sense of hopelessness, and poorer health. They also mentioned having fears of a worsening future, of death, of infecting newborns, and of being the sole breadwinner of the family. One woman described her situation: “I felt that my temper became worse. I am angry at little things very easily. I feel that my body had changed and it got old very easily. I am also fearful every time I have a medication allergy. I would develop dots and black patches all over.”

Recurrent negative thoughts were described by many of the participants. Six women (in sero-concordant relationships) were notably fearful of losing their spouse. They tend to worry about their children’s future should they and their husbands pass away. Most of these women had less than secondary level of education and were in their thirties.

In the years following diagnosis, most women (n=43) expressed that negative feelings were amplified. Such negative feelings included a sense of anger, depression, sadness, fear or even suicidal thoughts.

8.2 Negative interpersonal changes

Women in sero-discordant relationships (where their husbands are HIV-negative) described that their husbands started having extra-marital affairs following the women's diagnosis. A foreign HIV positive woman married to a HIV negative Singaporean husband described her situation with tears: "Life was stressful ever since my husband got himself a girlfriend. He would bring her home and sleep with her. I will have to hear unfriendly comments from his girlfriend." The relationship with her husband later became abusive. "My hair was pulled and I was hit and got slapped by my husband when I asked him why he had money to take care of his girlfriend but had no money to take care of your son. Sometimes, I would be locked in the house and my son will be taken away from me for days. My son will be brought to the girlfriend's house."

A variety of reasons made it difficult for the women to leave abusive interpersonal relationships such as the fear of breaking up, dependency on husband for financial income and the possible negative repercussions on their children. This is especially true for HIV positive foreign wives who are married to HIV negative local men and have children with them.

Some HIV positive women allowed their HIV negative husbands to have other sexual partners as they felt other women were more able to provide for their husband's sexual needs.

About one-sixth of the participants across different age groups experienced social isolation post-diagnosis. They withdrew themselves from their previous social networks and reduced the frequency of contact with people outside of their families. One participant described: "I had to cut down on my social life... I prefer to solve my own problems. It was not necessary to tell everybody everything as they cannot always help you."

A minority of the women experienced a struggle of having multiple caregiving roles. For example, one had to care for both her HIV positive children and her HIV positive husband.

8.3 Positive Intrapersonal Changes

About two thirds of the women were interviewed at least two years after their diagnosis. Hence, most of these participants had already accepted the diagnosis and adopted various coping strategies to alleviate the negative emotions that accompanied their illness. In addition, they were better able to control their health by taking

proactive measures to protect themselves, such as having proper and nutritious diet, regular exercise, adhering to medication therapy and maintaining good hygiene.

Close to half of the women interviewed indicated a positive change in their attitudes and beliefs about life or a general better outlook. These changes include: resilience in the face of adversity, optimism/acceptance, better self-care, greater control over emotions, feeling grateful for what they have, having stronger faith in God or spirituality, improved coping strategies and motivation to decrease behaviors such as smoking, drinking or gambling.

Some participants began to reevaluate their own lives and sought to change their own shortcomings in their personality. One local Chinese woman shared her experience: “I used to have a bad temper last time... I’ve now learned to see things in a light-hearted manner. I learned to be less uptight about issues and not suffocate my husband with my hot temper.”

Optimism was repeatedly brought up in the accounts of many participants as an important coping strategy: “When I am sad, the bad bacteria will win which make me sick.... I often told myself to relax, take things easy and maintain a happy mood. Happiness has been an effective medication and is free (of charge).” Another said: “When a road is blocked, there is always another way out.”

Another commonly used coping strategy was distraction: “I occupy myself with household chores, caring for my relatives and husband, making handicrafts. I am so busy that there is no time for me to even think about negative things.”

Others showed tenacity and acceptance that may be driven by a fatalistic view of life in general and these were reiterated in one woman’s account: “I felt that I am fine after having contracted the disease. How long a person can live is due to fate. Even if I have to die someday, I want to die as a happy person. AIDS was never a frightening disease. I am able to live like a normal person as long as I take my medication. There is no pain like cancer.”

Faith and prayer are also listed as personal resources integral to coping. Importance of spirituality was reiterated in a woman’s account: “The greatest comfort that I had after diagnosis was from Christ. Whenever I had a problem or felt like ending my life, I would read through the pages of the bible and there will always be a quote that would be applicable to my situation.”

8.4 Positive Interpersonal Changes

About half of the participants had improved relations with family and friends. They had supportive friends, family members, support from NGOs and healthcare professions. Some felt motivated as a caregiver for other family members, and others decided to contribute and even helped out at the CDC.

One participant described her underlying motivation for being positive: “I remained positive because being unhappy would affect my family in a bad way. My daughter motivates me to be healthy. I want to give my best to my child.” Another woman explained: “I do not want my children to be upset and I would bring my children out of the house to get away from the sad atmosphere at home. I would bring them out to eat and try my best to make them happy. Whenever my children smile, I would feel happy and better too.”

Another mentioned how doctors and medical social workers motivated her to better her life: “Each time I saw the doctor and her medical social worker, I feel energized and there is hope and I want to take care of myself. I will listen to them and take my medication diligently and eat healthily.”

Some women in sero-discordant relationships reported receiving support, love and companionship from their HIV negative husbands after being diagnosed with HIV. Their spouses were often a main source of both emotional and financial support for them: “... I almost wanted to give up on life but my husband encouraged me to carry on and said, ‘You try, I support you’. Although my husband is a Buddhist, he will drive me to church every Sunday.”

Others had supportive and loving family members: “When I was in the hospital, my son-in-law would buy food for me from the hawker center regularly because he knows that I do not like the food from the hospital. My son will travel to Thailand every year to buy medicine for me. Another of my son even went to the temple to pray for me to get better and bought me an amulet”.

9. INTERVIEWEES’ CONCERNS

9.1 High cost of medication

Of all the concerns raised, the cost of medication was most prevalent. The cost of medications from Tan Tock Seng Hospital ranged from \$800 to \$1,000 per month in 2006-2009. In recent years, the price of the medicine has decreased to around \$400 to \$600 per month. This was attributed to the doctors who have bargained with pharmaceutical companies to provide many of the highly active anti-retroviral medications at lower prices. Despite the lower price, some participants still find it

extremely difficult to pay for their medical bills. One local participant complained about the financial burden:

“Although now we are able to get cheaper medications, the initial high cost of medication placed us into heavy debts for a long time. Why is this medication not subsidized by the government? Why was AIDS singled out this way? ... unfair... (this is) just another illness.”

Most Singaporean women, however, managed to obtain some form of subsidy from the medical social workers.

One-sixth of the participants defaulted their medication or postponed the commencement of drug therapy when they were first diagnosed with HIV due to the high cost. One participant resorted to reducing the dose of her medication by half on her own to save money. Another participant shared that some patients developed a system of borrowing medications from a wealthier patient and returning the same type of medication to the person when they had more cash fluidity.

Given the high cost of medication, a significant number of women (n=14) tried to obtain cheaper alternatives by asking their friends to help them purchase medications from Thailand directly. Of these women, about two-thirds were in sero-concordant relationships, and faced the stress of having to manage medical bills of at least two persons in the family. By getting medications from overseas, the cost became much lower and amounted to approximately \$200 per month.

Many of the participants worked to pay for their medication. However, when they were too ill to work, they struggled to afford the life-giving medication. Some participants reported having to take loans to pay for their medication.

9.2 Financial constraints, unemployment, need to work, work permit

More than one third of the participants (n=24) expressed facing financial constraints. These difficulties arise from a low household income, existing debts, unemployment and having multiple dependents. One HIV positive widowed woman, a Chinese Singaporean, had to deal with loan sharks and her husband's debts after he passed away from complications related to AIDS. Now as the sole breadwinner, she was forced to hold an office job, night jobs and odd jobs to care for her three children. Another HIV positive couple was unemployed for long periods because of their poor health status. They were unable to maintain housing loan installments. The Housing Development Board (HDB) eventually repossessed their flat.

When symptoms of HIV were severe, it greatly affected some women's ability to work. A local Chinese single woman said: “I was unable to work because of my frequent cough... Everything was troublesome.”

A few women expressed their difficulty in getting time off work to collect their monthly supply of medication. One local participant decided to take on a part-time job instead of a full-time one so that her job performance will not be affected too badly.

Due to financial pressure, foreign wives married to Singaporean husbands expressed the need to work. They raised a concerted concern that they could not depend on one person's income to survive, as the cost of living in Singapore is high. The married women, who were dependent on their HIV positive husbands' income, could not imagine how they would cope if their husbands were to fall ill and stop working. Even if they were to work at the CDC and get a few hundred dollars a month, the amount would be simply inadequate to meet the needs of a HIV-negative family with young children, much less for a family with one or two HIV positive parents.

About half of the foreign wives (n=10) married to local husbands brought up their concerns regarding their social visit pass and their failed application for a work permit and/or permanent residency, due to their HIV positive status. They were worried about their plight after their husband passed away. Marriage is a prerequisite to maintain and renew a yearly social visit pass. These women feared that they would be sent back to their country without the pass and may eventually be separated from their children who were born in Singapore. In addition, they were afraid that they would not be left with any possessions from their husbands such as the house, money and other material needs. One woman said:

“I feel insecure about my future. I cannot imagine what would happen to me if my husband dies. My Permanent Residence (PR) application is not approved although I am married for 3 years. If my husband dies, the house cannot be transferred to my name as I am not a PR.”

A few women faced difficulties renewing their social visit pass, as they had to have their pass renewed more frequently after being diagnosed with HIV. To illustrate an example, one participant shared her troubling experience: “My social visit pass was previously renewed annually and must now be renewed on a monthly basis (after diagnosis). I asked why and I was told that my case was classified under ‘pending investigation’ and that my social visit pass was dependent on my doctor issuing a letter every month. I was also told that this was the routine procedure here.”

Four women, all of whom were foreigners, reported taking illegal jobs to earn a living. They did cleaning, cooking, baking, handicrafts and laborious jobs at dry cleaning shops. One worked as a clothing store sales assistant. A HIV-positive Indonesian woman in a sero-concordant relationship was told by her doctor that she only had 5 years to live because she had leukemia. She was afraid that her young children would be left with nothing. She took multiple jobs and slept only two to three hours a day. She ate only once or twice a day to save money. She explained that: “I was desperate and did so for my children and to survive.”

Another 32 year old Indonesian who is in a sero-concordant marriage verbalized that being able to work is a right and helps maintain the dignity and pride of her as a human being. She said this:

“...Just give me a chance to work. That’s all. To earn my sweat and tears. I cannot depend on Medical Social Workers my whole life. At least I can pay \$50. I have pride. I don’t want to take assistance for free. Even if they allow me to contribute 1 cent or 2 cents, I will feel better.”

Along the same lines, another woman shared: “I do not want to depend on others. I’d like to pay for my medications on my own. I started to work to pay them at the CDC. When I saw that there were more sickly people in CDC who were less fortunate, I told my social worker to release my subsidy and use it for those who need it more.” A 39 year old, Thai HIV positive woman married to a HIV negative husband expressed: “I feel like a useless person as I have to rely solely on my husband for money.”

One 42 year old Thai woman, who is HIV positive and married to a HIV negative husband, hoped that in the near future, people living with HIV can be allowed some form of work permit to contribute to Singapore’s economy. “We are not useless people. We can sweep, wash dishes, sell items, work in factories, anything.”

9.3 Disfiguring side effects of medications

About one-sixth of the women complained about the adverse and disfiguring side effects of consuming the long-term medications such as hair loss, sunken face and fat loss in their arms and legs (lipodystrophy or lipoatrophy). They were worried about changes in their physical appearance, as it might alert other people about their positive HIV status. In a participant’s own words:

“I am concerned about changes in my physical appearance due to the side effects of medication. I will ask my non-HIV positive friends if I looked thinner or if my body changed? I am afraid that others can tell that I have HIV.”

Lipodystrophy or lipoatrophy was one of the most distressing aspects of living with HIV for many of the women and it had the potential to influence their decision to start or stop taking antiretroviral therapy. Some patients stated that there seem to be a lack of understanding on the part of the medical providers regarding the effect of the physical changes on an HIV-positive person’s emotional and mental health and quality of life.

9.4 Concerns about having children

At least eight of the younger HIV-positive women in their late twenties and early thirties expressed their desire to have children. One HIV-negative woman who loved her HIV-positive husband dearly wanted to bear a child for him. Another HIV-

negative woman felt her biological clock ticking and felt a yearning to conceive whenever she saw her siblings with their children. At least three women felt the pressure to conceive from their in-laws who did not know about their condition. One Chinese national felt rather lonely and is considering adopting a child from China.

One Chinese HIV-positive woman who had a 7-year old HIV-negative daughter and is currently married to an HIV-negative man said:

“I feel bad that my husband cannot have a child because of my HIV infection. He may leave me one day for another woman if I do not bear him a child. I feel that I am not fair to him. I may leave him so that he has a chance to find another woman who can bear children for him. Also when I play with my 7-year-old daughter, I feel that I should give her a little brother or sister as companion. However, I have to keep on reminding myself that I cannot take the risk of getting pregnant and giving birth to a HIV-positive child.”

10. PROCESSES OF STIGMATISATION

10.1 Internalised stigma

Although some participants shared that they did not face any unpleasant situations in which they were discriminated against, almost all of them had negative beliefs, views and feelings towards themselves and HIV positive people. They felt ashamed, guilty, worthless, dirty, and deficient as women and as mothers for being HIV positive. One 34-year-old woman explained:

“At times, I feel angry and want to take out my dirty blood.”

Intense feelings of shame and self-loathing were evident. One woman shared that:

“I felt different from the rest of my colleagues and did not dare to mingle too much with them. I felt dirty. I was uncomfortable sharing food with relatives and friends. I would encourage people on the same dining table to use a ladle to scoop their food.”

Many women expressed fear of discrimination if they were found out to be HIV positive by family, friends or colleagues. One 42 year old, Filipino, degree-holder expressed: “I fear that once people know (about my diagnosis), they would treat me differently.”

Another woman herself held certain beliefs about HIV/AIDS: “I myself have negative opinions about AIDS patients and referred to AIDS as ‘that kind of illness’.”

10.2 Enacted stigma from family, friends, and others

About one third of the participants experienced discriminatory actions from those around them. Their family, friends, and strangers had irrational fears of contracting HIV and falsely believe it can be transmitted through casual contact. They would keep a physical distance from HIV positive people and often make insensitive remarks.

Relatives' unfounded fears often lead to them taking excessive precautions to prevent themselves and others from becoming infected. One participant recalled her painful experience with her relatives during Chinese New Year when her niece and nephew were told to avoid contact with her: "Don't go near Auntie as she carries a lot of germs." Another discussed the time when her symptoms first appeared:

"My sister would wear a long-sleeved jacket plus gloves whenever she came to visit. She would be paranoid when I scratched myself. My sister-in-law will not come near me for fear of the disease."

One woman recounted an incident when she travelled on the bus and noticed how passengers would move away from her. She said: "The rashes on my arms were unsightly and visible to others. There would be empty seats all around me." One woman even reported that taxi drivers refused to drive her to the CDC. They would say: "It's a very sick place, I don't want to go there."

The women attributed these actions of family, friends and strangers to a general lack of understanding and awareness about HIV/AIDS. All of the women who experienced these situations felt some form of hurt and rejection. One participant said that she had lost some of her friends through the stigma of her husband being hospitalized at the CDC.

10.3 Stigma in the workplace

A few women (n=4) encountered unfriendly remarks from colleagues and bosses once their HIV status was made public. All except two of the women currently working had not informed their employer for fear of job loss and discrimination. The two women who had informed their employers were afraid of health screening at their workplace because their HIV status may be revealed and they may lose their jobs. One Chinese national, who has become a PR Singaporean citizen, used to work as a seamstress in a small local garment factory. She said that her employer got to know about her HIV status when she renewed her work permit. He has unwittingly revealed her condition to her peers. Her employer has also exploited her situation by not granting her leave and making her work on weekends. If she did not comply, he would tell her "You better listen to me and do as I say as it is going to be very difficult for you to find another job with your present condition." The malicious and stigmatizing attitudes of her work colleagues and her employer had become so unbearable that she quit her job.

10.4 Stigma in the medical setting

At least one-sixth of the participants reported discriminatory actions by health care providers and they expressed outrage and disbelief at being treated insensitively by them. Participants shared incidents of what they perceived as discrimination in health care settings. One woman recounted:

“Very often a relatively large, bright orange hazard sign sticker is positioned on my reports for all to see including the cashiers where I have to make medical payment. I feel uncomfortable with this. I am afraid my mother might find out. I am uncomfortable about leaving my medical report by the bedside in the hospital open to visitor’s view.”

Another woman recounted similar worries on behalf of her child: “I am concerned about what was written in my child’s health booklet. It said: ‘Significant event at birth: maternal retroviral infection.’ I am concerned that my condition was not confidential and that it was open for all to see. Will my child’s chances for admission into a private school be affected by this?”

Some participants reported being labeled and treated differently when receiving healthcare. The healthcare providers’ fear of becoming infected was illustrated in the following account by one of the women. “At a clinic that I used to visit, the nurses there gave me strange looks.” Another stated during the delivery of her first child at the National University Hospital: “I felt that the nurses...were uncomfortable taking my blood samples.”

Overall, a few of the women expressed that they had encountered indifferent attitudes of the health staff, and long waits for services, which were perceived as manifestations of discriminations. One of them said: “I had to wait for a few hours after my scheduled appointment. For example, when my appointment was scheduled at 2pm, upon arrival to the clinic, my appointment would be pushed back to 3 or 4 pm.” This participant thought that the dentists must have her medical record and rescheduled her appointment to prevent contamination of instruments.

One woman reported that she was selling handicraft made by HIV positive patients at a fund raising event at Tan Tock Seng Hospital and someone exclaimed: “Are you sure I won’t get infected by touching the bag?” These types of stories and comments made the women feel alienated, stigmatized and very lonely in their communities.

11. DISCLOSURE

More than two-thirds of the patients shared that they disclosed their HIV status to at least one other person, be it their spouse, family members, friends, relatives or spiritual leaders.

In other words, they chose to engage in a partial or selective disclosure. None of the participants chose full disclosure or were comfortable declaring their HIV status openly.

It was observed that foreign HIV positive women were more likely to share their diagnosis only with their immediate family members or with their spouse, when compared to local Singaporean women who usually have a larger circle of social support that includes relatives, friends and acquaintances. Educated women with secondary or tertiary level of education appeared to be more comfortable sharing their status with friends. However, women carefully chose with whom to share their HIV positive status. The recipient of the information must have a readiness and openness to accept the condition, be trustworthy, and appear unlikely to reject the participants or have a low risk of burden of knowing the diagnosis.

At times, disclosure was involuntary, caused by an undesignated agent such as a breach of confidentiality through employers or health care professionals. A woman recalled: “My medical record was left open and unguarded on the ward counter. My sister and niece read it and found out about my illness through this.”

Some women (n=13) choose to conceal their HIV status from certain people by using strategies like lying, keeping silent and passing when confronted with their diagnosis. Some examples of women trying concealing their status include:

- **Lying:** “When asked by my friends about why I had to go CDC, I would tell them that I was getting treatment for Dengue Fever there.” Other women lied about having asthma and heart ailments.
- **Keeping silent:** “I did not tell anyone at my workplace. I just showed my MC when I missed work.”
- **Passing:** “You can choose what you want to believe in. If you’d think it is (HIV), it is. If you’d think it wasn’t, then it is not.”

11.1 Reasons for disclosure

A majority of the women disclosed their HIV status to secure social support, protect loved ones and prevent transmission of infection. One woman revealed her HIV status to a friend who was an insurance agent to obtain more information on insurance policies and health coverage. Another said that she could not afford to lie to her family members because she did not want them to “fight and blame each other” if she happened to pass on.

11.2 Reasons against disclosure

Reasons cited by the women for not telling others their HIV status included

- **Preserving social support:** “I had only one best friend but I did not reveal my diagnosis to her as I fear losing her as a friend.”

- **Preventing discrimination and stigma:** Non-disclosure about being HIV-infected protected them from stigmatizing reactions.
- **Preventing suffering and burdening of loved ones:** “I kept my illness from my family not because I am afraid that they would not accept me, but because I did not want my parents to worry about me.”
- **Fear of job loss:** “I was fearful to change jobs. I don’t want to let my employers know that I’m HIV positive. I am worried about having health screenings at workplaces too.”

11.3 Mothers’ concerns and behaviors regarding disclosure of HIV status to children

Seven women, who were all mothers, expressed the perceived inability of young children to understand or cope with the impact of maternal HIV or to keep a secret. They worried about the negative impact of HIV related stigma on children and had a strong desire to protect them. One participant did not want to tarnish the father’s image in front of her children and wanted to safeguard the good relationships between parents and children: “I do not look forward to the day when I have to tell my illness to my younger daughter. I am afraid that my daughter will hate her father when she finds out he had HIV. My daughter thinks the world of her dad and he is her God. I do not want to disappoint her.”

One 30-year-old Singaporean Chinese woman expressed concern about her HIV positive son: “Given my son’s young age, he will not know of his own (HIV positive) condition. When it comes to medication, I bluff him that they are vitamins. I am worried when he enters primary school in two years’ time, I will need to tell him about his condition. I am worried about other parents’ misconceptions about the illness. ”

Another 35-year-old Singaporean Chinese woman explained: “I am worried that my daughters might not be able to face the truth that their parents are HIV carriers so I have been preparing them for it. I recently watched a TV series about AIDS patients (bu fan de ai) with my daughters. I asked them if they would be afraid if there were AIDS patients around them and they said that they would. I continued to ask if they would be afraid if Daddy or Mummy was one of them and then they said that they would not because it would be their own parents and therefore need not fear.”

11.4 Positive impact of disclosure and social networks

More than one-sixth of the women experienced relief after disclosure, and support from their trusted ones. There was a heightened sense of understanding between the women and the people they choose to disclose to. A participant recalled an incident where she was out for a meal with her friend after revealing her illness to him: “He said it was alright not to dish out the soup separately and shared the soup from the same bowl as me... [he] realized that it was not something that could be spread by every day contact so he did not discriminate me in anyway. I found that very affirming and supportive.”

Eleven of the participants shared that they preferred friends who were HIV-positive as they did not need to conceal their status or put up a front. The level of understanding and support that they had received from other HIV positive women was a great form of comfort. Evidently, a peer support group is very important to help HIV positive women to cope with their negative emotions that were related to their condition.

One woman, a 34 year-old, Indonesian woman who is HIV-positive and married to a HIV-negative husband, recounted: “My mother-in-law would console me as well. She would say, ‘Cry for what? Don’t you want to stay in your marriage? I don’t want to see you die. You did not kill people; you did not take other people’s things. This (being HIV positive) is ok. Never mind it.’”

A participant shared her experience with a good boss after disclosing her HIV status:

“My boss would say things like ‘I see you look normal’ and ‘don’t worry about your condition’ ...I am very grateful towards him for not discriminating against me.”

Social networks of HIV-positive women emerged as a vital coping resource. Many women described the benefits of support groups in helping them cope with stress. Support groups also helped them combat feelings of isolation. One woman noted: “I find it very difficult to befriend HIV negative people.” In addition to combating loneliness, support groups provided a forum for sharing experiences and learning. One woman explained:

“I thought that I am the only person in the world who had HIV. I am glad that I am not alone and that I can help those like myself.”

A peer support group also helped to mitigate negative effects of stress of interacting with other people without the disease and helped the women develop new skills in living with HIV. Support groups helped some of the women to transform their lives as they view HIV as a blessing in disguise and a motivator for positive change. One woman explained:

“There will always be people who are less fortunate than me... When I look at these cases, I realized that my problems are less significant and unimportant.”

12. SUMMARY OF FINDINGS

- Non-sex worker women have low perceived risk of acquiring HIV/AIDS: Non-sex worker women in Singapore, especially married women, have a very low perceived risk of acquiring HIV/AIDS, even when they are aware of their partner’s or husband’s infidelity. This is due mainly to a low level of knowledge of HIV/AIDS infection on its transmission routes and its prevention. It was

common among the women to believe that HIV/AIDS only affects homosexual people, sex workers, drug users and Westerners.

- Married women faced barriers in protecting themselves against HIV/AIDS: Most women feel powerless when it comes to negotiating condom use with their husbands. Either the women themselves do not know how to use condoms, they and/or their husbands find them uncomfortable, or they believe condom use shows that there is no trust within the marriage. Sometimes, the husband could be aggressive, occasionally leading to physical violence against the woman.
- HIV-related stigma affects women's quality of life significantly: Women experienced stigma from family, friends, colleagues, employers, health care professionals and social service providers. Disclosure and concealment of their HIV status could strengthen or jeopardize relationships.
- Effective coping is dependent on receiving timely and accurate information on HIV/AIDS: Most of the emotions experienced by the women immediately after diagnosis were negative, ranging from anger to depression. The few women who coped positively had accurate information on HIV/AIDS prognosis and treatment given to them immediately after diagnosis, which helped them feel in control of their fate.
- A strong support system helped women cope with diagnosis: Effective coping was also dependent on a strong support system. A strong sense of family duty, as well as support from family and friends motivated HIV positive women to stay healthy. A heightened sense of self-understanding, healing, empowerment, purpose and pride were observed in women who received strong social support. Support groups also provided role models to emulate. Many of the women described feeling empowered and inspired by sharing their experiences in a safe and supportive peer environment.
- Women cope better when they feel themselves a part of society: Women who felt they still played a role in society arrived at a new meaning of their HIV infection. Accounts of prevailing through adversity, a sense of empowerment and "championing" others in the community equate the characteristics of women who had successfully reintegrated back into the community as a person living with HIV. Many women described how a reprioritization occurs when they develop meaningful relationships with loved ones and are able to contribute to the community in meaningful ways. These women also learned to become an advocate for other women living with HIV.

13. RECOMMENDATIONS

This qualitative study provided an in-depth understanding of the needs of HIV infected non-sex worker women and their barriers to compliance with medications and the adoption of safer sex behaviors. Based on the findings, we propose the following recommendations for the following target groups (i) HIV-positive non-sex worker women, (ii) health care providers and (iii) the general population.

13.1 HIV-positive non-sex worker women

Women living with HIV need holistic care. It increases compliance with medications and follow-up care, reducing progression of the disease and improving quality of life. The dedicated team of doctors, nurses and medical social workers at CDC are currently providing treatment and counseling on HIV/AIDS prognosis, treatment options, self-care and coping strategies to the women living with HIV. We propose the following strategies to complement the care currently provided by the health care providers.

- **Form support groups for single HIV positive women:** Support groups are currently undifferentiated and comprise women of differing marital status. The needs of single women are quite different from those of married women. Single HIV-positive women, for instance, face a different and potentially more damaging kind of stigma, as could be seen in the difficulty in recruiting them. As the number of single women with HIV increases, support groups for single women should be formed. In order to establish and maintain these groups, some financial support and facilitation by health care professionals should be provided.
- **Provide marriage counseling tailored to individual concerns:** The vast majority of HIV-positive women experienced much hurt and strain in their marital relationships. Many of the younger HIV-positive women in the study were keen to start a family and have children. There is a need for more support and counseling services in these areas. As many of those women studied also experience domestic abuse, and this directly affects their ability to negotiate condom usage, social workers and counselors should be alert to the possibilities of such abusive relationships and develop action plans for HIV-positive people.
- **Alternatives to condoms:** Given that married women with HIV-positive husbands reported difficulty in persuading their husbands to use condoms, we should consider providing other alternatives e.g. pre-exposure prophylaxis and post exposure prophylaxis for those who are not able to practice protected intercourse, such as those in unhealthy relationships.

Introduce anti-discrimination policies in employment and residence: There is no law to protect individuals living with HIV in regards to employment. Implementation of an anti-discrimination workplace policy or law would protect this vulnerable population. Additionally, non-national HIV-positive women with Singaporean husbands should not

be denied the ability to live with their children in Singapore. Our study found that non-national women with HIV face difficulties in applying for permanent residency due to their HIV positive status. Presently, these women would have to leave Singapore should their HIV positive husbands pass on. This would separate them from their children, which is unacceptable.

13.2 Providers of healthcare, social services and other services to HIV positive women

- **Provide affordable healthcare:** The recent relaxation of Medifund rules by the government for the purchase of highly active anti-retroviral medications should be commended. However, the government should consider providing less expensive generic drugs and subsidized care to further increase affordability and compliance with medications. More affordable medication will decrease external sourcing of medication and improve health outcomes. When patients have access to affordable treatment, they are more likely to be healthy enough to maintain employment, reducing dependence on other family members and the state.
- **Increase awareness on the psycho-social issues of HIV positive women among healthcare providers:** Education programs for healthcare providers in hospitals (excluding the Communicable Disease Center) should be intensified to increase their awareness of the impact of HIV on the physical, psychological and social well-being of women and couples living with HIV. Training and education will help healthcare staff to feel more confident when interacting with HIV positive patients. Once providers are more prepared they will likely show more understanding, empathy and sensitivity toward HIV-positive women.

13.3 General population

- **Prevent married women and women in long-term relationships from contracting HIV from their partners:** Education programs on HIV should be implemented for women of all ages to increase their HIV awareness and reduce their risk of acquiring the infection. Almost all (85%) of the 55 women in the study did not perceive themselves to be at any risk at all of acquiring the infection. The message “be faithful to your spouse” often depicted in public health education programs is neither appropriate nor relevant for married monogamous women. HIV-positive married and single women should be involved in awareness building campaigns to contextualize and bring reality to the messages on HIV to women. Programs on sexual health and sexual empowerment should be implemented for married women through non-governmental organizations (NGOs), lifestyle organizations and organizations that work with women e.g. AWARE. These programs could be conducted in the community centers or workplaces.

- **Convenient access to condoms:** We should explore the feasibility of displaying condoms for sale in less conspicuous places like in toilets or health and beauty products section rather than at the check-out counter in pharmacies or convenience stores to reduce the embarrassment for women buying condoms.
- **Intensify public education on HIV prevention to heterosexual men:** HIV prevention strategies for women must involve men given the observed imbalance in wife-husband relationships. We have to address the realities that some men will engage in extramarital affairs and paid sex. Condom use should be promoted in public education programs. A positive appeal rather than the traditional disease-oriented approach should be adopted to promote condom use. Presently, promoting the pleasure enhancing aspects contravenes the Singapore Code of Advertising Practice 2008, section 6.7.3 on condom advertisements.⁵ Given this barrier, the cultural appropriateness and acceptability of the pleasure-focused messages should be explored by consultation and dialogue with the community and policy makers. The Code of Advertising Practice on condoms should be reviewed concurrently in view of the ineffectiveness of the disease-oriented approach in promoting condom use in casual sex in Singapore.
- **Provide public education to reduce stigma and promote acceptance of HIV infected women in the family, work and the community:** Stigma against non-sex worker women with HIV, including the monogamous women in our study, is still highly prevalent despite the fact that they did not engage in what society might define as “immoral” or “irresponsible” behavior. More public education is needed to fight stigma and promote acceptance of women and people living with HIV in the family, healthcare settings, the workplace and generally in the community. Information about HIV/AIDS could be weaved into TV dramas and documentaries. It is also important to normalize HIV as a chronic disease, and to portray it realistically, in that people with HIV on regular treatment are often healthy and lead normal lives.

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