SOCIAL, BEHAVIORAL AND PSYCHOLOGICAL DIMENSIONS OF HIV INFECTIONS: GAINING INSIGHTS FROM INTERVIEWS WITH HIV-POSITIVE PRISON INMATES

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ABSTRACT

The spread of HIV/AIDS has always been associated with the so-called high-risk behaviors – drug-taking and sexual activities. While adequate information about its distribution by age, ethnic groups, occupation, and marital status is available, there is little data pertaining to the actuality of factors, which influence an individual’s involvement in those behaviors. This study was an attempt to understand aspects of HIV-positive persons pertaining to their family background, social life, and risk-behaviors, with a focus on drug-taking and sexual activities. It was part of a major study among HIV-positives in eight prisons in Peninsular Malaysia. Data was collected using standardized formats containing closed and open-ended questions. Interviews were carried out in the prison of study by the Principal Investigator and trained research assistants. Focus group discussions were also held to get group’s views on the problems and ways to prevent them. The data was divided into two categories – quantitative and qualitative data. Quantitative data was analyzed by using SPSS while the qualitative was analyzed interpretatively. This paper presents the analysis from quantitative and qualitative data gathered from among 158 respondents (127 Marang Prison; 31 Pengkalan Chepa Prison). Five themes emerged from the analysis (i) discontentment with personal life (ii) knowing or not knowing about the consequences of drugs and HIV (iii) multiple entry to prison (iv) imprisonment and its reality (v) making a promise for a different life after release. This paper concludes that a better understanding of HIV/AIDS can be gained through qualitative research, and that this study has demonstrated that despite its limitations the use of in-depth interviews has provided a deeper insight into such a complex problem as HIV/AIDS transmission and control.

1.1 INTRODUCTION

HIV/AIDS is widely perceived as a social problem as it is related to human behavior – sexual practices and taking drugs. Of these, sexual behavior is seen as a naturally human desire for pleasure and reproduction. Drug taking, on the other hand, is related to the wider cultural, economic and political forces

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impacting on the human population. Viewed closely, the phenomena are situated within the community’s cultural environment that witnesses the destruction of values and norms. According to one statement, “AIDS is an epidemic linked to social ills. It cannot be seen outside of the context of the social norms that shape human sexuality and the social forces – such as poverty, conflict, and the powerlessness of women and children – that make societies vulnerable to the to the problem (Balgos 2001).

A local newspaper report (Berita Harian 1993) provided evidence that the phenomenon affected all layers of society. The unemployed constituted 33.7% of those infected by the infections. Clearly, this reflects a social characteristic that could immediately be linked to conditions in society where poverty, low level of education, income, and social class are found. The distribution spread to many other social groups, which included both professionals such as teachers, engineers, executives, airline stewards, and other groups like artists, sex workers, tourists, fishermen, manual workers, policemen, and housewives and children under seven years of age. In another newspaper report (NST 1993), it was stated that of the 28 children who were tested for HIV, some were identified as child prostitutes and drug users. The scenario tallied closely with the Ministry of Health’s report covering the period between 1986 to April 1999, which among others pointed out that the unemployed, fishermen, factory workers, uniformed staff, and long distant lorry drivers were infected with HIV. With reference to drug addicts, the figure released by the National Information Centre on Drug quoted that between January to April 1999, 53.26 % of the cases were new.

Statistics such as the above cannot tell us more about the reasons why people get involved in drugs and sexual activities. We might want to ask 'What do you know about the consequences?' and 'How did it all begin?' We expect to get answers that tell us about the kind of knowledge and meanings people attach to their life experience. Hence, a qualitative study is thought to be more relevant to the understanding of 'high-risk' behaviors among HIV-infected people. The relevance is brought into context of reality when the "presence of voice in the text" is incorporated into the qualitative report (Eisner 1991:36). A qualitative study among drug users in prisons may not be representative of the entire drug users and HIV-positives in the country. Nevertheless they can be researched on their past activities and current thoughts relating to the problem.

1.2 ABOUT THE STUDY

The study was proposed under the Intensification of Research in Priority Areas for funding for a two-year period 1998-1999. The main objective of the research was to gather data pertaining to the social, behavioral and psychological aspects of persons with HIV infections. The study population would comprise all HIV-positive persons in prisons since it would be more difficult to get infected persons from the streets. In 1998 there were a total of 7,608 (including 171 women) persons with HIV infections in prisons nation wide (Ali Othman 2002). These alone would form a large group for studies on various aspects of the problem.
In view of the regulations and constraints imposed by the Prison Department, relating to visits and interviews with prisoners, a cross-sectional study was planned. Eight prisons with HIV-positive inmates were included in the study – Kajang (274), Johor Bharu (105), Pulau Pinang (36), Taiping (80), Kamunting (60), Pengkalan Chepa (31), Marang (127), and Telok Mas (12 juveniles). Four prisons were visited in 1998 and four in 1999. Total inmates interviewed were 725.

Apart from the above, studies among the public were conducted in areas near prisons in Johor Bharu, Pulau Pinang, and Marang. The objective of the studies was to find out about the community’s understanding and perception of HIV/AIDS and control activities. Another component of the study was that of knowledge, attitude and perceptions of teacher trainees attending the Teachers Training Colleges at Ipoh, Pulau Pinang, Pengkalan Chepa and Batu Rakit. In all these studies data were gathered using standardized questionnaires.

This paper will present some of the data gathered from the Marang and Pengkalan Chepa Prisons study.

2.1 RESEARCH PROCESS

*Getting official clearance from Prison Department Headquarters*

After getting approval of funding from IRPA, clearance from the Prison Department had to be obtained. A copy of the research proposal was sent to the Director of the Prison Department, Bukit Wira, Kajang together with the approval letter from the Ministry of Health, Malaysia.

*Meeting with prison officials*

Subsequent to the approval, a visit to the Prison Dept. HQ was held to discuss research requirement and other matters. In response prison officials informed researchers that as prisons are restricted areas, every precaution, particularly that which pertain to the safety of visitors had to be adhered to. Apart from those researchers had to respect the confidentiality of prisoners in the research. The findings, however, could be used by the Ministry of Health and the Prison Department for research and policy purposes.

*Training of research assistants*

Intensive training on ethics and conduct of interviews was provided to five research assistants. They were recruited from a pool of social science graduates.
for the project. Matters on safety were stressed, and most importantly they were trained on how to get depth answers, particularly on drug-taking history and sexual activities. They were cautioned not to counsel or provide information on HIV/AIDS.

Preparing the field visits

A table for visit and activities was designed and was later forwarded to the Prison Dept. Headquarters together with copies to respective study prisons. Adequate time was given to each study site which included travel time and research in communities surrounding the prison.

Interview formats

An interview format containing 83 items was used in the study. They are divided into FIVE sections. Section One contains items that relate to the respondent’s socio-demographic characteristics and history of occupation. Section Two relates to the respondent’s family and family relationship. Section Three is on personal problems that respondents face at school, home and the workplace. Section Four focuses on behaviors related to drug-taking and sexual activities. Section Five relates to the respondent’s prison history, present activities, support from family and aspirations and hopes. Section One gets data that are mostly quantitative. However the other sections allow for data that deal with more than simple answers in response to the interviewers probing. Questions evolved in responses to respondent’s answers.

Beginning research

Researchers had to surrender their identity cards and bags at the reception office. Only money was allowed to be taken in. Camera, tape recorder and other personal items (e.g. pen knife, food) were not allowed to be carried inside the prison walls. Before adjourning to the study rooms, researchers first had a brief meeting with the officer-in-charge. An officer was later assigned to take the researchers to the interview room. In small rooms the guards stood outside but within view of researchers and inmates. In large rooms they sat at the corners. In one corner or some distance from the interview place, a group of would-be respondents was made to wait for their turns.

Facing the HIV-positives

A group of between 5 to 6 respondents was brought in per session, and each was brought to a researcher. Each was given a chair in front of a researcher and soon was explained about the research. A statement of agreement to participate in the research was either read or given to the respondent. Except for one, all respondents faced the researchers without handcuffs. And except in one prison, the interview sessions were held face-to-face. In one prison, the interviews were conducted behind bars. All looked well (no obvious signs of sickness, e.g. coughs or colds). A few looked slightly pale. They answered all questions. At
times they looked behind at the guard. They did that to make sure what they say was personal and private and that they would not be stopped. They were advised that it was all right to express their views to us since permission was granted by the authority.

The focus group discussions were done more freely without the barriers of desks or tables. Some 8-12 respondents were made to sit in semi circle. Two researchers acted as facilitators – one posed the questions and the other recorded their responses. Compared to the one-to-one interviews the focus group discussions were livelier. There were smiles and laughs. Participants talked more freely.

Acts and regulations for drug related offences

Drug related imprisonment is handled under several acts which include the Dangerous Drugs Act 1952 (Act 234) (revised 1980), Sale of Drugs Act 1952, The Drug Dependents (Treatment and Rehabilitation) Act 1983 & Regulations and Rules. The latter is considered to be a comprehensive piece of legislation covering treatment and rehabilitation. It came into force on 15th April 1983 as a result of shortcomings in Chapter VA of the Dangerous Drugs Act 1952. At the end of 1996, 10,807 persons or 43.7% of the prison population were drug offenders. Of these, 51.4% were 'addicts', 33.9% were 'addicts-cum traffickers' and 15.7% were 'traffickers' (Choo 1998).

Upon entry at a prison, an individual is classified as being 'citizen' and 'non-citizen. All will be quarantined and subsequently will undergo a prison orientation program and placed at temporary quarters. Following results of their blood tests, those with positive results are separated from the others and from then on will have to undergo several counseling sessions and second blood tests after six months. Post test counseling is given to all, and after this stage if the person is HIV-negative, he will be placed in Zone 1, while the HIV-positive will be placed in Zone 3.

3.1 STRUCTURE OF DATA PRESENTATION

Data are presented using the emotionalism perspective, which is concerned with ‘eliciting authentic accounts of subjective experience.’ (Silverman 2001). As key issues have revolved around predisposing factors (family and early socialization),
involvement in drug use and sexual activities (individual’s behavior), imprisonment (correctional institution and its impact), and the intent to change, data analysis has also been structured in response to these issues. “Emotions are treated as central to such experience’ (Silverman 2001) All interview notes were transcribed and analyzed according to broad areas - their social and family background, behavioral characteristics in relation to drug-taking and sexual activities (risks) and psychological aspects (impact on self). For the purpose of this paper five themes within these areas were selected. These are (i) discontentment with personal life (ii) knowing or not knowing about the consequences of drugs and sexual activities (iii) multiple entry to prison (iv) imprisonment and its reality (v) aspirations and hopes.

The FGDs are presented under three topics, namely (i) understanding of HIV/AIDS (ii) prison’s management of HIV-positive inmates, and (iii) to reveal or not to reveal their HIV status.

3.2 SOCIAL AND FAMILY BACKGROUND

**Theme 1: Discontentment with personal life**

For the majority of the lay people, HIV infection may not be something they can easily recognize. Those with the virus may remain healthy for years. As is characteristic of other infectious diseases, the causative factor is linked to others that are located in the social and cultural environment of the human population. The family being the smallest social unit of any society is where many social ills are rooted.

As revealed by this study, the beginning can be traced to conditions surrounding the individuals. Although most respondents said they seldom had any problems with their parents and sibling, the large family size occupying limited living space made them uncomfortable so that they chose to spend much of their free time outside the house. **MD**, a 32-year-old male respondent is from a large family. He is the sixth of nine children. He said ‘Well, it’s good to have so many sisters and brothers, but all the time…’ He further said -

My house was small and there were nine of us. I heard laughter and screams of my brothers and sisters. I know my mother pretended not to hear them. I got to go out or else I…
My elder sister helped with the cooking. She spent so much time preparing for the whole family. I pity her. I thought if I leave the house there would be less people for her to serve.

Months later when a friend I met during a Hari Raya told me he was going back to Kuala Lumpur, I made up my mind to follow him. I left school. There were no regrets. I didn’t think much about the future anymore. Even if I finished secondary school I wasn’t sure what to do then. For a while I thought of joining the army – at least I would get some money. But it seemed like a long time. I saw no future in my family.

So I decided to follow my friend to Kuala Lumpur. I know I would get a job so I could support myself. My friend worked as a lorry assistant. He too didn’t finish schooling.

The family is the basic unit where socialization takes place. Children turn to their parents for guidance and other parental care needs. In traditional Malay families the father has the role of setting the rules for behavior and inculcating the norms and values for all members to adopt. If he dies or leaves the family due to divorce or some other reasons, it may give rise to situations where the female spouse finds it difficult to perform her role in family matters. Families led by mothers become less intact especially when they could not have much say in the children's activities. Loosening of the family ties may be one cause for individuals to turn to drugs. Lost of one or both parents would certainly affect any family situation. On the other hand both parents may be alive, but because they are preoccupied with their economic and social activities, they have less time for their children. Such is the case that affected ML.

At 14 ML faced a situation where both her mother and father were too busy working. Financially, the family never experienced any crisis. She got two brothers and a sister. Except for her youngest sister, she and her brothers attended school, first in Kelantan then in Kuala Lumpur. She attended school regularly up to Form two. When she was in Form Three, she began to dislike two teachers. Then she hated everything…

I didn’t like school – I didn’t like the lessons. I found the homework burdensome. There was no one at home to help me do my homework. So, I didn’t do or I passed up late, and for that I got scolding from the teacher.

So, I ponteng (skipped) school. A friend asked me to join her group. We then went to the disco three times a week. My family found out about my activities. My mother got angry because she also found out I had not gone to school. But by then I was too happy with my life. I had to find money – I stole my grandmother’s saving. It didn’t stop there – I got involved in dadah at 15. My first was ‘chase’
3.3 BEHAVIORAL RISKS

**Theme 2:** Knowing or not knowing about the risks of drugs and sexual activity

**RH,** who is now 37 years, admitted that he was shown the way to a brothel when his father made him his companion to Thailand. He was nine years then. His father was a fisherman. Once a month his father would ask him to follow him to do some shopping. His father would tell his mother that he would take his son along to help bring back goods they would purchase from Siam.

As a kid I didn’t ask why my father had to stop by a shop house every time we finished buying things for our family. I saw him go in and I heard laughter inside. Then I saw father coming out smilingly.

I saw women – some old some young. They would wave at me, but I kept quite. Then one day a nice woman asked me to follow her. She asked my name and asked about my family. She gave me food and would tell me stories about her village in Thailand.

I liked her. One day she asked me if I liked her to massage my body. I didn’t say anything – I just allowed her to take off my shirt.

HIV...no. I never knew about it. I knew that what I did, I mean going to the prostitute was bad according to my religion. I never thought that I would get any disease. I looked at my father – he looked all right.

After I was told about HIV I could only relate it to my going to Thailand. I could not do it in Terengganu because people would know what I did. I go to more than one prostitute. No protection. The women never asked about safety, and I never know about condoms.

Many respondents said that they never heard of HIV or AIDS until they were informed about it either when they were at Pusat Serenti or prison. They knew why they were caught – dadah. They also never knew why they had to have their blood tested. They were caught for using drugs or possessed them. The term used by the prison personnel was ‘kuman HIV’ and ‘penyakit AIDS’. They were told that the mode of transmission was drug taking through injection and sexual activities with prostitutes or multiple partners. HIV is a strange word to many. It is something the drug addicts have to live with since being imprisoned for drug offences and being repeatedly informed about its connection with their past activities.
NMD said she could never forgive herself for what she did. She was 13 when her parents died in Thailand. She later followed her brother to Kelantan where he got her a job in a restaurant. The place was always full of people, and there were many young men who not only wanted to eat but also asked to take her out. She was totally naïve. As she began to like the job she also entertained some of the men. She liked the job since it not only gave her the money she needed but the pleasure of drinking alcohol and having sex with different partners. One day in 1998 her aunt persuaded to take her to Sabah. When she returned to Kota Bharu she decided to marry MO as she wanted to turn a new leaf. The marriage was fragile – they always quarreled. She could see that her husband was a jealous person and always suspicious of her character. They finally divorced after being together for nine months. But then she found out she was pregnant. She was caught not because of dadah but because she was having an affair with a man in Kota Bharu. On being informed of her blood test, she said to herself.

'I want to die…die. I am just 18 and pregnant. What will happen to me? I hope to die after I give birth'

'How could I get HIV? What is it? I was never on dadah. I only took alcohol'
ML blamed herself for the condition. She was working as a bar girl for three years before she was arrested for drug. Being a bar girl was the only job she could get. She tried to avoid sexual activities with her clients. She never wanted to destroy her chance of marrying someone nice one day. So she kept ‘clean’. One day ZK visited the bar and that was the beginning of an end to her job as a bargirl. She left the job for good and was happy to get three daughters.

Now in the prison she has been thinking hard about her three children. The prison officer quietly said ‘You have been tested for HIV, and, you have be found to have HIV’. I asked ‘What is it?’ The officer answered ‘It means you have got the virus HIV inside you. It must have been because you had taken drugs’. The news was indeed a blow to her. ‘How could it be? Drugs?’ These were her immediate response. Over the next few days she kept quiet. Then someone told her that a prisoner had died of AIDS. It struck upon her that she got HIV because she had multiple sex partners earlier prior to her marriage. Her marriage failed when she found out that her husband was also involved in drug, in fact, he was dealing in drugs. They separated and she found herself looking for her drug friends.

ZM, a son of a fisherman, has two brothers. As he recalled he never have any ambition during his childhood days. He never imagined what his future would be. He dropped out of school when he found no purpose in the school activities. Since he needed money to support his livelihood he got himself to be a fisherman, a job he found it easy to try. He told us how he started the drug habits.

For a few days I was out at sea with the other men. When we returned to the shore I would have some money. There weren't much to do in – I mean not many things that I could spend my money on. Then, one day I followed 'Abang Mang'. He introduced me to his friend and to ganja.

From then on he was gradually pulled in into the drug-addicted group. He found the group sociable and always willing to share what they possess. They used needles to inject heroin into their body. He felt 'good' about it. Since 1974 he had been caught four times for drug use. He entered Penjara Marang in 1996 and soon was informed that he had contacted HIV. He said ‘I was a little shocked. I wondered what has drug got to do with HIV. Gradually I had to accept my fate
because I had forsaken everything to get dadah. We shared needles. I could have got one of my own but it was too troublesome to go to a pharmacy. Since someone had got one already we just borrowed from him.

Another respondent, KW is also a fisherman. He got about RM40 per sale of fish once they brought back their catch. He said he was a quiet man – never talked much with the other while they were out at sea. One of them seemed to be a ‘know all’ guy. He would tell of the different girls he slept with. He kept telling the others that ‘One must know how to choose to get the right taste’. Well, it didn’t interest me.

Yet one day I had so much money, and I thought I wanted to travel to Thailand to visit a friend there. I was there for a week. On the last day my friend persuaded me to accompany him to a massage parlor. It was the beginning…

25-year-old AM from Kuala Terengganu had attained an upper secondary level education at an urban school. Being the youngest child, he spent more time at home and frequently helped his mother with the household chores. Though he wished he could become a soldier, he did not like school. The school expelled him. Talking about his first experience with drug.

My brother was a ‘kaki dadah’. I saw him hide the thing in the cupboard. One day he caught me meddling with it, and he immediately warned me ‘mu jangan cuba benda ni! Mu tau? Biar Abang sorang cukup...jahanang...(Don't you try this thing. You hear? Let me be the only one...the culprit...)

Instead of obeying he stole it when his brother wasn't around. He was nine years old then. After doing it for eight years on a more or less regular basis, he turned to injection as the mode of addiction. It had occurred to him that it might do harm but he continued because of the pleasure he derived from it.

Trying dadah is not mainly due to the influence of friends. More than anything it was curiosity. Staying together in the company of friends and observing the way they took dadah stimulated some respondents to try heroin. Explained a 28-year-old male.

I like my friends who stay with me. They like me too. They never tell me what they take and why. I asked them. ‘It's something that you enjoy’ they said. Then I asked ‘Enjoy – how?’

Months later I asked to try it. So they gave me. And I began to enjoy it.

3.4 PSYCHOLOGICAL IMPACT ON SELF

Theme 3: Multiple prison entry
Most of those HIV-positive interviewed had been in and out of prison, which means that Marang Prison or Pengkalan Chepa is not the first time for them. As stated by the Prison officer “Every time we release them we tell them ‘Don't let us see your face again here!’ But a few months or years later we see them being brought back to the prison”. For some the first experience in a rehabilitation institution is Pusat Serenti (where persons caught with possessing dadah are sent to).

**SO**, a 30-year-old respondent who had been caught twice, once in Kuantan and once in Terengganu, gave his reason.

I was ever ready to change – I had promise myself not to go back to dadah when I returned home. Once again my family accepted me although I could sense the worry on my parents’ face. I behaved well spending most of my time at home. One evening my father confronted me. ‘Did you steal Pak Mat’s goat?’ I said ‘No, I did not.’ ‘The villagers are pointing at me – it's your son. It must be him! He got back from the prison, didn’t he?’ I tried to stay calm. But then there was another theft. And my father became furious. He said ‘Our family does not hate you, but the villagers are putting all the blame on you!’ My kampung hated me. So I went back to my dadah friends. They welcomed me. Soon I got back the habits again. The police caught me for possessing dadah and sent me to this prison.

To **WA**, a 35 year old from Pahang, the prison is what he calls ‘tempat’ (place)

I feel safe here. My drug friends outside cannot influence me. Inside I have the time to repent, to ponder over what I have done. They give us religious lessons. For the first time in my life I began to pray.

Well, this does not mean I never prayed before – I did when I was small. The prison is my second home. You can say I have two homes – one in the kampung and one here. I behave myself so they let me out. But life in my other home is not the same – I’m a stranger. So I purposely did something - I stole to get caught. This is my ‘tempat’.

Entering and existing the prison more than once may appear habitual to the outsider. However, the reality is something related to the social world lived by the inhabitants of prisons. According to 39 year old **AA**:

I've been in and out of prison – in fact this is my 9\(^{th}\) time. Why? Do I like to go into prison?
I want to change – every time I'm caught I promise myself to hidup semula (live again). I leave one prison and I leave the district. In another area I look for jobs. No, there is nothing out there but bad company. There I go again – drug, stealing, drug...and finally they (the police) catch me again for drug possession. I hate drugs, yes I do hate it! But it's the only thing that means something to me. I get friends because of drugs...I lose friends because of drugs. We live with drugs.

**Theme 4: Imprisonment and its reality**

To many prison entry has become regular affairs. Pusat Serenti has given many an experience to live with drug users and addicts of various categories. Life in Pusat Serenti is liken to house confinement for minor offences. The inhabitants are called residents. Unlike being in the prisons, those who are sent there are liken to criminals (by virtue of the law). Irrespective of whether the person is caught for using dadah or possessing dadah, all are treated in the same manner. They are prisoners in the eyes of the public. They may not be criminals – just prisoners who must be confined and controlled. So they have to obey orders from the authority, and if they disobey they would be punished.

In reality the prison is another social world. It's a different social world compared to the ones outside, but it is a physical environment where people learn to behave differently. MM, a forty-year-old male, who has been in the Marang prison for three years, says this about his imprisonment.

I get used to be a prisoner. In fact I have been a prisoner for seven years. I've been in and out of five prisons – all because of drug. The drug is part of me; it's like my belongings. I stay in the prison and I'm free from dadah. But if I'm free and I go back to society I cannot free myself of dadah.

Here we share the same fate. We are ex-drug users. No one is different. We try to be good – this is why we are here. We love this place but we do not want to die here. It's a good place while we correct ourselves. But we want to die outside with our family. Yet the prison officials would pass remarks such as ‘you have HIV – you're getting AIDS. You’ll die you know’

We have HIV. That’s why we are segregated from the others. We can do things to occupy our time, but we have to be careful-we must not bleed.

What about our families outside? We do miss them. We can write to them, but they very seldom reply. It’s as if we are not part of them anymore.
Theme 5: Aspirations and hopes

Being caught again and again could have been a strong factor why most respondents thought they would change for the better. The other reason could be the support they get from their family members. Says a medical officer, ‘the moral support especially from the family members is the miraculous cure in stimulating patients to fight AIDS thus lengthening their lives (Mingguan Malaysia Nov. 2003). ZZ, a 29-year-old male, responded to this topic by saying.

I was hoping my family would visit me one – maybe during Hari Raya. But no one came. I wrote to my sister twice. I told her I was sorry for causing shame to the family and that I wanted to be a new person after my release. No one wrote back.

I feel that no family would want to accept anyone with a record like me – drug, stealing, sexual activities. I believe most families and society too are never ready to accept people with HIV.

What I wish most is to tell my family that I have HIV. But it’s going to be worse for them. Already people have stigma toward drug users. Now drug users have another problem, HIV or AIDS. What do you think?

It is the Prison’s policy to counsel prisoners in preparation for results of their blood tests, and also to encourage them to inform their family members of their HIV status. This is done with the purpose of preventing the transmission. In reality this is a hope than anticipation. Thirty one year old RM, who has been in the prison for six months, says,

Should I tell or should I not tell? Every night I will say ‘I must tell my family – at least my sister because she is so dear to me’. But in the morning when I think of how prisoners with HIV are treated I change my mind. We are made to appear there is no future for us so long as we have HIV.

What good will it do? We have to change ourselves…Here we are given training – we can try to do what we have learnt outside. To avoid people’s wrong perception of us, we cannot tell them we have HIV. No one wants to talk to us.

The present and the future of HIV and AIDS preventions are very much related to how society labels the persons associated with the problem. As much as the problem is rooted in their cultural context, so is its manifestations, stigma. As
succinctly stated by Pataki-Schweizer (in Haliza & Pataki Schweizer 2002) ‘Stigma is eminently “cultural” in the sense that it is cultural coded, learned and valued”. This statement attests to the reality that respondents express about their aspirations and hopes, both while they are in prison and after release.

3.5 FOCUS GROUPS DISCUSSION

The focus group discussions were held to find out about ‘individuals definition of problems, opinions and feelings, and meanings associated with various phenomena.’ In this study the groups were asked for their opinions and perceptions about HIV and AIDS, drug-taking and sexual behavior.

**Topic 1: Understanding about HIV/AIDS**

The discussions began with ‘What was your first reaction when you were first told you had HIV’. One participant by the name of R had no hesitation when he said ‘They told us that HIV is a disease. Well, if so why wasn’t I sick. I should tell here that since they (the Prison Dept.) told me I got HIV I have been okay – no serious illness.’ N agreed on this ‘To me a disease, be it HIV, AIDS or TB is just a disease. A disease can kill but a person can die because of other reasons. In this country so many people die because of road accidents. They say we will die of AIDS. Who knows?’

The problem with AIDS is that we accept our fate. If we don’t have AIDS we might another disease – we don’t know. The trouble is people condemn us. They say we are the ones who bring the disease to society. May be we have been bad in our younger days, and we know we should face the consequence. Never mind us, but the government should take care of our young brothers. Tell them not to try dadah.

We are not having AIDS, yet we are being discriminated. They say there is no discrimination, but we have to stay in different block. We cannot eat together with other people. I feel we are being treated unfairly for our past doings.

**Topic 2: Prison’s management of HIV-positive inmates**
There is a clinic that we can go to if we get sick. For me, I’ve been there twice, and I think I would not go again. What we get is the same medication for every illness.

They do send our inmate friends to the hospital in times of emergency. At other times we have to wait to see the doctor. At night if we feel sick we try to bear as long as possible. In the morning we might go to the clinic.

We do not know how long this disease is going to affect us. The other time some people said to us not to despair. There might be hope if we take care of our health now. So I think this is what I’m going to do. That’s why I play in the field so that I’m strong.

Most said that they find the religious programs conducted by the Prison Department to be of help to them. According to one respondent ‘since I’ve been here I know about my religion better. What a difference from what I knew when I was a kid’.


**Topic 3: To reveal or not to reveal their HIV status**

Most would prefer not to tell their family about their HIV status. They think their family must have been emotionally disturbed when they become drug users and are serving their sentence in prison. Some might tell a close friend or family member about their infection. But the majority prefers not to let others know about it. They fear the public would further stigmatize them and therefore they would lose their chance of making a change to their lives.

**4.1 IMPLICATIONS**

One side of the story has been made available in the study. There are undiscovered data on the side of the other persons/partners with whom the respondents have had experiences in drug-taking and sexual activities. The stories illustrate the past situations lived by the respondents – family disintegration, loosening of family and social ties due to social and economic
change, the moving out from traditional base (kampung) to urban base where social ties are freer. Hence, the data is provides useful insights into the ‘social ills’ in specific cultural environment.

The HIV/AIDS stories are about socialization process at family, school, and societal levels. HIV infections occur over a long time, during which time the individual is undergoing physiological, mental and psychological changes. They might never know the so-called ‘high-risk behaviors’ in their childhood and adolescent years. Hence, it is vital that health education be imparted to susceptible groups, particularly children and young adults.

Drug taking is only one facet of the web of interacting factors that contribute to a person's susceptibility to HIV. Each facet is a subculture by itself, and as such requires further depth understanding. The other subcultures include drug taking through needle sharing and sexual activities. Each in turn needs to be studied in-depth to reveal patterns which can explain the probability of infection among those involved in risk behavior.

Another implication of the study concerns those who share their life with the HIV-positive persons. Their sexual partners (married or unmarried), and their children have to bear the consequences of the problem. In light of evidence that children get infected through their mothers, there is urgency to make HIV-infected persons fully realize of the consequences of their behavior to their family and society at large.

5.1 CONCLUSIONS

In-depth interviews are useful in gaining better insights into such complex problems as the HIV infections and their manifestations in AIDS. Whereas quantitative analysis will reveal distributions and associations in terms of numbers, qualitative data allows for the underlying factors and the cognitive and psychosocial processes contributing to risk behavioral factors be discovered. While interpretations of qualitative data are limited to the context of study, qualitative research has given both researchers and participants to voice their
experience and to give them meaning. Some might argue whether there is truth and validity in the responses. The truth depends on the contexts and how much the persons attach their emotions to the events and activities they participated in.

REFERENCES


BALGOS, C C A (2001). Drugs, Death and Disease: Reporting on AIDS in Southeast Asia. Philippine Centre for Investigative Journalism and UNESCO.


• Prepared timetables
• Checked interview formats and photocopied
• Visit to prison according to schedules
• Meeting with prison authority prior to commencing research
• Begin research in arranged rooms (with tables and watched by prison guards)
• Explain purpose of interview and request respondent to read/sign consent form

Talking with villagers in Terengganu

One day we went in to visit an HIV-positive person in his village. He was inside getting ready to leave the house. We knew he was uneasy. We wanted to talk to him more but he made an excuse that he got something urgent to do. He looked normal and healthy. He
worked as a long distant lorry driver. We did not begin to ask him anything about his life and activities. We could see that he was restless once we said that we came to talk to people about drug addiction.

Instead we talked to the father. His father was talkative and soon we found him eager to tell us that there were young people who were addicts. Referring to HIV “No, no. Yes the youth have got the ‘disease’ (hisap dadah), but AIDS – no no. None of the youth got AIDS!

The tourists bring in aIDS. Look at them – they are so free. They go to our islands, and they do what they like. They don’t dress decently. Our youth like to follow their styles.

INTRODUCTION

Global, Regional, Local Scenario

- CDC
- Health statistics from SEA Region (WHO)
- Malaysia

HIV/AIDS is widely perceived as a social problem as it is related to human behavior – sexual practices and taking drugs. “AIDS is an epidemic linked to social ills. It cannot be seen outside of the context of the social norms that shape human sexuality and the social forces – such as poverty, conflict, and the powerless of women and children – that make societies vulnerable to the disease.” (PCIJ 2001)