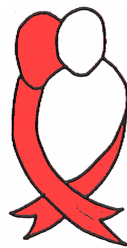


Documentation of Human Rights Violations against People Living with HIV/AIDS in Indonesia

A Peer-Group Documentation Project



Spiritia Foundation



Joint United Nations Programme on HIV/AIDS
UNAIDS
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Acronyms and Abbreviations

APN+	Asia Pacific Network of People with HIV/AIDS
ARV	Antiretroviral (drugs)
AusAID	Australian Agency for International Development
IEC	Information, Education and Communication
NAB	National Advisory Board
NGO	Non-governmental Organisation
OI	Opportunistic infection
PLHA	People living with HIV/AIDS
STI	Sexually transmitted infection
UNAIDS	United Nations Joint Programme on AIDS

Executive Summary

Human rights violations against people with HIV and AIDS (PLHAs) in Indonesia have frequently occurred over the last decade, including by mass media and the authorities. So far such violations have been seen as occasional incidents and therefore they have not been taken seriously or addressed systematically. A documentation of AIDS-related discrimination and human rights violations was carried out by the Spiritia Foundation, the Indonesian National Peer Support Network for PLHAs. It is a part of the APN+ 's project in four countries, the others being Thailand, The Philippines, and India. Indonesia is the first country to complete the documentation, with funding from UNAIDS, AusAID (the Australian foreign aid agency) and the Ford Foundation.

The main objectives of the project were to:

- Systematically collect data on AIDS-related discrimination in Indonesia.
- Produce a report detailing the nature, extent and pattern of such AIDS-related discrimination.
- Train HIV positive people in research and documentation of AIDS-related discrimination.

A questionnaire was used to collect the data. The questionnaire was developed by APN+ members and had ethics approval from UNAIDS and Udayana University in Bali, Indonesia. This questionnaire has over one hundred questions covering possible discrimination in the areas of health and treatment; privacy; liberty and security of person; inhuman and degrading treatment or punishment; employment; education; family; and self-determination and association.

A National Advisory Board (NAB) consisting of a leading AIDS activist, a government official, an academic, and representatives of a funding agency and an international organization assisted the project coordinator and interviewers.

Positive people were recruited and trained by other positive people as interviewers in data collecting. One aim of the training for interviewers was to raise their awareness of human rights and to provide them with research related knowledge, skills, and information on ethics.

Findings indicate that the major problem to be addressed is stigma and discrimination in the healthcare sector, including in counselling and testing. In addition, the survey identified a number of social support problems. Documentation alone brings little benefit to stigmatised PLHA; it is the follow up advocacy that is crucial for change. An advocacy strategy is now being developed, in cooperation with the National Advisory Board.

Background

Research location:

Indonesia. People from the provinces of Jakarta, West Java, Jogjakarta, East Java, Bali, West Sumatra, Riau, South Sulawesi, Papua, and East Nusatenggara were interviewed in West Java, Jakarta, Bali and South Sulawesi. The research took the form of a participatory survey, carried out by five peer interviewers, coded F, P, R, Y and N.

Research period:

The research was carried out from July though October 2001, with data collected simultaneously by the five interviewers at the locations noted above.

Respondents:

The respondents were 42 people living with HIV/AIDS (PLHAs) willing to participate in the research by being interviewed, and identified primarily by “snowballing” recruitment. This represented all those who could be identified and were willing to participate. It is accepted that this does not constitute a statistically representative sample; however this is not intended to be a quantitative analysis, and percentages in this report are quoted to allow readers to understand the proportions more easily.

Research instrument:

The instrument for collecting data was a questionnaire completed by the interviewers based upon the interviews. Besides the multiple-choice questions in the questionnaire (yes, no, and not appropriate/no answer), the data collection also used a Likert gradation scale (rarely, sometimes, frequently, always and no answer) and in-depth interviews to obtain accurate information.

Data analysis:

The data was documented after cleaning, processed with SPSS 10.0, and analysed. Qualitative analysis was performed on statements and clarifications of the answers to multiple-choice questions.

Results of the Study and Discussion

Demographic data:

During the period July through October 2001, 42 respondents were interviewed. They consisted of 20 males, 20 females, one transgender, and one with sex not reported. The average age of the respondents was 26.5 (range 16 to 42 years); most respondents were in the age range 21-30 years. Marital status, formal education and employment of the respondents can be seen in table 1 (demographic data).

Table 1. Demographic data

No.	Item Detail	Frequency (n)	Percent (%)
1.	Gender:		
	Male	20	47.6
	Female	20	47.6
	Transgender	1	2.4
	Not recorded	1	2.4
2.	Age:		
	Youngest	16 years	2.4
	Oldest	42 years	2.4
	Average	26½ years	
	Age groups with greatest number	21-30 years (24)	57.1
3.	Marital Status:		
	Legally married	14	33.0
	Widowed	5	12.0
	Separated/Divorced	2	5.0
	Single	21	50.0
4.	Education:		
	Primary School	9	21.4
	High School	22	52.4
	Tertiary Education	10	23.8
	Not recorded	1	2.4
5.	Employment:		
	Student	1	2.4
	Unemployed	13	31.0
	Self-employed	8	20.0
	Other	16	39.0
	NGO Staff	3	7.0
6.	Interviewed in home town		
	Yes	21	50.0
	No	21	50.0
7.	Place of interview		
	Private room	19	45.0
	Home/residence	9	21.0
	Public place	8	19.0
	Other	5	12.0

The even numbers of respondents from each sex (20 men and 20 women) indicate that the information collected will not be gender-biased. With regards to age, the respondents in this research reflected the general prevalence of reported infections according to the WHO, i.e. age

between 20 and 49 years, with the peak between 20 and 30 years. Most of the respondents were educated to high school level (over 50%); the remainder had either primary school or tertiary education, with almost equal numbers of each. This proportion among the PLHAs reflects the education level of the general population, and will assist in efforts to look after PLHAs, especially in prevention, care and support by peer groups (peer support).

In regard to marital status, half (50%) of the respondents are still single, with some of the remainder married (33%) and several separated or divorced.

The place for the interview was chosen to be comfortable for the respondents, to provide an atmosphere conducive for answering the questions. In addition, a comfortable place helped the interviewers to capture the expressions of the respondents and note their psychological reactions. During the interviews, much of the discussion was about the HIV status and the experiences related to this status, so whether the respondent was aware or not, it opened certain old wounds which was not always easy for them. In the research, most interviews were carried out in private rooms (45%), or in the houses or homes of the respondent (21%), but they were also carried out in public places (19%), for example in parks, which did not hinder the interview process.

Health matters and the right to health

The respondents were asked to answer 20 questions intended to identify PLHAs’ current health status, health facilities and experiences related to the right to health. The right to health is defined as the right to receive nursing care, treatment, opportunities to take part in clinical trials of antiretroviral drugs and opportunities to obtain health insurance.

From 42 respondents, 50% considered that their health condition was good, more than 26% stated it was ‘just okay’, while 24% of respondents replied that they were in poor health. These statements about health condition are naturally subjective, being based upon what was felt by respondents using their own assessment. Because of this, it is not clear if reported ill health was due to their HIV infection or if there were other medical problems.

Among 22 respondents who had known their HIV status less than two years, more than 50% reported that they were in good health, while six respondents (25%) stated that their health was poor. Among the four respondents who had known their HIV status between six and 11 years, two stated they were still healthy (up to the time of the study), one’s health was ‘just okay’ and one reported ill health. Of the 14 who had known their HIV status between two and six years, seven noted good health, six ‘just okay’, and one was in poor health (see table 2). However, attempting to relate the length of time respondents have been aware of their HIV positive status with their current health condition may not be relevant, because the period of awareness of HIV status does not necessarily show how long they have actually been infected.

Table 2. Health condition with reference to period HIV status known (n = 40)

Period HIV Status Known	< 2 years	2-6 years	6 - 11 years	Total
Health Condition				
Good	12	7	2	21
Just okay	4	6	1	11
Ill	6	1	1	8
Total	22	14	4	40

To address health problems, 40% of respondents were taking some form of medicine. Among the 17 who were taking medicines, six were using them to prevent or treat opportunistic infections (three being still in good health), four were using traditional medicines (most of these

by those who reported 'just okay' health), and six used other treatments, such as vitamins. Only one respondent was receiving antiretroviral therapy, and this respondent reported poor health, (table 3).

Table 3. Use of medicines with reference to health condition (n = 17)

Type of medicine	ARV	OI Prophylaxis	Traditional	Other	Total
Health condition					
Good		3	1	6	10
Normal		2	3		5
Ill	1	1			2
Total	1	6	4	6	17

Note: ARV: antiretroviral; OI: opportunistic infection; Other: vitamins

From the 42 respondents, 31% had been refused treatment by a hospital or a doctor, 15% experienced treatment delays, 9.5% had been recommended by friends, family or health care workers not to seek health care, and 5% reported that they were required to pay extra for treatment. As no respondents had health insurance, none reported being refused insurance coverage or refusal to pay an insurance claim after their HIV status was known.

Access to antiretroviral (ARV) drugs was very limited, including access to clinical trials of such drugs. Two respondents reported taking part in clinical trials of drugs, although only one could remember the name of the drug, knew the objectives of the trial, the risks and effects of the drug being studied, and only took part in the trial for 10-11 months. Both had requested to leave the trial, but one was still taking the treatment at the request of the mother. ARVs are very expensive and not easy to use, requiring close monitoring by doctors and laboratories, and there is a relatively low demand for such drugs by PLHAs. The high price and low demand have a mutually reinforcing effect, resulting in lack of availability of ARV services.

Personal freedom

Thirty-two questions were directed towards assessment of the personal freedom of the respondents. The questions in this section were connected with violation of personal rights in relation to the HIV test and HIV status.

Results: Respondents were asked the reason why they wanted to be tested. Seven stated that they personally wanted to know the result, three for reasons of employment, three as a result of opportunistic infection, three because they knew their partners to be infected, one as a result of referral to an STI clinic, and one because she was pregnant and her partner was infected. The remaining 23 quoted other reasons (not recorded).

Tests were most frequently carried out in hospitals (38%), private laboratories (17%), clinics of private doctors or specialists (14%), while 31% reported tests carried out in other locations (not recorded). Sixty percent stated that they were ready to be tested at the time of the test, while 38% were unready. Seventy nine percent reported no coercion, while 17% felt coerced. The majority (55%) reported that they were given no information before the test. For those who were provided with information before the test, 63% of such information was in the form of counselling, 11% general advice and 5% other information.

The test results were given to respondents by: doctors (36%), social workers (21%), nurses (5%) and others (31%). Fifty seven percent reported that there was a third person in the room at the time that results were given. The third person was a family member (33%), other friend (25%) or others (29%). In most (63%) of the cases in which there was such a third person in the room, this was not at the request of the respondent. At the time the test results were given, 43% received information in the form of counselling, 19% as general advice, other information (24%), both

counselling and general advice (5%) and counselling, general advice and other information (2%), with 7% of respondents not providing a response.

Respondents were asked about the confidentiality of the test results. Twenty-six stated that their test results had not been given to others without their approval, while 16 respondents reported that others were informed without the consent of the respondent. In the questionnaire there are ten choices of groups of people to whom test results are often given without approval of the person concerned: health care workers; family members; co-workers; spouse; sex partners; media; government officials; NGOs; police; and others. Respondents whose results had been passed on without their approval reported that this was to health care workers (3), family members (2), both health care workers and family members (4), and health care workers, family members and NGOs (1), while four reported information given to others. One reported that many people were aware, including co-workers, spouse, media, and government officials.

In connection with the feelings of the respondents after they were aware that others knew of their HIV status, their responses were very variable. Some didn't care and accepted it; others were shocked, upset, embarrassed, disappointed, hopeless, in denial, afraid of rejection, and feeling uncomfortable, some even had thoughts of suicide.

Sixty percent of respondents had revealed their HIV status to friends, siblings or others, with whom they normally shared their sorrows and secrets. In fact most (67%) of the friends or family members with whom they shared respected their confidentiality, and only 30% told others. Even then, the information was only shared with other family members and close friends.

After knowing their HIV positive status, most (93%) did not experience discrimination in the family, and although three respondents did experience discrimination, two of these respondents stated that such discrimination rarely occurred. Discrimination in social activities in the community and discrimination by superiors and co-workers also rarely occurred. This contrasts with treatment in health care settings such as hospitals and by health care workers where the numbers of cases of AIDS-related discrimination were higher, with 35% experiencing different treatment compared with other patients. Even so, 59% of these reported that this was rare, 29% fairly frequent and only 12% very frequent. Among their friends, 83% did not experience discrimination, although 12% (five respondents) reported different treatment by their friends, with 50% of such behaviour occurring frequently.

Liberty and security of person

Ten questions to respondents assessed the personal security of PLHAs. Discrimination against PLHAs can cause a reduction in feelings of liberty and threats to personal security.

Between 2.4% and 7.1% of respondents had experienced violence in the form of eviction from public places, eviction from housing, threats of injury, actual ill-treatment, coercion in medical procedures, or requirement to reveal HIV status when leaving or returning to their country. Although the numbers of cases of the latter are small, this is probably because few respondents had ever attempted to travel overseas. Twenty-nine percent of respondents had been ridiculed/insulted and 12% had been isolated or segregated because of their HIV status.

Inhuman and degrading treatment or punishment

Three questions were directed to assess such situations. In response to the question whether they were aware of others who have been tested without their consent or knowledge, 40% answered yes and 55% no. When asked if, as a result of their HIV status, they had been denied benefits/privileges/services given to others, 68% answered no, 26% yes. No respondents reported being charged sued or brought to court on an offence or act related to HIV status; one respondent did not answer this question.

Right to employment

Respondents were asked nine questions to assess the right to work as experienced by PLHAs. Most (83% or 35 respondents) had not experienced workplace discrimination related to HIV status. However, many respondents have never been employed or are self-employed; responses to this question might have been different if more had been employed. Nevertheless, seven respondents did report discrimination in the workplace. The form of discrimination experienced included loss of work (one respondent), change of duties or responsibilities (2), income reduced (1), and feeling uncomfortable in the work place (2). None reported loss of opportunity for promotion or being offered early retirement.

Right to marry, found a family and form significant relationships

Nine questions were used to assess this. From 37 respondents who replied, three had been tested while pregnant. Nine respondents had been abandoned by a partner because of their HIV status, though none of these had been financially dependent upon the partner. Most (98%) reported continued financial support from family members. Following HIV diagnosis, 41% (16 respondents) were advised not have a child, and 70% of these stated that they were given adequate information on how to prevent transmission of HIV from mother-to-child. Only one respondent stated that she was forced to abort or be sterilised.

Right to education

There were two questions about the right to education. From 34 responses, most (29) stated that they had never experienced discriminative treatment related to their right to education, one reported discrimination, and the remainder said the question was not applicable or did not respond. There were eight respondents who did not complete this section.

Right to self-determination and association

There were nine questions regarding right to self-determination and association among PLHAs. Discriminatory treatment against PLHAs in the form of exclusion from membership of an association, or prohibition to associate with PLHA groups did not occur, according to most (98%) of respondents, and 63% had been referred to support groups. Twenty seven percent (11/41) of respondents had experienced being involved in a decision-making committee related to HIV/AIDS, and all of these considered such involvement was beneficial. Ninety percent of respondents knew of PLHA support groups, and all stated a wish to associate with such support groups in the near future.

Results of observations and comments (by the interviewers)

There were six questions related to observations by the interviewers about those they interviewed.

Interviewers stated that more than 50% of respondents required referral, mainly for counselling (33%), legal matters (17%) or both counselling and legal (33%). When asked to assess if the respondent was a potential candidate for case studies, only 35 responses were recorded and of these, 48% stated this was not necessary, while 36% reported a need to follow up.

Results of other observations:

Interviewers were provided with the opportunity to note their observations about the respondents while the study was being carried out. Only 24 questionnaires included such observations, and most observed depression and a closed attitude (five respondents each), hopeless/uncaring (3), angry (3), anxious (2), talkative (2), appeared tired (1), and in denial (1). On the other hand, three appeared calm, and two were reported as spirited and wanting to take part in activities related to HIV/AIDS (2).

Conclusions

Although this study was carried out in towns and provinces in Indonesia that have many health care facilities or hospitals, such as Jakarta and its environs, Bali and Makassar, which are centres of medical education and clinical studies, in fact this study shows the unreadiness of such health care facilities in these places to handle PLHAs. It appears that the biggest problem is not from the medical-technical viewpoint, but indeed mainly as a result of the discriminative attitude and behaviour of the workers towards PLHAs. This is evidenced by more than 30% of respondents who had ever experienced rejection by health care workers and 15% whose treatment was postponed because of their HIV status. Perhaps because of fear of such discrimination, one in ten respondents had been advised not to seek health care help by friends, family or health care workers themselves. The lack of readiness to look after PLHAs is also evident from the disregard for the correct procedures in connection with counselling and testing for HIV by staff in test sites, (table 4).

Table 4. Summary of discrimination experienced by PLHAs related to their HIV status

Type/place discrimination occurred	% (n = 42)	Remarks
Health facilities	31 15	Rejected by hospital Treatment deferred
HIV Test	17 38 55 57 63 of the above	Coerced into taking test Felt unready for test Not provided with explanation for test Results of test given with others present Presence of third party not at request of respondent
Family	7 12	Not included in activities Placed in separate room
Community	2	Not included in activities
Friends	12	Treated differently
Workplace	14 2 5 5	Discriminated against in the workplace Discharged Duties changed Income reduced
Public places	5 7 2 29	Rejected/moved Asked to move house HIV status at immigration Mocked/insulted

In contrast to health care facilities, discrimination against PLHAs in the family, community, among friends, and in the workplace, while occurring, does so at a much lower level than in health care facilities (table 4). Jakarta, Bogor, Bali and Makassar are places where NGOs concerned with AIDS have for many years carried out their activities, both in the form of IEC

and in support for PLHAs. However, such activities do not seem to have been successful in preventing discrimination against PLHAs.

Recommendations

Families, friends and the community in general will follow the example of the actions of the health care workers caring for PLHAs. If the actions of such workers still show discrimination against PLHAs, as revealed by this study, then general discrimination will continue to occur. Furthermore, health care workers are members of the community, so what they do at least partly reflects the general attitude of the community towards PLHAs.

One approach to addressing discrimination against PLHAs is to increase the understanding of HIV/AIDS by the public, especially among health care workers and particularly about care. This in principle emphasises the importance of universal precautions, so that confusion does not arise. In addition, more counsellors must be trained so that implementation of testing and counselling for HIV can be carried out following appropriate procedures. Increased understanding about HIV/AIDS is needed to change the attitude and views of the public towards HIV/AIDS and PLHAs, and ultimately reduce discrimination against PLHAs.

Notes for researchers:

Although the questionnaire had previously been tested, at the time of collection of data there were several questions that were unclear, resulting in difficulties in interpretation. For example before the question about rejection of insurance, it would be better if the respondents were asked if they had ever had insurance or not. Similarly with questions about behaviour towards children; it would be better to have a question which asked if the respondent had children or not, if the children were natural or adopted, and only then ask about what was experienced by the children. In this study, more than 50% of respondents were not married, so that if there had been a clear structure to the questions, this would have provided clearer answers that could be more easily analysed. In addition, there must be assurance that the interviewers can capture the information that is given by the respondents and determine the answer before filling in the questionnaire. This especially applies to the questions with choices of answers: Yes, No, Not Applicable/No Response. For example: if the respondent has not been employed or doesn't have children, or has never been overseas, how can we hope for sensible answers to such questions from their personal experience. Thus, the interviewer must always remember and refer to the respondent specifically, whether the question is appropriate to be asked of the respondent. We can be sure that the result will be different if responses are not from personal experience.

Appendix 1: Case Studies

Case Study A

From 1997, Dina worked in a red-light area that received special attention from the Social Welfare Department. One day a sample of Dina's blood was drawn; the official who drew the blood did not explain the reason or the purpose for this. Dina submitted to this to avoid hassle. After several months, the official came back and asked Dina to go to the community health centre. The doctor at the community health centre then said it would be best for Dina to have a contraceptive implant. For the second time, Dina complied with the request.

Several months after this, Dina decided to marry her partner. Dina was amazed at the attention paid to her marriage by the officials concerned. Several days after the wedding, Dina felt that she was receiving abusive treatment from her new neighbours.

Finally, Dina learned that her wedding photograph had been published in a newspaper, together with her name and details of her village. The newspaper presented it as news of the marriage of a person with HIV. Dina was very surprised, because this was the first she knew that she was HIV positive.

The neighbours asked Dina to move immediately, and if she didn't they threatened to report to the owner of the house. The next day, the owner came and evicted Dina and her husband. They moved to another village, but a policeman demanded that they should not live in that village. Similar situations happened six times.

Dina's marriage was disrupted, but with support from an NGO, Dina's husband finally decided to stay with Dina. Later they decided to have a child. However, the doctor who inserted the contraceptive implant looked at her medical record and stated that he could not remove the implant because Dina was HIV positive. He justified this by saying that the equipment used to remove the implant would have to be destroyed and it was in limited supply.

To increase her income, Dina opened a salon in her house. Accidentally, a child became aware that Dina was HIV positive, and without understanding the meaning told one of Dina's customers. In this way the news was spread, with the result that Dina's customers did not come any more; sadly Dina had to close down her business.

Case Study B

Ratih has lived in Jakarta for a long time. Around September 1998, she found she had cancer, and was admitted to a hospital in quite a bad state. At that time, she was asked to have an HIV test on grounds connected with her sickness. But she felt somewhat pressured, because if she had been given information about HIV through counselling, she would not have agreed to the test. On the other hand, she felt that the questions about her behaviour were very judgemental. After the test, Ratih had to fetch the results from the hospital laboratory and read them herself, because there was no counselling.

Since the result showed that she was HIV positive, Ratih didn't want anyone else to know. But in fact the results were leaked widely, with the result that her oncologist refused further treatment. Even the catering staff at the hospital who usually delivered the food refused to enter her room any more, and passed the food through a window. Before her diagnosis, Ratih was placed in a ward with 6-7 other patients, but after it was known that she was HIV positive, Ratih was moved to another ward alone. She was due to have lung and heart tests, but the staff member was not willing for the test equipment to be used on Ratih so the tests were cancelled.

Ratih was also included in research by the Health Department. About 50cc of her blood was drawn, but Ratih did not know why, and following this, she was given no news or information.

Ratih has joined a peer support group for people with HIV, based on the suggestion of several concerned doctors. As a result of meetings with her new HIV positive friends, she now has much greater will to live.

Case Study C

During the rapid detoxification at MK Hospital, Jakarta, the doctor in charge told my parents that there was something different about my body. He assumed that I might not only be using heroin, which was true, but that I was actually a poly-drug user. Without permission from either my mom or me, without any announcement or any document to sign, without counselling, the doctor took a blood sample from me and tested it. My parents and I didn't know what was happening, didn't know what the blood was tested for. How would I know? I was comatose, in the detox process.

The next day, when I was half awake from the effect of sleeping pills, the doctor came into the room, simply called my parents over to the corner, and told them that the result of the blood test was ready. Very easily, without any feeling of concern, the words "Sorry, she is infected with hepatitis C and HIV" came out of his mouth. After a few minutes, my parents, the doctor and a nurse came near to my bed and told me that I was HIV and hep C positive. The doctor told me as if he was telling me that I had got influenza; he was telling me as if it wasn't going to change my life. Neither my parents nor I received any counselling. I wasn't fully awake so my feeling was not really affected. I was a little bit shocked, but my parents were shocked. The doctor just told us to go home and make an appointment to meet an internist the next week. When my parents asked him about what they should do with me now, my parents were told to put my sisters in different rooms and to arrange separate cutlery and crockery for me. So... I went home the next day.

At home my feelings were chaotic. I couldn't sleep for ten days and ten nights; I just thought about what I was going to do with my life. My feelings were mixed up. I was confused, I was lonely, unmanageable, angry, sad, denying, disappointed, hopeless and desperate. I felt that it was useless for me to live anymore and I preferred, at that moment, to die. It was very hard for me to accept. In fact my life was already hard enough as a newly clean addict; now my life became even harder. Often I thought about my future, I am a female, an addict and infected by two viruses; who would marry a girl like me? Self-pitying. Ha..? I would get scared thinking that I would be dumped in the hospital bed and none of the doctors or nurses would want to take care of me, that nobody wanted to be my friend because I have the AIDS virus, what if I am sick and nobody supports me? All sorts of negative thinking came into my mind.

What did I do every day then? In the afternoon I went to work and helped my mom at her boutique. At night I cried, I mourned my life. Finally I decided to surrender all my life for my parents. I wanted to be a good girl and give all my life to them; it's my time to pay back. It didn't last long...

My parents did as what they were told by the doctor, we went to the internist. At the internist's office, I didn't get counselled. He said that, for now there's no medicine yet for HIV and hepatitis C but he was optimistic that there will be someday. He told my parents to do the same things as they were told before, to separate my eating utensils. So we went home.

At home, I was discriminated against, alienated and isolated by my family, because my parents did not get enough information about HIV/AIDS and they obeyed what the doctor told them to do. The doctor said, "Be optimistic, I believe that one day there will be a cure. However, for now just stay clean and live healthily." What kind of healthy life? Just physically? How about my mental, emotional and spiritual health? I felt lonely at home, I was like a stranger in the house, and I was sad, embarrassed, angry and struggling. I had no one to turn to, I couldn't talk to anybody, and I had no shoulder to cry on who would ever listen to me? I couldn't share my feelings and my status with my close friends or my family. I was afraid that they would keep their distance from me, so I had to keep it closed in my heart. I was able to stay clean for three months... then...

Finally I succumbed again. I started using drugs again. I skipped home with three TV sets to get some money. Drugs could make me forget all my problems even though only for a while. To remove my emotions of loneliness and anxiety, I was afraid to be alone, I did not want to feel lonely. This time I was away from home for just one week...

Case Study D

In 1995, Dr. S received a visitor who told him that a family member was HIV positive and had reached the AIDS stage. The visitor always took the HIV positive person to Australia each time he got an opportunistic infection. Not infrequently they consulted with the doctors in Australia by telephone.

Advising that such treatment could be obtained in Jakarta, Dr. S proposed M Hospital, since the CM Hospital was full. And since this was customary in management of patients, Dr. S did not expect any problem. However, once the patient arrived, he was not allowed to enter, with the reason given being that he had AIDS, and the health care workers at the M Hospital said they needed approval from the directors.

Following this, Dr. S met with management of the M Hospital and queried this. The hospital managers responded that the M Hospital was not ready to accept AIDS patients, and would need to wait another five years. So Dr. S offered help to train the health care workers at the M Hospital in care for AIDS patients.

Following completion of the training, another AIDS patient requested admission. He was admitted, but later M Hospital requested him to move to another hospital, because the hospital had no doctors capable of treating AIDS patients. In fact, Dr. S and two other doctors had frequently treated AIDS patients at the CM Hospital, and all of them also practiced at the M Hospital.

Later, a patient with breathing difficulties arrived, but Dr. S had to halt treatment because he had to go overseas to attend a seminar. Several days after he returned, after he had continued treatment of the patient with breathing difficulties, Dr. S heard from the patient's family that he could no longer accept patients with any illness. It transpired that the policy to prohibit Dr. S from practicing was issued by the M Hospital because Dr. S had treated AIDS patients there.

To solve the problem, Dr. S met with the management of the M Hospital. At the meeting, Dr. S explained that treating AIDS patients was in accordance with the doctors' oath and the AIDS control strategy. M Hospital should accept this. However, M Hospital stood by their policy.

Finally, Dr. S reported the prohibition on his practice to the Health Department and various other parties. After receipt of this information, many parties threatened a boycott of the M Hospital. Following attempts to defend themselves, the M Hospital management apologised and stated that they would no longer discriminate, and Dr. S was again allowed to treat patients there.

Case Study E

In Bali, in 1996, Reni's husband had a fever, and was taken to Dr. XXX and later, according to the doctor, he had died of AIDS. Following this, Reni found that she was HIV positive.

At the time that she was given the result, she couldn't believe it, denied the result, afraid. She wondered how her family and community would accept the result, would it be reported in the mass media, what about the stigma which would result if she became an object of reports in the media.

Later, Reni shared her status and that of her husband with her mother, whom she really trusted, but it turned out that her mother had already heard. Her mother had even been stigmatised by the community. Her mother had heard from a relation who was a doctor at the S hospital. This doctor was aware of Reni's status and that of her husband as a result of this being revealed by Dr. XXX during a doctors' meeting. This doctor/relation told the family, although Reni herself had not yet informed her family of her status or that of her husband because of concerns for the good name of the family.

Appendix 2: Project Framework

An English version of the Project Framework was not prepared. Please see original Indonesian version report for a copy of the framework in Indonesian.

Appendix 3: National Advisory Board

This research project was supported by a National Advisory Board, which consisted of:

- Abby Ruddick from AusAID/ASA
- Jane Wilson from UNAIDS
- Retno Windrati from the Pelita Ilmu Foundation
- Djoko Prayitno from the National AIDS Control Commission
- Chris W. Green from WartaAIDS
- Dr. Tuti Parwati from the Udayana University, Bali

Indirectly, the existence of the National Advisory Board indicated that the research was both national and international in nature. This facilitated the implementation in various sectors, as well as making the respondents feel safer. The National Advisory Board was also available to assist in accordance with its capacity in case problems arose during the research.

During the period of the research, no problems sufficiently serious arose that required the assistance of the National Advisory Board. There was one case of a misunderstanding with one respondent, but this was addressed with the project coordinator and the interviewer.

Appendix 4: Ethical Clearance



DEPARTEMEN PENDIDIKAN DAN KEBUDAYAAN
FAKULTAS KEDOKTERAN
UNIVERSITAS UDAYANA

JL. PB. SUDIRMAN DENPASAR

☎ 222510 Fax: (0361)246886 E-mail: fk.unud@indosat.net.k

ETHICAL CLEARANCE

No.: 178/J14.17/PL.06.10/99

This is to certify that the following study project entitled :

Living with AIDS in the Asia/Pacific:
An APN+ peer documentation and action research on social stigma,
discrimination and AIDS

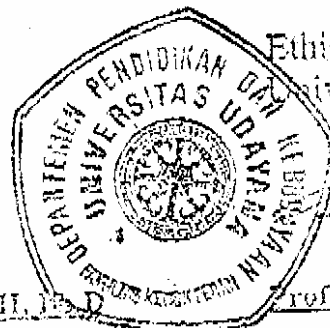
Country researcher: Tuti Parvati Merati, MD

has been evaluated in accordance with the ethical aspects in using human being as a
study subject and considered proper to be executed.

Denpasar, February 18, 1999

Dean
Medical School,

Prof. Ketut Spafa, MD, DPMH, FRCG



Ethical Committee Udayana
University Medical School,

Prof. Dr. Nyoman Adiputra, M.D: M.O.H

Appendix 5: Guidelines for Carrying Out the Survey

Please do not attempt to administer this instrument to other respondents without first familiarising yourself with the attached interview guide and completing the questionnaire once by yourself.

When you interview respondents, remember to ensure their privacy. Conduct the interview in a private place, preferably alone with the respondent.

Begin by administering the information sheet and consent form. Please make sure you read out this section and get the respondent's oral consent to participate in this study. You must get the informed consent before the interview. If the respondent refuses consent for the interview, please thank him/her and terminate the interview.

Boldly mark the number corresponding to the correct answer to each question in the third column. Some questions will not be applicable to everybody or a respondent may not want to respond. If the answer is "other" please provide a description. The timeframe of the questions is since the respondent has known his or her HIV status.

During an interview, if you feel that some follow-up questions are important, please note them down promptly in the space available besides each question for notes. You may remark on any significant observations about issues that arise in the interview and suggest modification of any questions, additional questions and difficulties in canvassing responses to the survey. If respondents have experienced instances of severe discrimination and are willing to discuss this in detail, you can probe the questions at the time of the survey or make a time to return for an in-depth interview later. Before case studies can be audiotaped, respondents must give further consent to this.

Sometimes while interviewing respondents you may face adverse reactions such as emotional outbursts, anger or hostility to the interviewer. If you feel you cannot continue, you should stop the interview.

Familiarise yourself with the list of local resources and contacts, which you have already prepared. If you need additional support or need to make referrals for medical, emotional or legal support, the local resource list would be helpful.

At the end of the entire interview, check each questionnaire for completeness and accuracy and note down all the questions and concerns expressed by the respondent.

APN + Human Rights Team

Appendix 6: Information Sheet

INFORMATION SHEET A (For Questionnaire Respondents)

(A copy of this information sheet is to be given to all the participants. The interviewers are also expected to read out the form if it is necessary)

Introduction

This information sheet briefly introduces the APN+ research study on AIDS and human rights. This study is being carried out by the Asia Pacific Network of People living with HIV/AIDS (APN+), with the financial support of UNAIDS.

Purpose of the Study

The study intends to collect information on AIDS-related discrimination and stigma experienced by people living with HIV/AIDS in selected Asian countries. The study will contribute towards a greater understanding of the nature of AIDS-related discrimination, and in particular, the extent, pattern, and context of such discrimination. This is the first time such information has been systematically documented in your country.

Procedures of the Study

APN+ would like to interview you as part of the study. All information collected is to be voluntary, anonymous, and confidential. No record will be made of your name, or other identifying details. If you agree to take part in the study, you have the right to withdraw at any time, and to request that any data the project has gathered from you be destroyed.

During the interview you will be asked about your experiences, as a person living with HIV, in areas such as health, employment, education, privacy, security, freedom from inhuman treatment, family life, and self-determination, via a detailed questionnaire.

The final report of the project will include the overall national context, statistical results from all the interviews with people living with HIV/AIDS and specific case studies to illustrate the nature of discrimination. This report will be used as a tool for change, for example in challenging health or workplace policy, community attitudes, or for legal reform.

Risks

Although we are taking all the necessary steps to identify and reduce any psychosocial risk in participating in this study, there is a low risk of breaches of your confidentiality. In certain circumstances a breach of confidentiality could lead to stigmatisation, such as losing social status, deprivation of services, loss of job, media exposure, losing family and community support, being targeted by the authorities, or pressured by authorities to disclose the status of other participants.

All interviewers are themselves, HIV-positive, are been trained in human rights documentation, and have signed agreements to protect the confidentiality of the participants. All data collected during this study will be kept confidential and stored in a locked filing cabinet in the office of the Principal Investigator (Name and contact details of P.I. in each country) until six months after the completion of the project, when all data will be destroyed.

Discomfort

There is the possibility that you may experience some emotional distress during the interview. You may decide to pause or stop the interview at any time, if necessary.

All the associates of this study have a primary responsibility to protect participants from physical and mental harm. In the event that you do need psychological or physical support (such as counselling or legal assistance), or advice concerning educational, health, or social support, a list of referrals to appropriate professional support services is available to you. A copy of the ethical principles guiding this project is also available on request.

Inconvenience

The interview process takes approximately 45 minutes to one hour.

Benefits to Participants and Others

APN+ hopes that the data collected in this study will contribute towards a greater understanding of the nature of AIDS-related discrimination experienced by people living with HIV; to understand the range of discriminatory attitudes and actions, and the pathways of AIDS-related discrimination and stigma. We believe that such data is essential in developing appropriate legal, social, cultural, and institutional responses to combat discrimination and human rights violations experienced by people living with HIV /AIDS.

Alternatives to Participation

If you prefer not to participate could you recommend somebody else who might want to participate in the study?

Appendix 7: Informed Consent Form

(Note: The final Indonesian version of this form which was used in the survey differs somewhat from this English, as a result of input from various parties. Please see original Indonesian version report for the form used.)

Informed Consent Form (For Questionnaire Respondents)

(Before beginning the interview, the researcher will read out this form, and leave one copy of the form with the respondent.)

My name is _____.

I am collecting data for the APN+ Human Rights Initiative, described in the accompanying Information Sheet.

This study is being conducted by _____ (Name and contact telephone number). If you have any questions about any aspects of the study, please feel free to contact them.

Before you answer any questions I would like you to know that:

- a) Your participation in this study is entirely voluntary
- b) You are free to refuse to answer any questions
- c) You are free to terminate this interview at any time.

The data collected in this interview will be kept strictly confidential and will be available only to members of the research team. Excerpts from individual interviews may form part of the final research report, but under no circumstances will your name or any identifying characteristics be included in the report.

May I seek your consent to interview?

(If the respondent declines to be interviewed, please thank the respondent and discontinue the interview.)

Thank you for agreeing to take part in this study.

I will now declare that you have given oral consent for the interview.

Has oral consent been obtained?

Yes / No

Name of the interviewer:

Signature of Interviewer:

Date of Interview:

Section 3 Right to Health**In this section the questions relate to your health and your experiences with treatment**

3.1	How would you describe your current health status?	[1] Good [2] Just okay [3] Unwell	
3.2	Are you currently taking any medication for HIV infection?	[1] Yes [2] No _____ [9] Not Applicable	Skip to 3.4 “
3.3	If yes, what medication are you taking?	[1] Antiretrovirals [2] Prophylaxis [3] Traditional medicines [4] Medicine for Opportunistic Infections [5] Other	
3.4	Have you ever experienced discrimination by any hospital or health care workers because of your HIV status?	[1] Yes [2] No [3] Don't Know [9] Not Applicable	Skip to 3.6 “ “
3.5	If yes, how often has this happened to you?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	
3.6	In the past year, have you been denied medical treatment or care because of your HIV status?	[1] Yes [2] No _____ [3] Don't Know	
3.7	Has a health care worker ever refused to treat you because of your HIV status?	[1] Yes [2] No [3] Don't Know	
3.8	Have you ever experienced any delay in the provision of treatment or health services?	[1] Yes [2] No [9] Not Applicable	Skip to 3.10 “
3.9	If yes, was it due to your HIV status?	[1] Yes [2] No	
3.10	Have you ever been persuaded or advised into not accessing health care services?	[1] Yes [2] No _____ [9] Not Applicable	Skip to 3.13 “
3.11	If yes, was it due to your HIV status?	[1] Yes [2] No	
3.12	Who advised or persuaded you into not accessing health care services?	[1] Family members [2] Friends [3] Health care workers [4] AIDS Service agencies [5] Other	
3.13	Have you been forced to pay <i>additional</i> charges for medical services/treatments (eg. dental care, surgical procedures) once you tested positive for HIV?	[1] Yes [2] No [9] Not Applicable	
3.14	Have you ever participated in any AIDS-related medical studies or clinical trials?	[1] Yes [2] No _____ [3] Don't know	Skip to 3.23 “
3.15	If yes, were the following aspects of the study explained to you?		

3.16	The name of the drug or the study/trial	[1] Yes [2] No	
3.17	Purpose of the study/trial	[1] Yes [2] No	
3.18	Risks and consequences of the study/trial	[1] Yes [2] No	
3.19	How long were you on the trial/study?	Months:	
3.20	Did you ever make a request to stop being a participant?	[1] Yes [2] No	Skip to 3.22
3.21	If yes, was your request honoured?	[1] Yes [2] No	
3.22	Were you offered treatment at the end of the trial?	[1] Yes [2] No [9] Not Applicable	
3.23	Have you ever been denied private insurance or benefits because you took an HIV test?	[1] Yes [2] No [9] Not Applicable	
3.24	Have you ever lost or been denied private insurance once your HIV status was known?	[1] Yes [2] No [9] Not Applicable	

Section 4 Privacy

In this section I will ask questions related to violation of your privacy in relation to HIV status

4.1	In what year did you find out your HIV status?	Year:	
4.2	Why was the test taken?	[1] Insurance [2] Employment [3] Pregnancy [4] STD clinic referral [5] Referred from hospital [6] I just wanted to know [7] Partner tested positive [8] Other	
4.3	Were you prepared to take the test at that time?	[1] Yes [2] No	
4.4	Were you coerced into taking the test?	[1] Yes [2] No	
4.5	Was it explained to you what the test was about before you were tested?	[1] Yes [2] No _____ [9] Not Applicable	Skip to 4.7 “
4.6	If yes, what information did you get before you took the test?	[1] Counselling [2] Advice/Info [3] Literature [4] Other [5] Nothing	
4.7	Where were you tested?	[1]Hospital [2]Specialist clinic [3]Private lab [4]Private doctor's clinic [5] Other	

Documentation of Human Rights Violations against People Living with HIV/AIDS in Indonesia

4.8	Who informed you of the results?	[1] Doctor [2] Nurse [3] Social worker [4] Other	
4.9	Was there someone else with you when you got your result?	[1] Yes [2] No _____	Skip to 4.12
4.10	If yes, who was it?	[1] Friend [2] Family member(s) [3] Co-worker [4] Spouse [5] Other	
4.11	Did you want them to be with you?	[1] Yes [2] No	
4.12	What information did you get when you received your test result?	[1] Counselling [2] Advice/Info [3] Literature [4] Other [5] Nothing	
4.13	Have other people been told about your HIV status without you wanting them to know?	[1] Yes [2] No _____ [9] Don't Know	Skip to 4.15 “
4.14	If yes, who has been told without your consent?	[1] Health care workers [2] Family members [3] Co-workers [4] Spouse [5] Sex partners [6] Media [7] Government officials [8] NGOs [9] Police [10] Other	
4.15	Have you told anyone about your status?	[1] Yes [2] No _____	Skip to 4.17
4.16	If yes, who?	[1] Friend(s) [2] Relative(s) [3] Colleague(s) [4] Other	
4.17	How widely is your HIV status known to others?	[1] Nobody else knows [2] Only immediate family [3] Family members and a few friends [4] Only a few friends [5] Widely known in the community [6] Not known in community but open elsewhere	
4.18	Have you, since your diagnosis, been excluded from usual activities by your family members?	[1] Yes [2] No [9] Not Applicable	Skip to 4.20 “
4.19	If yes, how often have such incidents occurred?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	

4.20	Have you, since your diagnosis, been excluded from any social functions because of your HIV?	[1] Yes [2] No [9] No Response	Skip to 4.22 “
4.21	If yes, how often have such incidents occurred?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	
4.22	Have friends ever discriminated against you because of you HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 5.1 “
4.23	If yes, how often do you feel this has happened?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	

Section 5 Liberty and Security of Person

5.1	Have you ever been refused entry to, removed from or asked to leave any public establishment because of your HIV status?	[1] Yes [2] No [8] No Response	
5.2	Have you been forced to change your place of residence once you were diagnosed HIV-positive?	[1] Yes [2] No [9] Not Applicable	
5.3	If yes, how many times have you changed your place of residence?		
5.4	Have you ever been ridiculed, insulted or harassed because of your status?	[1] Yes [2] No [8] No Response	
5.5	Have you ever been threatened by physical violence because of your HIV status?	[1] Yes [2] No [8] No Response	
5.6	Have you ever been physically assaulted because of you status?	[1] Yes [2] No	
5.7	Have you ever been forcibly required to submit to any medical or health procedure?	[1] Yes [2] No [3] Don't Know	
5.8	Have you ever been required to disclose your status in order to leave or return to your country?	[1] Yes [2] No [9] Not Applicable	
5.9	Have you ever had to disclose your HIV status in order to enter another country?	[1] Yes [2] No [9] Not Applicable	
5.10	Have you ever been quarantined, detained, isolated or segregated because of your HIV status?	[1] Yes [2] No [8] No Response	

Section 6 Inhuman and Degrading Treatment or Punishment

6.1	Apart from you, do you know of any other person tested without their knowledge or consent	[1] Yes [2] No [3] Don't Know	
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6.2	Have there been any benefits, privileges or services given to others that were denied to you because of your HIV status?	[1] Yes [2] No [9] Don't Know	
6.3	Have you ever been charged, sued or brought to court on an offence or an act related to your HIV status?	[1] Yes [2] No [9] No Response	

Section 7 Right to Employment

7.1	Have you ever experienced any AIDS-related discrimination in your work environment?	[1] Yes [2] No [9] Not Applicable	Skip to 7.14 “
7.2	Has your employer ever discriminated against you because of you HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 7.4 “
7.3	If yes, how often has this happened?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	
7.4	Have you ever felt discriminated against by your colleagues because of your HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 7.6 “
7.5	If yes, how often has this happened?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	
7.6	Have you ever lost your job because of your HIV status?	[1] Yes [2] No [9] Not Applicable	
7.7	Has your job description or duties changed because of you HIV status?	[1] Yes [2] No [9] Not Applicable	
7.8	Have you been offered early retirement?	[1] Yes [2] No [9] Not Applicable	Skip to 7.10 “
7.9	If yes, was it due to your HIV status?	[1] Yes [2] No	
7.10	Have you ever lost your prospect for a promotion because of your HIV status?	[1] Yes [2] No [9] Not Applicable	
7.11	Have you ever experienced harassment or discomfort on the job because of HIV?	[1] Yes [2] No [9] Not Applicable	Skip to 7.15 “
7.12	Did you have any ways to address these abuses or any recourse for action?	[1] Yes [2] No _____ [3] Don't Know	Skip to 7.15 “
7.13	If yes, were you satisfied with the recourse of the action taken?	[1] Yes [2] No	
7.14	Has your earning capacity decreased due to your HIV status ?	[1] Yes [2] No [9] Not Applicable	

Section 8 Right to Marry, Found a Family and Form Significant Relationships

8.1	Have you ever undergone mandatory HIV testing during pregnancy or because of an illness of your child (women only)?	[1] Yes [2] No [9] Not Applicable	
8.2	Has your partner deserted you because of your HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 8.5 “
8.3	If yes, were you financially dependent on your partner?	[1] Yes [2] No	
8.4	Have you ever lost any financial support from other family members due to your HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 8.8 “
8.5	What were the repercussions?		
8.6	Has your child (or children) ever been involuntary taken away from you?	[1] Yes [2] No [9] Not Applicable	Skip to 8.10 “
8.7	If yes, was it due to your HIV status?	[1] Yes [2] No	
8.8	Have you ever been advised not to have a child since you were diagnosed to be HIV positive?	[1] Yes [2] No [9] Not Applicable	Skip to 8.12 “
8.9	If yes, were you given information about mother to child HIV transmission?	[1] Yes [2] No	
8.10	Have you been coerced into an abortion or sterilisation due to your HIV status (women only)?	[1] Yes [2] No [9] Not Applicable	

Section 9 Right to Education

9.1	Have you or your child(ren) ever been dismissed, suspended, prevented from continuing with your /their education because of your status?	[1] Yes [2] No [9] Not Applicable	
9.2	Have you or your child(ren) ever been denied admission into any educational institution because of your status?	[1] Yes [2] No [9] Not Applicable	

Section 10 Right to Self-Determination and Association

10.1	Have you ever been excluded from any associations / societies / clubs / self-help groups due to your HIV status?	[1] Yes [2] No [9] Not Applicable	
10.2	Have you ever been restricted in your ability to meet with other people living with HIV/AIDS?	[1] Yes [2] No [9] Not Applicable	
10.3	Has your family ever restricted in your ability to join with associations/groups of people living with HIV/AIDS?	[1] Yes [2] No [9] Not Applicable	
10.4	Have you ever been referred to any self-help group of people living with HIV by an AIDS / health care worker or others?	[1] Yes [2] No [9] Not Applicable	

10.5	Have you ever participated in any AIDS-related decision-making committees?	[1] Yes [2] No [8] No Response	
10.6	Do you know of any local self-help group of people living with HIV?	[1] Yes [2] No	
10.7	Do you intend to join a peer self-help group in the near future?	[1] Yes [2] No	
10.9	If not, why not?		

Thank you very much for your participation You have now completed the survey.

Are there any further issues you want to talk about? If you are willing to permit a detailed interview about your experiences of discrimination we do request your informed consent to tape it.

Section 11 Observation and comments (by the interviewer)

11.1	Does this respondent need a referral?	[1] Yes [2] No
11.2	If Yes	[1] Legal [2] Counselling [3] Other
11.3	Is follow-up required?	[1] Yes [2] No
11.4	Is this respondent a potential candidate for case studies?	[1] Yes [2] No
11.5	If yes, appointment for next meeting	
11.6	Other observations	
11.7	Interviewer	
11.8	Field edited by	

Appendix 9: Report on National Seminar/Workshop

Launch Report of Documentation of Discrimination against People Living with HIV/AIDS in Indonesia

Introduction

Stigma and discrimination associated with HIV and AIDS are the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact. They have powerful psychological consequences for how people with HIV/AIDS come to see themselves, leading, in some cases, to depression, lack of self-worth and despair. HIV/AIDS-related stigma and discrimination affects the capacity of societies to respond constructively to the devastation caused by the epidemic. Despite the catastrophe, silence prevails and action is slowed because of stigma and denial and, ultimately, because of people's fears about being open. (UNAIDS: World AIDS Campaign 2002-2003)

Human rights violations against people with HIV and AIDS (PLHAs) in Indonesia have frequently occurred over the last decade, including by mass media and the authorities. So far such violations have been seen as occasional incidents and therefore they have not been taken seriously or addressed systematically. A documentation of AIDS-related discrimination and human rights violations was carried out by the Spiritia Foundation, the Indonesian National Peer Support Network for PLHAs. It is a part of the APN+'s project in four countries, the others being Thailand, The Philippines, and India. Indonesia is the first country to complete the documentation, with funding from UNAIDS and AusAID.

The main objectives of the project were to:

- Systematically collect data on AIDS-related discrimination in Indonesia.
- Produce a report detailing the nature, extent and pattern of such AIDS-related discrimination.
- Train HIV positive people in research and documentation of AIDS-related discrimination.

HIV-positive people were recruited and trained by other HIV-positive people as interviewers in data collecting. One aim of the training for interviewers was to raise their awareness of human rights and to provide them with research related knowledge, skills, and information on ethics.

Findings indicate that the major problem to be addressed is stigma and discrimination in the healthcare sector, including in counselling and testing. In addition, the survey identified a number of social support problems. Documentation alone brings little benefit to stigmatised PLHAs; it is the follow up advocacy that is crucial for change. This Seminar/Workshop is intended to disseminate the results of the survey and to consider strategies for responding to the findings.

Objectives of the Seminar/Workshop

The overall aim of the workshop is to stimulate a response to the discrimination against PLHAs in Indonesia. Specifically, the following objectives will be achieved:

Seminar:

- Disseminate the results of the survey to decision makers in the health care sector and managers of health care service providers.

Workshop:

- Determine strategy to address human rights violations against PLHAs both in health care settings and in the community, based upon the results of the survey.
- Identify key players and their role in the response to human rights violations against PLHAs.

Participants

Seventy-five participants attended the launching, not including members of the press covering the event.

Participants were individuals who are expected to have significant impact upon the response, with the ability to stimulate and institute the urgent changes required to eliminate discrimination against PLHAs in the health care sector. They came from government (primarily National/Provincial AIDS Control Commissions and Department of Health), professional organizations of health care workers (doctors, nurses, dentists, etc.), hospital management, academics, representatives of donor and UN agencies, NGO management and activists, and PLHAs.

Place and Date

The Seminar/Workshop was held in the Hotel Sari Pan Pacific in Jakarta, 12 November 2002, from 9:00 until 16:45.

Program

09:00-10:00 Opening session: MC Andreas Pundung.

- Report of Organizing Committee: Rainita Adisty
- Keynote address—summary of results of survey: Siradj Okta
- Official opening: Dr. Farid Husain, Secretary of the National AIDS Control Commission

10:00-10:15 Break/Press conference, chaired by Dr. Farid Husain, assisted by Chris Green, Daniel Marguari and Siradj Okta. A press statement was distributed in advance.

10:15-12:00 Seminar

- Details of Survey by Dr. Tuti Parwati, as Principal Investigator for the project. She described the results in both quantitative and qualitative terms, showing that violations of human rights of PLHAs most frequently occurred in the health care sector and connected with HIV testing.
- Conclusions and Impact of Survey by Chritin Wahyuni, a member of the team that collected the data for the project. She noted that the project had the effect of empowering PLHAs, both as interviewers and as respondents. The project raised the level of awareness of human rights among those participating.

- Response from Department of Health by Dr. Broto Wasisto. He presented an overview of discrimination in the health care sector, and suggested ways in which discrimination against PLHAs might be addressed. He concluded that information is the most vital element in reducing discrimination.
- Discussion, moderated by Irwan Julianto.

12:00-12:15 Opening of the Workshop and selection of breakout group members. Participants were divided into two groups, with a maximum of 25 per group.

Group 1 topic: Determine the strategy to address violations of human rights against PLHAs in the health care sector.

Group 2 topic: Determine the strategy to address violations of human rights against PLHAs in the community.

Group 3 topic: Determine the key players together with their roles in addressing violations of human rights against PLHAs.

12:15-13:15 Lunch

13:15-14:00 Group discussions, with topics determined as above. Each groups was provided with a facilitator and a PLHA as a resource person.

14:00-15:00 Plenary–group presentations and discussion, moderated by Chris Green. Each group presented the results of their discussion.

15:00-15:30 Break/Committee develop draft workshop outcome.

15:30-16:30 Plenary–The Moderator presented a summary of the group discussions, with discussion and correction of each point to reach consensus.

16:30-16:45 Closing by Jane Wilson of UNAIDS.

Other Matters

Funds to cover this seminar/workshop in the Peer-Group Documentation Project were provided by UNAIDS, AusAID, and Ford Foundation.

Results of Group Discussions

Results of Group 1 Discussion

Strategy to Address Violations of Human Rights against PLHAs in the Health Care Sector

- Vision
 - Provision of the same care to every patient regardless of status
- Targets and agents:
 - Health care workers and institutions
 - Decision makers
 - Leaders and managers
 - General public
 - PLHAs
 - Workplace
- Contents/explanations regarding:
 - What is discrimination?
 - What needs to be treated differently?
- What happens:
 - Discriminative services
 - PLHAs stigmatised
 - Does this represent a violation of human rights?
- Methods:
 - Pre- and in-service training
 - Continuing education
 - Preparation of various SOPs: universal precautions, VCT, etc.
 - IEC
 - Accreditation of health care institutions
 - Quality control/monitoring
 - Specific laws not required

Conclusion:

There is no need for special laws covering HIV/AIDS, but legal problems must be addressed. It was felt that special laws on HIV would in themselves constitute discrimination.

Results of Group 2 Discussion

Strategy to Address Violations of Human Rights against PLHAs in the Community

- Empower community institutions which currently exist to be information centres
- Empower PLHAs and people affected
- Advocacy/policy

Conclusion:

- Advocacy or policy should empower currently-existing community institutions, together with empowering PLHAs and people affected
- Optimise this empowerment by use of IEC material by community institutions as information centres.
- Advocacy must result in policy.

Results of Group 3 Discussion

Main Players and Their Roles

- Government
Role:
 - KPA/D (National/Regional AIDS Control Commissions), as coordinators
- Department of Health and Provincial/District Health Service
Role:
 - Determine rules of play
 - Instruct subordinates/colleagues
- Department of Justice and Human Rights
Role:
 - Involve laws regarding discrimination against HIV/AIDS
- Professional Organizations (connected with health)
 - IDI (Indonesian Medical Association)
 - Nurses and Midwives Associations
 - PDGI (Indonesian Dentists Association)
 - Continuing Medical EducationRole:
 - Connected with ethical code
 - Preparing SOPs (Standard Operational Procedures)
- Health care practitioners
 - Medical
 - Paramedics
 - Hospital owners (private) in policy developmentRole:
 - Hospital management systems
- NGOs
Role:
 - Provision of information about HIV/AIDS in ways to eliminate stigma and discrimination
- Educational Institutions (Schools, Universities)
Role:
 - Study curriculum to include HIV/AIDS as a subject
 - Provide additional training and education on HIV/AIDS
- Legal Practitioners
Role:
 - Represent PLHAs in claims and discrimination
- Community and religious leaders
Role:
 - Help to eliminate community stigma and discrimination against PLHAs
- Media
Role:
 - Cover HIV/AIDS information accurately, positively, appropriately, and non-discriminatively
- PLHAs
Role:
 - As resource people

Conclusion

Government in this case includes the legislature. Everyone must work together, with health as the leading sector, because it is the Health Department that is directly involved in the field of health. But Labour and Education Departments must also be involved.

Role of educational institutions is to provide information to students. Include social effects to address HIV/AIDS. And also include continuing medical education, teacher training, and parent-teacher cooperation.

Summary

The organizing committee summarized the results of the three groups' discussion in six points below. This attempts to summarize the recommendations of the workshop participants in line with the topics of each group. It is expected that all will play a role depending upon their function in coordination with other players. The summary is as follows:

1. There is consensus that although the health sector is the main player in efforts to address discrimination against PLHAs, the National and Regional AIDS Control Commissions (KPA/D) must take a more proactive role, involving all related government sectors, legislature, NGOs, community and religious leaders, and PLHAs themselves. An urgent and integrated effort is required to show that discrimination against PLHAs is not acceptable and will be prosecuted.
2. Special laws are not required to address discrimination against PLHAs. Discrimination in general is outlawed by the Constitution. Laws, central and local government regulations, and other instruments that already exist must be used to the utmost, and if these are found to be lacking, efforts must be made to revise them.
3. There must be an effort to document all laws which impact on discrimination, and which can be used to fight discrimination.
4. The roles of PLHAs and people affected by HIV/AIDS (family, partners and friends of PLHAs) are very important in documenting violations of their rights. There must be a special effort to empower PLHAs, and PLHAs must be provided with advocacy and public speaking skills.
5. Few NGOs have strong advocacy capability. Guidelines and training are required so that NGOs understand the importance of advocacy, ways in which it can be carried out, and the major targets.
6. As representatives of the public, the role of the legislature is extremely important. Members of the national and regional parliaments must be involved and provided with correct information. Prior to the 2004 general election, there must be an effort to stimulate discussion about HIV/AIDS during the campaigning.