

HIV/AIDS INFECTION AMONG INDIAN-MALAYSIAN WOMEN: SOCIOLOGICAL VULNERABILITIES AND IMPLICATION FOR FAMILY SOCIO-ECONOMIC DEVELOPMENT

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ABSTRACT

Malaysian housewives are more at the risk of being infected with HIV/AIDS as compared to commercial sex workers. The Ministry of Health in Malaysia in 2011 reported that nearly 40% of these infected women are housewives, and was infected through their husbands. The qualitative study aimed to explore the social vulnerabilities of HIV/AIDS among Indian mother living with HIV/AIDS and its implication on their socio-economic development. The paper draws participants from 5 Malaysian states, namely, Johor, Penang, Selangor, Perak and Kuala Lumpur. It is sufficient to say that these women suffer various forms of indignity including discrimination, stigmatization and socio-economic injustice. Furthermore, they also lack in reliable documentation such as marriage certificates, identity cards or birth certificates of their children. Thus, stringent corrective measures should be designed to address their problem. The present HIV prevention and intervention strategies need to focus on their burden in order to improve their health.

Keywords: HIV/AIDS, Women's health, gender and HIV/AIDS, Indian-Malaysian, HIV vulnerabilities, HIV Socio-economic impact

INTRODUCTION

Among 81 000 HIV cases between 1986 and 2015, 11653 were women in Malaysia (record by ethnic group for female PLWHA is not disclosed by Ministry of Health). In fact majority of them acquired HIV infection via heterosexual transmission (UNAIDS, 2015). Indians recorded 8461 of 81 000 cases (Malaysian AIDS Council, 2015). According to the Ministry of Health, Malaysian housewives being infected with HIV is at an alarming rate and they are five times at risk of than sex worker (Najimudeen M & Mat Rosy M, 2011; UNICEF, 2008). Whereas, in 2004, it is observed that 44% of all 4,477 reported HIV women were housewives (UNICEF, 2008), 658 (6%) is sex workers (UNAIDS, 2015). Meanwhile, the cumulative number of female injecting drug users not recorded in recent years (Wickersham et al., 2016), however UNAIDS in 2006 estimated 300 (2%) female IDU of 13058 injecting drug users in Malaysia (UNICEF, 2008).

There are numerous arguments on HIV vulnerabilities and their impact by gender. In Africa based on studies by various researchers (Karamagi, Tumwine, Tylleskar, & Heggenhougen, 2006); the lifetime risk of contracting HIV due to risk behaviour appears to be approximately balanced between female and male gender. However females tend to be infected earlier in life and have lower mortality (Michel & Nathalie, 2001). The popular literature reports women face more physical, socio-economic and psychological challenges than men. For

instance, the ratio of male to female HIV transmission (especially to housewives) is higher than female to male transmission. This fact portrays monogamous housewives as innocent victims (Aparna Mitra & Dipanwita Sarkar, 2011). Further, women are more likely to have less financial support than males. For example, HIV/AIDS related deaths or physical disabilities of male spouses decreases the household income and increases burden on a woman who leads the family (Schatz, Madhavan, & Williams, 2011). Women are more likely to carry more household burdens, including as a traditional family caretaker, caregiver to their HIV children and positive partner, as well as being the family breadwinner. Moreover, the situation become worse if the female householder themselves is a HIV person, the burden of the HIV/AIDS epidemic on household socio economic development can be severe.

With community stigma and limited financial support, women need to focus much effort on planning regarding their savings and other family resources in order to survive. In contrast, some Western research shows that men were also carry as much burden as women; most of them were in the Gay community and willing to care of their infected partner (Wight, Aneshensel, & LeBlanc, 2003). It is also notable that the male PLWHA (People Living with HIV/AIDS) experienced depression due to high workload and financial hardship (Wight, 2000). However as Larkin (2000) noted, HIV-related health problems such as gynaecological infectious are unique physical challenges faced by women rather than by men. Comparison studies with transgender women remain unanswered in current literature.

Response to the HIV epidemic among women in Malaysia is more focused on key affected populations, especially sex workers, pregnant women population. Programmes for female injecting drug users implemented by the National AIDS Programme under the Ministry of Health and NGOs in Malaysia recently took steps to include women in addiction treatment and needle exchange programmes (Wickersham et al., 2016). There were limited studies that examined the prevalence of HIV infection among housewives in a sociological perspective. That is although current literature also contains research on clinical and medical perspectives of housewives and pregnant mothers; the HIV social awareness programs on sex negotiation power among married women are not clearly targeted to housewives due to various cultural barriers (such as patriarchy norms) and religious belief which might trigger controversy in a conservative community. The HIV risk among monogamous housewives is invisible unless their husbands disclose their HIV risk behaviour (e.g. sexual history, injecting drug use behaviour) and have an HIV screening test as well as health counselling (Nasarruddin Aishah, Saifi, Othman, & Kamarulzaman, 2016). Malaysian government health clinics encourage all to have a free HIV screening test, known as an 'HIV Kit Test. The Johor State Islamic Council implemented a mandatory HIV test for all Muslim pre-marital couples in Johor. However, this is only in Johor and not mandatory in other states due to community stigma and breach of human rights (Manakandan & Sutan, 2016).

Even though there are limited qualitative studies found in Malaysia on exploring minorities' ethnic and genders, few multi-ethnic studies concentrate on the psychological and physical impact of HIV among all genders. (Marina Mahathir & Zawawi Ibrahim, 1999; Narayanan, 2001; Siti Norazah Zulkifli, Soo, Yun, & Lin, 2007). Socio-economic deprivation such as poverty, lower educational level, unemployment, homelessness, prior criminal justice involvement, substance use, a problematic childhood background as well as physical and sexual abuse are described as major structural factors influencing prevalence of HIV among Malaysian

women(Mashrom Muda & Aziz, 2015; Siti Norazah Zulkifli et al., 2007; Wickersham et al., 2016). Number of studies in Malaysia indicates women struggling to perform their role as a head of household, single mother and sometimes caregiver for HIV spouse and children (Lua PL, Norhayati M, & Ahmad Kashfi AR, 2013; Mashrom Muda & Aziz, 2015). It shows that HIV has deteriorated socio- economic development of Malaysian women, Indian HIV women are not the exception. Indian women living with HIV/AIDS are an invisible part of their community. Thus this study aims to explore the sociological pre-existing conditions to HIV risk behaviour and the salient life issues of minority ethnic Indian women living with HIV/AIDS. The sociological vulnerabilities and perceived HIV impacts vary between different kinds of ethno-cultural communities and localities in Malaysia. The findings from this study will hence provide fundamental guidance for improvement of sexual health and socio-economic status of ethnic Indian women in Malaysia.

METHODOLOGY

The qualitative descriptive approach study is conducted with 14 participants of Indian women infected with HIV in Malaysia. They were from both rural and urban places in Johor, Penang, Kuala Lumpur, Selangor and Perak. The study comprises face-to-face, in-depth interview session with key informants. They were HIV-infected Indian women between the age of 18 and 55 years. The individual interviews were conducted in Tamil language and audio-taped. The snowball sampling was used whereby each participant was requested in assisting to find another participant. The data transcribed in Tamil and translated into English version was analyzed using N-Vivo version 10 Qualitative Software (QSR). All participants were given assurance of confidentiality and were explained on the purpose of the study. The consent to take part in the study was elicited verbally and later an agreement between each participants and the researcher were officially signed.

DEMOGRAPHIC BACKGROUND

There were a total of 14 Indian HIV-infected women interviewed. four (28%) of them are legally married women and staying together with their husband, meanwhile another four (28%) of them are cohabitating or living in relationship with customarily married husband. , five of eight of their husband were disabling /hospitalized due to HIV related health problem. Four (28%) women are widowed and two (14%) is separated.

Among 14 of them, ten (71%) participants reported a history of monogamy and stated they acquired HIV via heterosexual intercourse with their husbands. Two (14%) had a history of having several sexual partners such as previous male friends. None of the women had a history of being commercial sex worker. The remaining two (14%) participants were former injecting drug users, had history of exchanged sex for drugs. 84% of women identified as South Indians and two (14%) are North Indians, majority eleven (79%) are Hindus, two (14%) are Christians, one (7%) Indian-Muslim. Approximately 60 % of the women had finished their primary and lower secondary school form 3 (SRP/PMR), 30% had finished upper secondary school form five and form six (SPM/STPM), whereas one (7%) of them had completed college/ university diploma studies. All the women reported having part time or full time job; with median monthly income was RM500. They were working as street cleaner, cleaner in shopping complex,

waitress/ cleaner in restaurants, caregiver in shelter; none of them reported having permanent job.

FINDINGS AND DISCUSSION

Problematic family background and domestic violence

A majority of Malaysian ethnic Indian women are of South Indian heritage. A number of them were brought up in conditions of social disorganisation and an economically disadvantaged living environment (David, 2012; Institut Analisa Sosial, 1989; Sachavirawong & Heufers, 2006). Women experience having lived in domestic violence and poverty for two or three generations. They experienced domestic violence in childhood and even in life after marriage. Women's stories illustrate alcoholism among their grandfathers as a major factor for domestic violence in their grandparents' era (in the 1960s), Meanwhile it was estimated that in 1980s alcoholism and injecting drug use among their fathers were main triggers of domestic violence in their family. The women stated that together with their mothers they suffered a lot despite effort to build their family. These women experienced multiple drug use and promiscuous behaviour among contemporary male partners, which are linked to domestic violence and HIV risk behaviour. The violence at home, drunkenness, separation from parents or death of parents makes it more likely that they experienced emotional and behaviour problems related to HIV/AIDS. Dysfunctional family ties and domestic violence are reasons many respondents don't complete their education, mingle with problematic peers, run from a family, are betrayed by partners and exposed to HIV risk behaviour.

As mentioned by these women, domestic violence had a deleterious cascading effect on socio-economic transition and has caused deterioration since the colonial period (1874- 1957). Being labourers in plantation estates historically, Indians were physically isolated in rural areas and habitually drank. A hidden social-political agenda in colonial Malaya made toddy shops in estates readily available. Indian labour became addicted to the cheap alcohol of arrack and 'samsu' (Belle, 2014; Heath, 1995; Institut Analisa Sosial, 1989; Janakey Raman, 2009). Meanwhile during national economic transformation from agriculture to industrialization in the 1980s and a recession in the mid-1980s many estates closed. This led many rural youngsters to be unable to get jobs and plantation workers to lose their job (A.Rahim, 2001; Ling & Jomo, 2009). Many ethnic Indians migrated to economically disadvantaged slum areas in towns. The unstructured living environment, unemployment and problematic neighbourhoods in towns were multiple social-environmental vulnerabilities to drug use among Indians (Janakey Raman, 2009). In contemporary times, rising socio-economic status among Indians has reduced alcohol addiction yet increased multiple-drug use, premarital and extramarital sex as risk factors for HIV infection.

Lack of awareness

The findings indicates that the participants are more inclined to relate lack of knowledge and awareness on HIV/AIDS to their infection reason . Lack of social program in educating the public on sexually transmitted disease in Tamil language ceases the level of awareness and knowledge on the issue among participants. Sex and sexually transmitted infections (STIs) issues are seen as

taboo, unfavoured and sensitive. Therefore, these topics are not openly discussed among Indians and various other religious organizations. The participants stated that they had roughly heard about the HIV basic transmission mode and its prevention idea through television or other media but they are not well-informed on the clear picture of HIV /AIDS. It is notable that the lack of awareness and misconception about HIV lead to many women being unaware that HIV can be transmitted through their husbands.

'I have heard of 'it' (HIV) they show it in television. I've heard of 'it' (HIV) and usually scared of this disease. I get scared as I wonder how people acquire it. No. I don't know much 'it's' (HIV) effects. I couldn't accept the fact when I knew I had 'it' (HIV), 'it' come from my husband. Wasn't thinking it can infect me... I was crying and was certain that I will die soon'.

(Age: 41, married, completed primary school education)

'I have heard on that time, but I don't know what actually it is (HIV). I know people will die if get infected. I don't know how can get it , how to prevent ...I don't know at all'.

(Age: 42, widowed, lower secondary school education)

'I don't know much... (HIV knowledge) ...Those days I don't know anything about HIV, I don't even know how 'its' (HIV) infect people...'

(Age: 36, separated, completed upper secondary education)

Ignorance of women and patriarchal norms

Women ignore to monitor their husbands' social activities. Over dependency and low economic status of women were the main reasons why Indian housewives are betrayed by unfaithful husbands. As stated by Sidi, Puteh, Abdullah & Midin (1999; 2007), Malaysian women are not encouraged to openly discuss sexual issues due to cultural and religious barriers. Having said that, Indian women are not an exception in this category as it is evident that many participants rarely discuss about sexually transmitted disease or HIV related issues with their husbands in an open manner. In other cases, some women are aware of their husband's philandering activities, but fail to exercise their rights in stopping their husband from philandering. (Bhattacharya, 2004) The economic dependency makes women feel sufficient if their husband provides safety, love, and financial support for them and their children (Janakey Raman, 2009). Even though, many Hindu religious scriptures and ancient philosophers, classical literatures pointed that, both spouse have equal right, equal shares of one heart and soul, they are equal in every respect; therefore, both should join and take equal parts in all wealthy and difficulties in a family life (Laungani, 2015; Raines & Maguire, 2001; Sundram, 2005), it is manual for some women echoes their cultural habitual to blindly follow patriarchy and betrayed by their unfaithful husband.

Number of women simply smiled, saying the Tamil proverb '*Kanavanae kann kanda deivam*' (Husband is the visible God) and '*Kallanum Kanavan pullannulam purusan*' meaning that the wife should constantly accept and be tolerant whether her husband has stone hearted (tough character) or grass character (soft -hearted or has any weaknesses). Therefore, women always remain silent and refrain from discussing about their husband's promiscuity as they worry if it may trigger family problems and eventually lead to separation although they go through emotional abuses by remaining silent about it.

“Few of my friends told me...err... he has someone (other sexual partner) at outside, that time I never bother much, don't want raise voice. Because he is a good husband to me and father to my children... gives us enough love and money (financial support), so I never raise much this issue” you know right, there is says ‘Kallanum...kanavan...’ (Tamil proverb) if we argue it may lead to separation... very difficult to say... if divorce or anything happen I have to answer to my family(respondents birth family & relatives”.

(Age: 38, married, married, completed primary education)

“Because of women...(extra- marital relationship) he get ‘it’ (HIV)...when he was in Singapore he has many girlfriends. I heard so many stories. Sometimes I never bother much...I am not earning, financially depends on husband... if I provoke issue it will lead to family problem... he will get angry ...I just maintain my life as casual. Sometimes I feel heart sick also... what can do...they are men what...we can do”.

(Age: 41, widowed, completed upper secondary education)

Cultural practices on arranged marriages

Typically, number of women from the traditional arranged marriages are linked with HIV infection. These women blaming their in-laws' families for hiding their sons' misbehaviours before they got married. On the other hand, the affected women mentioned that their parents push them into marriage before they get to know the man's character, their parents and elder kin consider caste, horoscope compatibility, family reputation and financial status as criteria for marriage instead of investigating groom's personal character.

Women were not given much freedom and time to go out with their fiancé to understand each other before getting married. Their marriages will be arranged within 5 to 8 months once they get engaged. In some cases, these women manage to identify their fiancés' misbehaviours prior to marriages. However due to their parents' insistence, they lose their rights to break the marriage. This is because of the community stereotypes leading its people to believe that break-off a marriage will affect their family dignity as they will lose face to the community. However women agreed not all the arranged marriages in Malaysia result to HIV risk, meanwhile relate past birth *karmic* reason for their disease and sufferings.

“After register (marriage registration) then only he came once in a while to take me to the temple, my mom doesn't like it. Even though we married legally but she sounds oppose we go out together, because we never marry customary yet. Everything was happened very fast ...in one year time period. Both families met together ... discuss together ... finally arranged our married ...no space at all to talk and get to know him more. I felt something fishy on him, sometimes he sounds okay, while sometimes not. If I know his character earlier (as a drug user), sure I would call-off a wedding. By right they must tell the truth after marriage (in-law family) but they hide it until last minute when he hospitalised. Earlier, his brother and sister convinced me much to get marry him but they also hide this from me. I don't know my husband is a drug addict, they reveal it when I gave birth to my first daughter...”

(Age: 42, widowed, diploma holder)

“Both of us not compatible, don’t like each other, I told my mum ‘I don’t want to marry him’, no use she forced me, (respondent’s mother) very stubborn, and said “I say you marry him... you must listen”... shameful to face relatives if broke off...”

(Age: 36, married, completed upper secondary education)

Implication

Previous studies have proven that even though HIV is a biological phenomenon, the PLWHA may be negatively affected in all dimension of life, such as in terms of socio-psychological aspect and household economic deterioration. Mothers in the late 30s stated that their health deteriorates as they get older and the sufferings include loss of physical strength and weight, lack of eyesight and memory power, unpredictable illness and skin problem. Health issue becomes major challenge to the breadwinner women who work more than 8 hours a day to generate household income. According to them, they don’t have other choices to provide primary financial support to their family although they are sick. Many of them stated they suffer from HIV-related illness such as TB, brain infection, blood pressure, asthma, hepatitis C, uterine problem as their immune system weakens.

When asked about their free time, one of mother responded as follow:

“Free time”? ... I really cannot mean it (don’t have free time), if I break for a while, I will lie down ... all the times very tired because every day I am travelling is it? (Participant should travel two hours every day to reach her working place)”

(Age: 36, married, completed upper secondary education)

“in terms of heart feelings yes!... very tired, not enough rest. Even one day work off also I got no time, fully occupied with house work, wash school dress, wash school shoes...so many works ,hassles...etc”

(Age: 36, married, completed upper secondary education)

Some of them mentioned that the intolerance towards HAART (Highly Active Anti -Retroviral Therapy) drugs causes dizziness, drowsiness, muscle-joint pains and headache.

“I don’t know why... now days part of my hand swollen, damn tired ... doctor says because of taking HAART medicine”

(Age: 35, married, upper secondary education)

“...The medicine not suits with my body condition, that’s why I look like this (very weak). they (doctors) change medicine, current one (medicine) is still ok, at least it can get accord with my body. Previous medicine... I often omit, diarrhoea, non- stop. I am getting very weak. I also cannot work, I have heavy knee pain”

(Age: 42, cohabitate with partner, lower secondary educated)

“Really... those days even I sick, I still can go work...but now cannot. I felt very sick... cannot work. My leg swelled up... hand skin peels... however I have no choice rather than going work, have to support my family”

(Age: 34, lower secondary school educated)

Psychological problem and poverty

The women are mentally stressed exhibit symptoms like depression, anxiety, guilty of transmit virus to children, fear on children's future and financial stress. Financial stress is the commonly encountered problem by poorly earning mothers. To further elaborate on this, four interviewed participants have two new-born child and three HIV-infected children aged between three to twelve years. The children's HIV-infection was identified subsequently after their parents were diagnosed. These children often encounter health problem such as high fever, tuberculosis (TB) and asthma.

“My son is not feeling well... I think his CD4 (cluster of differentiation 4) is start reducing; doctor said he will start give medication once it (CD4) get reduce lower. In my case, I often get fever, headache and dizziness (due to HIV). He is a small boy not even able to talk, how he can express his pain. Now he gets fever very often...[crying]”.

(Age: 34, separated, lower secondary educated.

Some of the widowed participants and their children grieve on the loss of their father due to HIV and subsequently suffer from the trauma of death. Majority of the HIV-infected mothers fulfil dual role; as breadwinners and care-providers for their spouses and children. The family economic hardship results in women being unable to provide adequate food and educate their children, as a number of these women send their children to orphanage or shelter home. Many Indian HIV-infected women send their children to Christian, Buddhist, Muslim religious shelters rather than depending on their relatives for support. Some of them advise their older children to take care of the younger ones in the event of their death in future. Majority of the participants never trust their family members or relatives. This may result to child-headed household where the number of eldest children were stop going to school.

“No... no way (send children to relative's house). Now I can see what people doing to my children. If I die they will treat them more badly than this. In future days I don't want people blame my children as “your mother had this sick (HIV)”. They might do it again.

(Age: 40, widowed, upper secondary educated

“I told my eldest children they must taking care the youngest children if anything happened to both of us. They promised they won't seek for relatives help and don't want to go anyone's house. You know why? I had bad experience once, I sent my children to my brother's house. That time I was in difficulties, my husband was jailed (drug user). So my sister advises me to send my children to my brother's house. I also sent them there, my brother's family accused my children are misbehaving, fighting with their children, my sister-in-law blame my children for their children's mistakes and used to beat my children”.

(Age: 38, married, primary school educated.

Based on their experiences, most relatives or other family members are not willing to foster their children. This is contrary to the study conducted in Kenya. Their community people; the relatives, grandparents or neighbouring people take care and adopt the HIV/AIDS- affected or -

infected children (Foster & Williamson, 2000; Lloyd, 2008). In similar cases, African government supports the community to bring up the HIV-infected kids. According to their community members, poverty is not a barrier to build the spirit of civil society to prevent HIV/AIDS (Foster & Williamson, 2000; Lloyd, 2008).

Social stigma and Violation of Women's Right to Dignity

Through the observation of research, community stigma and discrimination are two of the key factors that affect women emotional and psychological wellbeing. Many of them still face tremendous fear to reveal the HIV infection to their family members or people surrounding them. According to infected, the disclosure of HIV/AIDS does not only relate to community stigma, but also deteriorates family values and ties with family members and relatives due to cultural sensitivity and beliefs in socio-religious mythology (Adeyi, 2003). For example, many infected women do not prefer to reveal their or husband's HIV infection to their birth family or male siblings as much as they do with female family members except sisters. This is because of their intention to not embarrass or humiliate their husbands or in-laws family members.

In many cases, women those disclosed their HIV status experienced social exclusion and some relationship problems between family members or relatives. They were stigmatized, discriminated and blamed by their surrounding people as well family members. This leads to some of infected mothers being separated from their children. Their in-laws family restrict them from to take care the children, touching their children. Thus, women isolating themselves from participating in social events or even refraining themselves from seeking NGO's help.

Lacking proper documentation or birth certification is a common issue among women who cohabitate with their partners but without legal marriage. Both they and their children do not have birth certificates or national identity card. Meanwhile, two participants mentioned that they do not possess marriage certificate as they are only married customarily or are unmarried to their partners. According to them, their partners forced them to not register the marriage only to eventually find out that their partners did so with the intention to hide their prior marriage status. The absence of legal evidence of marriages makes women feel betrayed as they are abandoned by their partners after being infected with HIV. Meanwhile, the absence of marriage certificate caused these women to be perceived as 'unwed mothers' and their children as 'child born out of wedlock' or illegitimate child. At the end, these women are marginalized by the community and also face challenges in fully assessing government social benefits such as medical assistance, education for children, loan applications and welfare aids.

CONCLUSION

Following this survey result, the infection of HIV/AIDS and its impact on Malaysian women is alarming. In order to effectively encounter and prevent the spread of HIV disease among Indian women or women of other ethnicities, Malaysia needs to escalate HIV/AIDS awareness and knowledge among women and housewives (Ismail Ghazali, 2008; Sern & Hasmah Zanuddin, 2013). The awareness and knowledge in terms of communication, printed materials, audios, videos and programs need to be facilitated in native languages and circulated widely to urban and rural areas. Nevertheless, it is extremely important to empower women and create employment opportunities. No doubt, the vocational skills development and training programs as

well as small business opportunities can help them to generate household income and reduce poverty. In Malaysia, many NGOs are operating with limited funds and only able to conduct limited training and awareness program for PLWHA (UNAIDS, 2010) Therefore, government support is very essential to empower PLWHA.

Addressing stigma and discrimination can only be done with the help of community and the support from youth among Indians. The interventions to eradicate HIV/AIDS stigma can be implemented through programs that encourage PLWHA to mingle and collaborate with surrounding community. Religious association and faith-based organisation should conduct HIV-related awareness programs in order to change the perception of the community in a positive manner.

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