A Qualitative Case Study on

PREDICAMENTS OF SPOUSES OF PEOPLE WHO INJECT DRUGS (PWID)

Substance Abuse Research Association (SARA)

3MDG Fund

December 2017
Acknowledgements

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<tr>
<th>Abbreviation</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>AEI</td>
<td>Accountability, Equity and Inclusion</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Anti-retroviral Therapy</td>
</tr>
<tr>
<td>CMA</td>
<td>Community Mobilizing Assistant</td>
</tr>
<tr>
<td>COPAK</td>
<td>Country Office Pakistan</td>
</tr>
<tr>
<td>DIC</td>
<td>Drop-in-centres</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>FSW</td>
<td>Female Sex Workers</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HTC</td>
<td>HIV Testing and Counseling</td>
</tr>
<tr>
<td>KII</td>
<td>Key Informants Interview</td>
</tr>
<tr>
<td>IBBM</td>
<td>Integrated Biological and Behavioural Surveillance</td>
</tr>
<tr>
<td>IDI</td>
<td>In-depth Interview</td>
</tr>
<tr>
<td>IDU</td>
<td>Injection Drug Users</td>
</tr>
<tr>
<td>MMT</td>
<td>Methadone Maintenance Treatment</td>
</tr>
<tr>
<td>MOHS</td>
<td>Ministry of Health and Sports</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental Organization</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>U.S President’s Emergency Plan for AIDS Relief</td>
</tr>
<tr>
<td>PMCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>PWID</td>
<td>People who Inject Drugs</td>
</tr>
<tr>
<td>SARA</td>
<td>Substance Abuse Research Association</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Form</td>
</tr>
<tr>
<td>---------</td>
<td>-----------</td>
</tr>
<tr>
<td>SRHR</td>
<td>Sexual and Reproductive Health and Rights</td>
</tr>
<tr>
<td>SS</td>
<td>Satellite Sites</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>United Nations Programme on HIV &amp; AIDS</td>
</tr>
<tr>
<td>UNODC</td>
<td>United Nations Office on Drugs and Crime</td>
</tr>
<tr>
<td>UNOPS</td>
<td>United Nations Office for Project Services</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>3MDG</td>
<td>Three Millennium Development Goal Fund</td>
</tr>
</tbody>
</table>
Introduction

According to the UNAIDS Gap report (2014), there were about 12.7 million people who injected drugs globally and nearly 1.7 million or 13% were living with HIV. Asia and the Pacific accounted for one-third of all PWID and one out of eight PWID in these regions were living with HIV (AIDS Data Hub, 2016). In Myanmar, HIV epidemic was also driven largely by PWID. In addition to these marginalized populations, spouses of PWID were also at higher risk of HIV infection compared to general populations (Karamouzian, Haghdoost & Sharifi, 2014).

Myanmar was among the highest HIV prevalence in Asia-Pacific region in 2015 (MOHS, 2017). Moreover, drug injectors in Myanmar together with those in Afghanistan, Pakistan and Vietnam accounted for 20-65% of new HIV infections (UNAIDS, 2016). According to Ministry of Health and Sports, Myanmar (2017), HIV prevalence among PWID was estimated to be 28.5% and the highest proportion of new infections among the population was 28% in Myanmar. IBBS (2014) reported that Kachin state (Myitkyina, Bamaw) was a high HIV prevalence region among male PWID respondents.

Figure 1. HIV Prevalence among populations in Myanmar (2015)

Although HIV epidemic of PWID was the highest among key populations, HIV testing coverage was the lowest for them. In addition, their comprehensive HIV knowledge was also the lowest compared to female sex workers and men who have sex with men (AIDS Data Hub, 2016). A figure in the country fact sheet of WHO (2015) showed that condoms used by PWID was also the lowest causing their spouses to be in high risk population. SARA also observed that, in 2015 and 2016, 38% of married PWID had HIV positive (468 out of 1248 male clients) in Myitkyina, Hopin, Namatee, Moe Hnyin and Moe Mauk townships in Kachin State. On top of that, there were increased services for PWID but accessibility to those services by their female spouses were very limited (Aung et al., 2016).

**Figure 3. Percentage of Condom Use by Key Populations**

<table>
<thead>
<tr>
<th>Condom use</th>
<th>MSM</th>
<th>PWID</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>82%</td>
<td>23%</td>
<td>96%</td>
</tr>
</tbody>
</table>

MSM = Male Sex Male
PWID = People who Inject Drugs
SW = Sex Workers

It has been witnessed that spouses faced social, economic and marital problems due to their husband’s drug injection. In addition, as stated in UNODC COPAK (2010), wives of male who inject drugs may be victims of physical and sexual violence and were vulnerable to HIV. Because of all of the above facts, PWID spouses were more vulnerable to psychological impacts as well, and they could voluntarily withdraw themselves from getting access to the testing services. Thus, it was crucial to examine the predicaments of these spouses and their protective measures against HIV.

Currently, only a few harm reduction services are available for spouses of male PWID and their needs have not been effectively addressed. Moreover, programs overlooked these bridging population in the context of HIV epidemic which could deter prevention of mother to child transmission (PMCT) efforts. This study aimed to explore the problems faced by female spouses of PWID, their HIV risk factors and protective behaviours in order to implement HIV prevention interventions and to find out support mechanisms for them.

Objectives

The objectives of the study were:

1. To identify the socio-economic stresses, marital relationship patterns and sexual relationship within the marriage context of couples with a PWID husband

2. Identification of HIV risk factors for the spouses of PWID and their coping mechanism to prevent acquiring of HIV from their husbands

3. To identify the characteristics of support mechanisms from the parents on both sides on preventing HIV transmission to the spouse from the PWID husband.

Methodology

A Cross-section Qualitative Case Study was employed using in-depth Interviews (IDI) and focus group discussions (FGD) with spouses of PWID and key informant interviews (KII) with parents-in-law, an intimate friend, an army nurse, a camp religious leader and a ward authority who was a secretary of drug abuse eradication team of his village. There are five project sites in Kachin State
under SARA implementation supported by 3MDG. The data collection was conducted in Myitkyina, Hopin, Namatee, Moe Hnyin and Moe Mauk townships where the Drop-in centers (DIC) or Satellite Sites (SS) of SARA situated. The spouses were recruited as followed.

**Figure 4. Sampling procedure of recruiting spouses of PWID**

Spouses with different HIV statuses (no HIV testing/ had HIV testing and HIV negative/ had HIV testing HIV positive) were selected. They were recruited through their PWID husbands. Regarding KII, any of the followings were considered to be selected in the study: Parents or Parents-in-law of spouses, intimate friends, ward authorized persons or one who knew well about these spouses. Target sample for each site was ten: 1 FGD, 2 IDI and 2 KII. The number of actual participants were shown in Table 1. The data collection was done in May 2017.
### Table 1. Study Participants

<table>
<thead>
<tr>
<th>No</th>
<th>Field Site</th>
<th>Place</th>
<th>No. of KI</th>
<th>No. of IDI</th>
<th>No. of Participants for FGD</th>
<th>Total No. of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Myitkyina</td>
<td>Myitkyina DIC</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>2.</td>
<td>Hopin</td>
<td>Hopin Anglican Church</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>3.</td>
<td>Moe Hnyin</td>
<td>Moe Hnyin Satellite Site</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>4.</td>
<td>Namtee</td>
<td>Namtee CMA’s resident</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>5.</td>
<td>Moe mauk</td>
<td>Moe mauk Satellite Site</td>
<td>2</td>
<td>3</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>7</td>
<td>10</td>
<td>22</td>
<td><strong>39</strong></td>
</tr>
</tbody>
</table>

An In-depth Interview in Myitkyina

A Key Informant Interview in Moe Hnyin
Data Analysis

Data transcription from the audio-recorder in Myanmar language was done and typed into a Word document. Thematic analysis was carried out based on different themes and sub-themes across the different study sites and type of interviews using “Atlas.ti 6” software. Analysis was completed in Myanmar language and key findings from themes and sub-themes were written in English. Selected quotations from relevant sub-themes were translated into English.

Ethical Consideration

Participants were recruited through field staff and invited to participate in the interview. The purpose of the study in general, the procedure of interview and expected duration of interview was explained by the facilitator, including the risks and benefits of participating in the interview. Verbal informed consent was taken from each participant. Withdrawal of participant during or after the interview was ensured if the participants no longer wished to participate in the study. Confidentiality and autonomy of the participants were guaranteed.

With permission of the participants, the interviews were audio-recorded and noted down and no names were recorded. Background information such as ages and residence as well as HIV testing and results have been included. This study also concerned with disclosure of confidentiality of certain retro positive patients and the consents were taken beforehand from all of the respective patients who were willing to take part in this study. Electronic data (typed transcripts and Atlas.ti database) were also kept confidential and only those who conducting the data analysis can access the data. The time given by the study participants during the interview was reimbursed and transportation cost was considered as necessary by the project team.
Results

Background Information of Participants

Overall, 10 in-depth interviews (IDI), 4 Focus group discussions (FGD) and 7 key informant interviews (KII) were conducted in the study. A total of 32 spouses: 8, 8, 7, 6 and 3 spouses from Myitkyina, Hopin, Namatee, Moe Hnyin and Moe Mauk respectively, participated in IDI and FGD. The mean age of the participants was 33. Half of them were in secondary education, i.e. Grade 6 to 11. Most of them were farmers or unskilled workers. 19 out of 32 participants lived in rural areas. Women had been married to their PWID husbands for an average of 10 years and 20 participants were in extended type of family. Three-fourths received HIV test and 9 of them were HIV positive.

Table 2. Background information of participants (Spouses of PWID)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Total Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age of Participant</strong></td>
<td></td>
</tr>
<tr>
<td>Mean(minimum-maximum)</td>
<td>33 (20-55) years</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>No Education</td>
<td>2</td>
</tr>
<tr>
<td>Primary Education</td>
<td>9</td>
</tr>
<tr>
<td>Secondary Education</td>
<td>17</td>
</tr>
<tr>
<td>Passed Matriculation Exam</td>
<td>3</td>
</tr>
<tr>
<td>Tertiary Education</td>
<td>1</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
</tr>
<tr>
<td>Dependent</td>
<td>6</td>
</tr>
<tr>
<td>Unskilled Workers</td>
<td>13</td>
</tr>
<tr>
<td>Farmer</td>
<td>12</td>
</tr>
<tr>
<td>Teacher</td>
<td>1</td>
</tr>
<tr>
<td><strong>Residence</strong></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>13</td>
</tr>
<tr>
<td>Rural</td>
<td>19</td>
</tr>
<tr>
<td><strong>Duration of marriage</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (minimum-maximum)</td>
<td>10 (1-25) years</td>
</tr>
<tr>
<td><strong>Type of family</strong></td>
<td></td>
</tr>
<tr>
<td>Nuclear</td>
<td>12</td>
</tr>
<tr>
<td>Extended</td>
<td>20</td>
</tr>
</tbody>
</table>
7 key informants: 2 mothers-in-law, a father-in-law, a close friend, an army nurse, a church religious leader and a secretary of village drug eradication team participated in the study. The mean age of the key informants was 53. Most of them were Kachin or Shan and Christians with different educational statuses. It was also noted that 3 out of 7 lived in rural areas.

Table 3. Background Information of Key Informants

<table>
<thead>
<tr>
<th>No</th>
<th>Site</th>
<th>Key Informants</th>
<th>Age</th>
<th>Ethnicity/Religion</th>
<th>Education</th>
<th>Work</th>
<th>Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Myitkyina</td>
<td>Camp Religious Leader</td>
<td>52</td>
<td>Lisu/Christian</td>
<td>Passed Metric Ex</td>
<td>Religious Leader</td>
<td>Urban</td>
</tr>
<tr>
<td>2</td>
<td>Hopin</td>
<td>Mother-in-law</td>
<td>61</td>
<td>Kachin/Christian</td>
<td>No</td>
<td>Farmer</td>
<td>Urban</td>
</tr>
<tr>
<td>3</td>
<td>Hopin</td>
<td>Father-in-law</td>
<td>60</td>
<td>Kachin/Christian</td>
<td>Grade 5</td>
<td>Farmer</td>
<td>Urban</td>
</tr>
<tr>
<td>4</td>
<td>Namatee</td>
<td>Close friend</td>
<td>31</td>
<td>Shan/Buddhism</td>
<td>Grade 5</td>
<td>Vendor</td>
<td>Rural</td>
</tr>
<tr>
<td>5</td>
<td>Moe Hnyin</td>
<td>Army Nurse</td>
<td>67</td>
<td>Shan/Buddhism</td>
<td>Graduated</td>
<td>Army Nurse</td>
<td>Urban</td>
</tr>
<tr>
<td>6</td>
<td>Moe Mauk</td>
<td>Secretary of Village Drug Abuse Eradication Team</td>
<td>44</td>
<td>ShanKachin/Christian</td>
<td>Grade 10</td>
<td>Secretary</td>
<td>Rural</td>
</tr>
<tr>
<td>7</td>
<td>Moe Mauk</td>
<td>Mother-in-law</td>
<td>58</td>
<td>Kachin/Christian</td>
<td>Grade 8</td>
<td>Farmer</td>
<td>Rural</td>
</tr>
</tbody>
</table>
Social Problems

It was observed that the community mostly had negative perspective and discriminated against injection drug user (IDU) and their spouses. Some participants mentioned that they were afraid of being known by the society because they had feelings of shame and low self-worth.

"People insulted us. They called me “ဖိုးသမားမိန္းမ” (wife of drug user). If I couldn’t pay a rent for our house, they bad-mouthed that it was because my husband did drugs. […] I have HIV, I dare not go to other houses even to the house where I wash clothes. As I am a drug user’s wife, they suspect I have the disease so they discriminate. But I haven’t told them. When they made noises about me, I worried that they knew my status and I felt belittled."

A 32-year old participant from Hopin

It was reported that neighbors worried of stealing their properties and thus, they treated the families with contempt. Some participants described that the label of drug user family can still be attached to them in spite of receiving methadone maintenance therapy by their husbands. Since social relations became disintegrated, they avoided other people and concealed their family problems with the fear of negative reactions and stigmatization which created social isolation.

“The community has negative prejudice against us. If my husband visited their houses, they suspected he would steal something. If he asked them to hire their motor cycles, they reacted like he would sell those in other places and told him off not to touch theirs. They scorn us because he is a drug addict.

A 28-year-old participant from Myitkyina

“In the ward, people looked down upon the drug user families to the extent that they were extremely discriminated.”

An army nurse from Moe Hnyin

Some participants bear double stigma as they were not only spouses of PWID but also HIV infected women. As the community has misconceptions about HIV, these spouses and their families were victimized.
“There are many social problems in my village. They talk bad things about us. When we went to churches, they didn’t want to sit nearby. Some shunned me and I noticed that. I love babies so when I saw them crying, I cuddled them up. They [parents of the babies] stayed near me as they worried that I made their babies infected knowingly. When I heard their ill-talk, I felt so much pain.”

A participant from focus group discussion in Myitkyina

Economic Problems

It was found out that there was a significant financial burden on spouses of IDU. Many participants relied on their husbands’ income, and their drug injection pushed them into serious financial hardship and prevented them to meet daily basic needs.

“When he was an addict, with no work, it was really difficult for us to meet household needs. We had days we didn’t even have 500 kyats. If he did drugs these days, my two children and I starved. We had such difficulties. I feel deep pain every time I think of that.”

A 32-year-old Namatee participant

As PWID husbands were often unemployed and had little or no contribution to household income, spouses became a sole source of income for their families. They had to shoulder an unfair share of household responsibilities including work, food, and clothing as well as to bear the education costs for their children.

“He didn’t do anything so I had to sell this and that. I had to think all the time as we had no money. It was going to rain but I didn’t have a choice. So, I fried dough in my house and sold them around the village. During the hot season, I cut watermelon into slices and soon after selling them, in the evening, I went to a garden and plucked some flowers to earn. I had to do like that to solve our financial problem. I had not done those before but I had to do for my kids.”

A 28-year-old participant from Myitkyina
Although the women worked poorly, they were struggling to pay basic household expenses. It became worse when a family member was unwell and required health care services or their children needed to attend extra tuitions. They had to borrow money with high interest rate which made them live in the cycle of debt. It was also observed that the lenders took away their property as some could not pay back their loans.

“I owed too much money. I sank deeper into debt. I still have to pay them back because of him. Before he did drugs, we were financially fine. He earned from buying and selling motor cycles and cows so I could wear gold. After he got addicted, I lost all of them. Nothing left. I had to pay all I earned by selling goods to him. If it was not enough, I needed to take a loan with interest. The debt goes deeper and deeper so I haven’t paid them off till now.”

A participant from focus group discussion in Moe Hnyin

“They loaned 10-lakh rice debt and needed to pay back 15 lakhs. They were unable to repay so the loaner took their motor cycle.”

An intimate friend of a spouse of PWID in Namatee

Some spouses were unable to provide all of the household necessities, and therefore dropped their children out of school and let them work to help her supply the household income. A key informant also experienced likewise hardships in the families of PWID.

“Eating, clothing and living were all difficult (for them). Some got more difficulties so they were unable to put their kids in schools. Some of the kids living in our camp dropped out of schools last year. Their mothers couldn’t afford to pay their tuition fees. As they know it was not okay if their husbands weren’t here, they let their kids stay at home while they worked.” There were about three households having their children quit schools.”

Camp religious leader from Myitkyina
Marital Problems

Frequent quarrels and fights were a common finding among the families of PWID. It was found out that quarrelling and fighting occurred during their discussions over husbands’ drug injection and when they asked their wives for money to purchase drugs. Some women threw their husbands out of their homes after the fights but others stated that they were subjected to violence or bore the brunt of abuse after denying to provide money.

“If I didn’t give him money to get drugs, he made troubles… big troubles like he was trying to kill me. Sometimes we wrestled for that. Though I am big and he is small, I can’t fight him.”

A 37-year-old participant in Hopin

“I was so hurt to see my kids beaten when he had drug cravings.”

A participant from focus group discussion in Moe Hnyin

“We quarreled a lot… when he asked me for money while I didn’t have. He thought I didn’t give him on purpose so… he didn’t beat me… but put the clothes into the fireplace or knifed them instead.”

A 28-year-old participant in Myikyina
Another possible act of drug injecting husbands if their wives could not provide them money was that they would steal things from their homes to fund their drug habits. It was reported that they lied about the missing household properties or did not divulge their theft at all. Although none of the spouses interviewed expressed about the theft of materials from other houses, it is possible for their husbands to thieve others’ possessions as stated by a key informant.

“If we had a motor cycle, he pawned it. If there was a cupboard in our house, he stole and sold it… to get drugs.”

A 35-year-old participant in Moe Hnyin

“They don’t want to work as they become addicted to drugs. Then, they steal things from others so as to get money for drugs.”

A secretary of drug eradication team of Aung Long Village, Moe Mauk.

Some spouses considered to end their relationships but only a few of them decided to leave their husbands and went back to their parents, as others concerned about the sake of their children. It was also noted that women attempted to fix their husbands’ addiction by warning them they would break up or inform the police to arrest them. Nevertheless, their efforts were not sufficient enough to alter their drug-use behaviour.

“Of course, I wanted to break up with him. I thought that about three or four times a day. But if I end this relationship, how about my kids’ education? It’s difficult for them to live with their grandma. Theirs would be incomplete and they would lose their faces so I let myself suffer till now.”

A participant from a focus group discussion in Moe Hnyin

“I warned him I would take him to police or inform Patjasan [Kachin anti-drug group] to quit drugs. He talked me back that he did drugs with his money… others couldn’t do if they didn’t have cash. He had work and money so he could do. It made me surprised… seemed like he was proud of doing drugs. So then, I changed my approach… because I don’t want to suffer in this vicious cycle anymore and need to consider my two sons’ future.”

A 26-year-old participant in Myikyina
Sexual Relationship

Many women were not aware of HIV status of their spouses or were aware of only after they attended a hospital for serious illness or pregnancy where they knew they already had HIV. Not only HIV status but also drug injection by their husbands did they observe later than others. It was reported that spouses who knew their husbands’ status were those who had some knowledge about HIV/AIDS and urged them to receive a blood test. Even though they asked their husbands for screening, there were a few men who refused to obtain HIV testing and thus, they could test only for themselves. It was also noted that some men who were informed of their status did not disclose to their wives.

“They (spouses) knew their husbands did drugs later than others (neighbors) did. So, when it comes to AIDS, they have no time for prevention. They only knew they had the disease when they went to the centers for illness and got tested.”

*Army nurse from Moe Hnyin*

“I urged him not to share needles with others. There was Thazin clinic in mining area so I told him to go and get tested there. I also went there for the test because I was too afraid to get infected.”

*A 35-year-old participant from focus group discussion in Moe Hnyin*

“He wanted to hide the status. Whenever I asked him to go for testing, he lied me he was already tested negative. But I saw the truth in his eyes. Maybe he didn’t want to disclose because I would leave him.”

*A 36-year-old participant from Moe Mauk*

It was reported that the majority of the participants were afraid of acquiring HIV but did not have sufficient knowledge on protective measures. As mentioned above, women with some HIV knowledge urged their spouses not to share needles with others and to undergo HIV testing since they knew their spouses were IDUs. However, protected sex was not practiced among the married couples. Some participants responded that they did not use condoms because their husbands were unwilling to use them while others trusted their husbands with regard to drug use and sexual
practices. Other reasons included dislike of using condoms, wanting to have a baby and feeling of insecure towards using condoms as they believe in monogamous marriage. There were also a minority of spouses who did not even heard about HIV.

“I told him to use condoms but he didn’t like them. He said men didn’t like using them because it was like taking a shower with a raincoat on. He asked me to try showering like that. And also, we didn’t have a baby so he wanted one.”

A participant from focus group discussion in Hopin

“I didn’t know HIV at that time. When I was aware of HIV transmission from sex, I was really scared. I was not afraid before because I didn’t have the knowledge.”

A participant from focus group discussion in Namatee

Few women admitted that their children were also infected with HIV while some participants told theirs had not undergone testing for HIV. Two cases were reported where all the family members had not obtained HIV test.

“I knew I had HIV only when I attended to hospital for testing during pregnancy. If I knew it earlier, I wouldn’t let my baby infected. I mean… I wouldn’t carry my baby. At that time when I was aware of my status, I’d already had a baby inside and I went there because of my illness.”

A 32-year-old participant from Hopin

HIV Risk Factors for Spouses of PWID

a) Lack of HIV knowledge

It was apparent that many participants did not know about HIV/AIDS, its transmission and how to protect themselves from the disease. Such women were more likely to not know HIV status of their husbands which made them vulnerable to contracting HIV. Conversely, women who had HIV/AIDS knowledge were aware of their spouses’ status and could urge them to avoid sharing needles, unsafe sex with others and to undergo testing. However, disclosure of HIV status by their PWID husbands was important for them to be aware of their risk of the infection as there were few husbands who concealed their status.
“I had no HIV knowledge before. A few months ago, I came here for the test and knew that I was infected. Then I asked my husband for taking the test but he didn’t listen to me… but at last, he underwent testing and was informed of the disease.”

A participant from focus group discussion in Hopin

Some women had limited HIV knowledge, and misconceptions on protection of the disease were common. It was noticed that knowledge, attitude and practice of condom utilization was low among them. Dearth of knowledge by their husband also increased the vulnerability of spouses. A participant stated her HIV-positive husband’s willingness to have another child but she thought it would be dangerous for her and the baby, and thus, decided to take oral contraceptives.

It was found out that many women did not know about female condoms. Still, a few women who heard about those expressed that approval from their husbands was needed for them to use. Occupations of their husbands such as driving trucks or working in mines, also had negative impact on them as they were more vulnerable to the disease than other husbands. However, no association was found between education level and HIV positive.

“I don’t think they knew about HIV when they lived in mining zone.”

Father-in-law of a spouse of PWID husband from Hopin

b) Unequal power relations between men and women

Living in a male-dominated society, many women experienced sexual violence and became more susceptible to HIV/AIDS. Owing to unequal power relations between married couples, wives of IDUs were inferior to their husbands and unable to negotiate for a safe sex which increased their risk of contracting HIV infection. Numerous findings in terms of patriarchal gender roles particularly associated with condom use were identified: women were considered to prove their fertility; marriage equated end of condom use as the act may indicate infidelity and distrust; husband, the head of household had reproductive control and female had to comply his decision.

“It’s (sex and sexually transmitted diseases from husband) unescapable problem for married women. It’s unavoidable.”

A 26-year-old participant from Myitkyina
“My mom-in-law told me why I married if I don’t wanna bear a child. She kept on telling that many times. So, I took a second pregnancy.”

A 36-year-old participant from Moe Mauk

A painful experience of a participant best describes the effect of patriarchy in transmission of HIV from a PWID husband to his wife. From the following conversation, it was evident that the hegemonically masculine husband had control over his wife, with involvement of usual violence. On the other hand, the women, upholding a dominant ideal of femininity, condoned and endured the violent behavior of her husband instead of defying this.

“Long time ago, while he was working, he spitted up blood. So, I told him to go to a hospital for testing but he didn’t agree. I had to talk delicately to convince him as he is the breadwinner. Only after 4 or 5 attempts, he agreed to go to the hospital where he was screened and given TB medications. Before that, he was tested for HIV and knew that he got the infection also. As soon as we returned home, he scolded me that he was ashamed because I took him to the hospital which he didn’t want to go to. I had to convince him to follow the instruction of the doctor and to take medications. The doctor also asked me for testing and I accepted to take a test but nothing bad was detected. So, they gave us condoms to prevent transmission. But he said he didn’t want to use them. Then, I asked him for going back to the hospital and taking HIV consultation. He refused that too. I thought it was better to not discuss this issue again because that would upset him. When I was pregnant and screened again, I was also tested positive.”

A 42-year-old participant from focus group discussion in Myitkyina

c) Access to health care services

It was found out that 7 out of 9 HIV positive spouses were from rural areas. Rural people had challenges in accessing health care services such as limited transportation and financial problem leading to increased contractibility of HIV infection. People who lived in mining sites had little or no knowledge about HIV, and their accessibility was limited as they were unable to attain health education sessions as well as HIV services.
“We had to work and it was difficult to come here as we didn’t have a motor cycle.”

A 32-year-old participant from Namatee

d) Language

Language barrier was also found out as a risk factor in this population. One participants mentioned that she was “Shan” and had incompetent Burmese language skills and hence, she found it difficult to understand health education by a nurse.

“I got HIV education by a nurse. But, I didn’t know Burmese well and she spoke fast so I didn’t understand.”

A 38-year-old participant from Moe Mauk

Coping mechanism

Many women worried of acquiring HIV from their husbands. Because of high risk perceptions, they urged their husbands to avoid sharing needles with others, to not commit adultery or use condoms at least, and to obtain blood test. The majority (25 out of 32) had been tested for HIV and amongst them, 16 reported they were negative. However, follow-up testing were needed for many women. In contrast, 7 participants had not screened and 9 had tested positive.

“I don’t wanna take a test. I don’t know I have HIV or not. If I take it and have the disease, I will be depressed. I let myself die. Whichever disease I have… let it be.”

A participant from focus group discussion in Namatee

Most of the participants admitted that there were no discussions about HIV and safe sex between their husbands and them. Even in the couples who discussed about the issue, negotiation for safe sex was very challenging. Male IDU did not usually share all the health information they obtained from the centers to their wives. Women who had access to some health centers seek help from them to educate their husbands about HIV.

Condom utilization was very low among the couples and only 9% of the participants reported that they used condoms regularly. Some people mentioned that they used condoms if they received from the center but did not voluntarily ask for or buy them when they had none. As stated earlier,
there were many reasons for having condom-less sex: dislike for condoms because of reduced sensation or its smell, trust in their husbands, desire to have a child, difficulties in accessing condoms, sheer embarrassment to obtain condoms and being in monogamous relationship. Few women had intention to use female condoms but did not ensure their spouses could agree to it. It was also impossible for most of the spouses to refuse sex with their husbands if they did not want to use condoms.

“The smell is very strong. How can we remove that? Also, it is very oily and irritates us. That’s why we don’t want to use.”

A participant from focus group discussion in Mytikyina

“Some women still have a misconception that men only use condoms to have sex with prostitutes. So they felt inferior if their husbands use condoms to have sex with them. Another possibility is that they would suspect them of having extramarital affairs.”

Army nurse from Moe Hnyin

Role of Parents in Prevention of HIV Transmission

Many spouses sought help from their parents who supported them financially and psychologically. However, most of their family members were not supportive in regard to HIV prevention as they had little or no knowledge about the infection. Those who knew about HIV urged them to take testing or to go to clinics for counselling. It was also observed that parents were more supportive than parents-in-law. While some participants had families who understood and support them, there were other participants who were unfortunate enough to receive hostile response rather than support.

“My parents-in-law also know we were taking medications (ART). They understand us. They always reminded us to take medications on time. They are supportive.”

A 32-year-old participant from Hopin

“When they (parents-in-law) knew we had HIV, they discriminated us. They made food only for themselves and did not want to eat together.”

A 32-year-old participant from Namatee
“Before my husband received methadone treatment, I was out of touch with my dad… for about 6 years though his house is near mine. He also drove me out of his house if I came to meet him. We lived in the only house near the stream. One day, the flood came and I did not call my dad for help. My husband and my child was in his parents’ place so I was alone that time. When the flood became higher and higher as it almost reached the front door, I ran to the other’s house. Not my father’s one.”

A participant from focus group discussion in Moe Hnyin

A mother of an intravenous drug user (participant in this study) living together with her son, her daughter-in-law and their two daughters in their hut in Moe Mauk Township, Kachin
It was certain that they needed someone to talk to about their problems. Few participants wanted support from close friends or their neighbors in order to express their feelings. A participant also requested to form a peer support group for spouses of PWID so that they could share their painful experiences and encourage each other to regain their self-esteem. Another woman was willing to see many health centers in each ward to lessen such predicaments in her community while others demanded to receive blood tests and Hepatitis B and C vaccination for themselves and their families.

Those whose husbands had MMT yearned for obtaining methadone earlier in the morning (7 a.m. rather than 8:30 a.m.) as well as to receive takeaway for the next several days to be able to go work well. In addition, they wished their husbands to be provided with regular employment. Regarding health information, spouses asked the organization to distribute pamphlets more and to diffuse via televisions, radios and social medias such as Facebook. If it was not enough for their husbands, they would like them to be given health education about HIV and safe sex. They also expressed their desire to receive monetary assistance for eating, living and sending their children to schools. Some women who had HIV positive only hoped for a medication to be invented to cure all HIV/AIDS people in the world.

**Discussions**

It was evident that spouses suffered not only social discrimination but also self-stigma due to their husbands being drug injectors. In order to lessen social stigma by the communities, education interventions, advocacy and awareness programs should be conducted so as to improve the knowledge and understanding as well as to contravene negative attitudes and beliefs. On the other hand, self-stigma should be reduced through establishing a peer support group in which they can share their concerns, discuss about health and psychosocial challenges and give each other advices and support. Providing family treatments which addresses emotional burdens of spouses could also help them.

In terms of economic problems, although spouses had to work solely for their families, earnings were not enough to cover all the expenses which was worsen by their husbands who stole money and materials to purchase drugs. Therefore, they had to live in the vicious cycle of debt and some
needed to drop their children off from schools. Providing treatment for their husbands could resolve their economic and marital problems as drug use was the core cause for their predicaments. In addition, development of income generation programs for spouses is suggested to alleviate their financial burdens. As mentioned earlier, beneficiaries who received MMT would be able to work by obtaining methadone earlier in the morning or takeaways for next weeks (rather than coming every day). It is also important to provide vocational training and job opportunities for rehabilitees.

Many women were not aware of their husbands’ HIV status and had little knowledge on the disease. Therefore, more HIV and health education sessions are recommended to conduct especially in rural areas, where women had very limited knowledge on the disease. Men should also be educated and those who obtained counseling should be advised to diffuse information to their wives. In other words, effective communication between husbands and wives about drug use and health related problems should be encouraged. Condoms promotion activities should be considered to enhance the condom-protected sexual practice. As knowledge on HIV counseling and testing among spouses was low, home-based HIV testing and counseling (HTC) services should be provided in the community.

Several HIV risk factors for spouses of PWID husbands were found out: lack of HIV knowledge, unequal power relations between husbands and wives, limited access to health care services and language barrier. ABCD prevention strategy (abstention, being faithful, condom use and delivering technologies for women to protect themselves including female condoms) should be adopted to prevent HIV transmission. Collaboration with faith based organizations to conduct health education sessions would also be better for the whole community including spouses and PWID to enhance HIV knowledge. As spouses of PWID husbands who are working in mines or driving trucks are more vulnerable to acquire the infection, workplace HIV/AIDS interventions might be the solution for those population.

To tackle gender-based violence, education for empowerment of women along with the engagement of men is crucial to promote respectful relationships and gender equality. Sexual and reproductive health and rights programs should be strengthened so does SRHR/HIV linkages through a multisectoral approach to improve coverage and access to HIV services. Safe sex negotiation skills for spouses should also be provided with the aim of consistent condom use.
Development of community based interventions could increase uptake of testing and treatment among rural communities and ethnic minorities who would then overcome language barriers. Health information should also be created in languages of minorities.

Support from parents is essential for spouses to alleviate physical and emotional pains and drug injectors to become non-users. Parental education programs are recommended to enhance the knowledge and understanding of parents and to support the families with drug use problems. Family based approaches are also suggested to treat substance use as well as to prevent HIV/AIDS. Diffusion of information through televisions and social media such as Facebook could also reduce social stigma and increase knowledge of the communities in order to understand and support families of drug users.

To conclude, HIV prevention interventions for women such as peer prevention programs, SRHR and education sessions should be integrated with current harm reduction programs for the sake of spouses of PWID husbands. At the same time, it is important to provide health education sessions for school-aged children as well as parents to prevent further substance abuse and HIV transmission. The contents should include wide range of topics from life skills to prevent drug abuse, HIV and sexual health rights. It is also important to cover rural areas and include ethnic minorities to ensure no otherness exists during service delivery.
References


https://www.3mdg.org/sites/3mdg.org/files/publication_docs/situational_analysis_on_drug_use_and_hiv-_final.pdf


Annexes

Annex 1. In-depth interview guideline

Introduction --- Good morning/afternoon! We are from the SARA organization. We would like to interview or discuss with you about your experience and point of view on your problems due to drug injection of your husband and HIV prevention for yourself. You may also want some help from people or organization to prevent HIV transmission. Your participation in the interview would be very helpful for our future health related services for you and other spouses like you.

Your participation will be completely voluntary and if you don’t want to continue the interview, you can stop any time. This will not affect your available health services. Your name and identity will be secured and we will not mention in the report. We are currently planning to interview about 30 women like you and you are one of them. We ensure that the information you are providing to us will be completely confidential.

The interview will last about 40 minutes with experienced interviewer/s. There is no right or wrong answer. We will take notes and recording during the interview if you agree to do so. Lunch and transportation cost will be provided for your time and participation in the interview.

Verbal consent taking --- Do you agree to participate? (YES/ NO) If you are willing to participate, we will start the interview.

1. Demographic characteristics
   - Age, ethnicity, religion, education, occupation, address (urban/ rural), duration (years) of marriage, type of family (nuclear/ extended) and HIV testing and status (if tested)

2. To identify the socio-economic stresses, marital relationship patterns and sexual relationship within the marriage context of couples with a PWID husband
   - What kind of socio-economic stresses do you face within the family since your husband is an injection drug user?
   - How do you perceive your marriage and how are you coping with the problems of having married a PWID husband?
   - How is the sexual relationship with your PWID husband?
- Are you aware of your husband’s HIV status?
- How do you feel about the problem of HIV for yourself since your husband is a PWID?
- Are you afraid of acquiring the infection from your husband?
- Do you have children who are positive?

3. Identification of HIV risk factors for the spouses of PWID and their coping mechanism to prevent acquiring of HIV from their husbands

- Do you use condoms during sex? If so, how frequently, in what form?
- How do you protect yourself from getting HIV from your husband?
- Have you tested yourself for HIV?
- Can you refuse sex from your husband if he does not use condoms?
- When do you think you are at the highest danger of getting HIV from your husband?
- Have you and your husbands discussed about the transmission of HIV during sex and how to prevent it?
- Have you ever thought about seeking help for yourself (not to get infected?)

4. To identify the characteristics of support mechanisms from the parents of both sides on preventing HIV transmission to the spouse from the PWID husband.

- What do the parents from both sides think about you, marrying a PWID with the risk of getting HIV from your husband?
- Have they ever talked about this HIV issue with you?
- What kind of help do you want from them?
- What kind of help do you think you need from someone else (NGO, Govt, religious groups, etc.)?

Now, you know, this is what we want to discuss with you. That’s all we would like to ask you. Do you want to add anything that we forget to ask? Or any further discussion? (Wait for her reply for a while)

If you want to add no more, our interview/discussion is complete and finished. Thank you so much for your participation!
Annex 2. Focus group discussion guideline

Introduction --- Good morning/afternoon! We are from the SARA organization. We would like to interview or discuss with you about your experiences and viewpoints on your problems due to drug injection of your husband and HIV prevention for yourself. You may also want some help from other people or organization to prevent HIV transmission. Your participation in the interview would be very helpful for our future health related services for you and other spouses like you.

Your participation will be completely voluntary and if you don’t want to continue the interview, you can stop any time. This will not affect your available health services. Your name and identity will be secured and we will not mention in the report. We are currently planning to interview about 30 women like you and you are one of them. We ensure that the information you are providing to us will be completely confidential.

The interview will last about an hour with experienced interviewer/s. There is no right or wrong answer. We will take notes and recording during the interview if you agree to do so. Lunch and transportation cost will be provided for your time and participation in the interview.

Verbal consent taking --- Do you agree to participate? (YES/ NO) If you are willing to participate, we will start the interview.

1. Demographic characteristics
   - Age, ethnicity, religion, education, occupation, address (urban/ rural), duration (years) of marriage, type of family (nuclear/ extended) and HIV testing and status (if tested)

2. What would you like to see being done to help you having to face your PWID husbands and why?

3. Questions 2, 3 and 4 from Annex 1 according to their responses.

Now, you know, this is what we want to discuss with you. That’s all we would like to ask you. Do you want to add anything that we forget to ask? Or any further discussion? (Wait for the reply for a while)

If you want to add no more, our interview/ discussion is complete and finished. Thank you so much for your participation!
Annex 3. Key informant interview guideline

Introduction --- Good morning/afternoon! We are from the SARA organization. We would like to interview or discuss with you about your idea, point of view and opinion on problems of spouse(s) of people who inject drugs because of her/their husband(s) being PWID and how she/they prevent(s) HIV as well as needs for her/ them to prevent transmission of the disease. You are one of the key persons who are closely living/ working with them and we believe that you can give us a lot of information related to those populations. Your participation in the interview would be very helpful for our future health related services for spouses of PWID.

Your participation will be completely voluntary and if you don’t want to continue the interview, you can stop any time. This will not affect your available health services and your role in this organization. Your name and identity will be secured and we will not mention in the report. We are currently planning to interview another two-three participants like you and you are one of them. We ensure that the information you are providing to us will be completely confidential.

The interview will last about 40 minutes with experienced interviewer/s. There is no right or wrong answer. We will take notes and recording during the interview if you agree to do so. You will be provided reimbursement for your time and participation in the interview.

Verbal consent taking --- Do you agree to participate? (YES/ NO) If you are willing to participate, we will start the interview.

1. Demographic characteristics
   - Age, sex, education, occupation, role and responsibilities
   - Relationship with spouse(s) of PWID
   - Other related experience for spouse
   - No. of people in touch with in the last year, total estimate during your experience

2. Self-impression on current situation
   - How did you get here?
   - How do you feel living/working with spouses and IDU
   - Opinion on recent situation of PWID and their spouses in this environment
3. Your Experience and suggestion
   - Have you ever talked with spouses of PWID?
   - What do you think?
   - What problems of spouses you see?
   - Her/Their ways to prevent HIV transmission from her/ their husband(s)
   - Any help you think they need

4. Any gap in knowledge
   - Do you think is there any gap in info?
   - What gap and Why?
   - How to close the gap? / Your Opinion
   - Any suggestion or comment

Now, you know, this is what we want to discuss with you. That’s all we would like to ask you. Do you want to add anything that we forget to ask? Or any further discussion? (Wait for the reply for a while)

If you want to add no more, our interview/ discussion is complete and finished. Thank you so much for your participation!