

# Women with HIV – A Case Study in a Rehabilitation Centre in Malaysia

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## Abstract

The main aim of this study is to examine the awareness and knowledge, lifestyle and education on HIV/AIDS. Utilising a semi-structured questionnaire, interviews were conducted among four Malay women who had HIV/AIDS in a Rehabilitation Centre in Selangor, Malaysia. A post-interview analysis of the transcripts was conducted through close reading of the entire transcriptions of the interviews in order to search for underlying themes/variables. The findings show three respondents contracted HIV through random sex and were infected during their early 20s and 30s while one respondent got infected through the husband. While poverty is an issue, awareness is still lacking on modes of transmission of HIV/AIDS. More concerted efforts by the government via education and health policies at primary schools to instil awareness on HIV and its consequences.

**Keywords:** HIV/AIDS, Women, Lifestyle, Knowledge and Awareness, Education.

## INTRODUCTION

HIV continues to be a serious health issue in many parts of the world. Globally girls and women make up more than half of the 36.7 million people living with HIV. UNAIDS, (2016) has highlighted that women continue to bear the brunt of the HIV epidemic. Its very alarming to note that in some regions such as in sub-Saharan Africa, young women are twice as likely to become infected with HIV as their male counterparts. Besides, its alarming to note that three out of four new HIV infections among 15 – 19-year-olds are among young women while seven out of 10 young women do not have comprehensive knowledge about HIV. Approximately 6900 adolescent girls and young women aged 15 – 24 years are newly infected with HIV every week around the world (UNAIDS, 2016)

In Malaysia, for the year 2016 there are 3,397 cases of new HIV infections in which 15 are children aged 13 years old and below. 413 cases of new HIV infections are from women and girls. From 1986 – 2016, 69 % of HIV infections are among the Malays, while 40 per cent are in the age group of 20 – 29 years old and 31 per cent are between 30 – 39 years old. 2,864 (84 %) of new HIV infection is through sexual transmission, while 377 (11 %) is through injecting drug users (IDU). Within a span of less than 10 years, infections through sexual transmission has more than doubled from 32 % in 2009 to 84 % in 2016 (Malaysia Aids Council, 2018)

The fact that all respondents have heard about AIDS but do not have a comprehensive knowledge about how it is transmitted may possibly place them in the high-risk group who are vulnerable to the HIV/AIDS infection. Youngsters not only have inadequate knowledge about prevention measures of HIV but also believe the myth that HIV can be prevented through a healthy diet even though more than 80 per cent of them believe that they will be involved in a steady relationship in the very near future (Saad et.al, 2013).

## **LITERATURE REVIEW**

Ignorance of HIV information affects the sexual behaviour of a person that leads to HIV epidemic. According to Oni (2005), wide practice of unprotected sex, high fertility, increasing incidence of sexually transmitted diseases and poor access to care and education are the factors contributed to the problem of HIV epidemic. In addition, information on HIV & AIDS was not formally being taught in most schools globally due to fear of sensitivity to the subject of HIV/AIDS, also its possibility to cause a negative community response (Aggleton et al., 2011).

Aggleton et al., (2011) further emphasises that the absence or uneven distribution of clear policy frameworks and guidelines, the absence of HIV from most school and education sector plans, yearly action plans and education budgets, lack of training for teachers in teaching about HIV and AIDS, and the absence of good-quality curricular materials are some of the challenges highlighted by UNESCO to make teaching of HIV & AIDS become more effective.

According to Urmil et al., (1999) sexually transmitted and HIV infections are common among young people within the age range of 15-24 years old. Although, youngsters are not encouraged to make an open discussion about sex, it was noted that the adolescents are sexually active. Nevertheless, an open discussion about sex is disapproved by adolescent. They believe that sexual health education will expose adolescents to indulge more in sexual activity (Inyang, 2013). Subsequently, it was found in China, students lacked the basic knowledge of HIV/AIDS and the mode of its transmission, which led to the spread of this epidemic (cited by Inyang, 2013 in Gao et al., 2012).

In contrast, a study done by Peltzer & Promtussananon (2003), reveals that life skills teachers in secondary school in South Africa who are knowledgeable about AIDS, feel moderately comfortable teaching students about AIDS and related topics. Hence, these teachers have the information and ability to teach about HIV/AIDS. Unfortunately, HIV/AIDS' knowledge obtained by the respondents were not from schools but from the mass media, communication with friends, health professionals and family members (Nur, 2012).

On the other hand, Corneille et al., (2008), allege that active older heterosexual women most probably is at higher risk to contract sexually transmitted due to lack of condom use. A research done by Awotidebe et al., (2014), found that 48 per cent of 113 participants who reported being sexually active have had sex before the age of 15 years, while 42.2per cent of them have had sex with more than one partner in their lifetime. However, only 44.8 per cent of the participants consistently use condoms for every sexual encounter. Thus, according to Chireshe & Chireshe (2003) as cited by Oni (2005), in Zimbabwe, it is estimated that 25 per cent of people aged between 15 and 49 years are infected with HIV.

Failure to discuss on HIV and safe sex life causes the adolescents to lack information about HIV epidemic. Hence, family members and parents play an important role in providing knowledge on HIV to their children. The need for communication between parents and children about HIV is essential. Edwards et al., (2013), indicate that 81 per cent of parents reported “sometimes” or “often” when communicating about HIV prevention. A subset of parents found these conversations is difficult, while 44 per cent indicated their desire for support. It was found that there was a need for communication skills that support HIV-infected parents in their efforts to discuss HIV-related information with adolescent.

Awotidebe et al., (2014), state that peer influence, especially among boys, is a factor that increases the preponderance of risky sexual behaviours in adolescents. Nevertheless, adolescents with more knowledge on HIV infection are more likely to use condoms for every sexual encounter. These adolescents include those with positive family relations, effective communication about sexuality and safer sexual behaviours, enhancement and support of academic functioning, and monitoring of peer activities. According to Perrino et al., (2000), HIV risk behaviours occur in a social context, and it is understood that the earliest and most effective way to intervene is in the context where one initially learns about relationships and behaviour of the family.

A study done by Baetjer, (2000), found that over one third of male and one fourth of female respondents testified that parents never spoke to them about sexual issues, their beliefs and expectations in regard to sexual behaviour such as how to react when it comes to sex. The existence of significant gender differences in the types and the patterns of sexual topics for those parents who communicated were also noted. The study also noted that some possible explanation on the low level of sexual communication between parents and children could perhaps due to majority of parents themselves have not learned much from their own parents. Other reasons could include not receiving an effective education from formal sex education, parents may believe that their children are not sexually active and the discussion of sexual issues and revealing their own past sexual experiences with their children might encourage them to become sexually active and many parents might only be worried about pregnancy and are unaware of other consequences of unsafe sexual practices.

Meanwhile, Pettifor et al., (2004), alleges that lack of sexual power, measured with a four-point relationship control scale and by a woman's experience of forced sex with her most recent partner, would decrease the likelihood of consistent condom use and increase the risk for HIV infection among sexually experienced women. In South Africa, women between the ages of 15 to 24 years old with limited sexual power was not directly associated with HIV but was more associated with inconsistent condom use. Hence, women with a low relationship control were 210 times more likely to use condoms inconsistently, while women experiencing forced sex were 577 times more likely to inconsistently use condoms. Inconsistent condom use was, in turn, significantly related with HIV infection.

Therefore, Bowleg et al., (2000), suggest that if women perceive that they are low or no risk, their gender roles, power strategies, and precautionary sexual self-efficacy will be inconsequential to their HIV/AIDS risk reduction practices

## METHODOLOGY

This study examined the awareness and knowledge of HIV/AIDS and lifestyle among Malay women. Interviews were conducted with four Malay women whom had contracted HIV/AIDS. The interviews were held in a Rehabilitation Centre in Selangor, Malaysia. Each interview was tape-recorded and lasted between forty-five minutes to one hour. All interviews were conducted in Malay.

Semi-structured questions were designed to obtain information on the awareness and knowledge on HIV/AIDS; and also, their lifestyles which lead them to the disease. In this study, the analysis of interviews was manually done to identify patterns, in-depth insights and irregularities of evidence gathered from the transcriptions, field notes and interview reflection notes (Bloomberg and Volpe, 2008), which were later used in generating rich description and interpretive meaning (Miles and Huberman, 1994).

A post-interview analysis of the transcripts was conducted through close reading of the entire transcriptions of the interviews in order to search for underlying themes/variables. A coding was carefully developed to assist in identification of the themes/variables emanating from the analysis.

## FINDINGS

A total of four Malay women were interviewed at a rehabilitation centre in Sungai Buloh Selangor. The age range of the respondents are between 22 to 50 years old. The lowest educational level among them is Sijil Pelajaran Malaysia (SPM or equivalent to “O”levels) and the highest is a Diploma. In relation to their marital status, two of the respondents are divorcees and the other two are single. The divorcees have between one to four children in the age ranges between 7 to 28 years old. The description is shown in Table 1.

*Table 1: Demographic Profile*

Interviewee	Race	Age	Education Level	Marital Status
Respondent A	Malay	28	STPM	Single
Respondent B	Malay	22	SPM (not completed)	Single
Respondent C	Malay	41	SPM	Divorcee
Respondent D	Malay	50	Diploma	Divorcee

Three respondents had contracted HIV through random sex while one respondent got infected from the husband. They were infected during their early 20s and 30s. When being diagnosed

with HIV, three of them feel very sad, humiliated and not able to accept their condition whereas one of them felt very indifferent.

### *Knowledge and awareness on HIV/AIDS*

Currently there is no channel through formal education of how HIV/AIDS is transmitted and how it can be prevented to youngsters. According to Saad et. al, (2015) the awareness of HIV/AIDS among young women is not sufficient and coupled with low-level knowledge on prevention of HIV/AIDS, will increase the risk of young women contracting HIV/AIDS.

All four respondents are aware that HIV/AIDS is a transmissible disease. Two of the respondents have modest knowledge on the source of HIV and how it is transmitted before they contracted the disease. One of the respondent's does not have the knowledge whereas only one knows that HIV can be transmitted through sexual relationship.

Three of the respondents did not have the knowledge on the possibility that HIV can be transmitted from one person to another. Only one of the respondents has little knowledge on the possibility that HIV can be transmitted. However, after contracted with HIV, all the respondents knew that there are ways to prevent HIV.

Respondents A and B were not aware that HIV/AIDS can be transmitted from mother to child and through blood transfusion. However, respondents C and D were aware that HIV/AIDS can be transmitted from mother to child and through blood transfusion. All four respondents had never attended health talk before they were contracted with HIV. Meanwhile, three of the respondents obtained information regarding HIV from the hospital except for respondent A who obtained it from the internet.

The findings show three of the respondents knew the clear signs/symptoms of a person who has HIV.

For example, Respondent A describes a person with HIV as  
“a person with a sore throat and will have no appetite and will feel tired”.

While Respondent C noted that,  
“the effect includes restlessness, no energy and not able to manage work efficiently.”

Lastly Respondent D remarks,  
“the body of a person with HIV will get thinner”

### *Lifestyle*

In terms of the lifestyles, religion was not practiced intensively. Majority of the respondents were not very religious, that is they were either moderate or lack religiosity. Only one declared her hobby is reciting al-Quran during her spare time.

In terms of school attendance, only one respondent said that she used to play truant and “skip school and have fun with my male friends at the shopping mall”.

In terms of night-life, one respondent claimed how free she was to move around at night. She said:

*“I used to go out during night time but with the permission from my sister. Nobody will be awake when I returned home because my sister would have slept off before I returned”*

The other respondents A and C never played truant from school and never went out during night time. While, Respondent D is not allowed to go out during the night time.

All respondents have been to club/pub/parties at their younger age. Three of the respondents never smoked and never consumed alcohol. They also did not take any drugs, opium, morphine and heroin. However, Respondent B is a heavy smoker, smoking 5 packets of cigarettes a day. She also used to consume alcohol and has taken opium, morphine and heroin. Apart from that she was also involved in drug trafficking.

All respondents except for Respondent D had sexual relationship with more than one partner and did not use contraceptive methods such as condom. However, all four respondents were not homosexual. Meanwhile, Respondents B and D were married to drug addicts but did not know that their husbands had HIV/AIDS.

### *Economic status*

Two respondents; respondent A and C completed their secondary school with Sijil Tinggi Pelajaran Malaysia (STPM) equivalent to ‘A’ Levels and Sijil Pelajaran Malaysia (SPM) equivalent to “O” Levels. SPM respectively. With the level of academic achievement, they only managed to do blue collar jobs with an average income of RM500 - RM800 per month. On top of that, both of their parents were not working, and they can be categorized as hard-core poor.

Respondent B did not complete her SPM and therefore never had a legal job. Nevertheless, she was engaged with drug trafficking internationally with countries such as Australia, Paris and

China to name a few. Her parents were formerly government servants but currently are not working. The parents had some source of income.

Respondent D completed her Diploma and managed to get a job with a salary of roughly RM2,500 per month, which is higher than the income received by Respondents A and C. However, she quit her job at the age of 29 but not due to HIV infection as she contracted HIV at the age of 31 years with her second marriage. Her father was in the army whereas her mother was a housewife. Hence respondent D's parents also had some source of income.

## **DISCUSSION**

Our findings show that, although four respondents are aware that HIV/AIDS is a transmissible disease. However, two out of the four respondents are not aware that it can be transmitted from mother to child and through blood transfusion. Perhaps the insufficient knowledge on how HIV/AIDS can be transmitted lead to lack of awareness and caused these respondents to be infected with the disease. In line with research done by Saad et. al, (2015), the respondents were not even aware that HIV/AIDS can be transmitted through breast feeding and other bodily fluids such as semen and vaginal fluid apart from blood.

Despite their different lifestyles, the respondents contracted HIV/AIDS because of the sexual relationship with more than one partner and at the same time did not used contraceptive methods. However, a respondent who is loyal to the partner could contract HIV/AIDS if she did not practice safe sex.

The economic status for majority of the respondents except for one respondent can be considered as in the Bottom 40 level (B40) in Malaysia. Findings show income earned by three respondents is below RM800 and having parents with low income or without job might lead them to have multiple male friends.

## **CONCLUSION AND RECOMMENDATION**

In this study which was conducted at a Rehabilitation Centre in Selangor, a few important themes emerge. Firstly, in terms of awareness on HIV/AIDS, all the respondents have little knowledge about it, but they are not aware of the most important knowledge about how it can be transmitted. Secondly, their free and easy, uncontrolled night lifestyle had its negative consequences. Thirdly, they all had minimum 11 years of education and were not really very poor, except for one respondent. It is a choice they got into due to lack of awareness of the life-long consequences if infected with HIV/AIDS.

The government could have a more intensive exposure of awareness at school level, as early as primary school. Sex-education should be taught to students at primary school level. Parents

should also talk to their children, both boys and girls on these matters. Future research should look at a large sample in and compare with other states.

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