

Full Length Research Paper

Disclosure of information by patients about HIV/AIDS infection in Northeastern Thailand

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Few studies have focused on the processes in which patients reveal their HIV infection to others. This study sought to understand these processes. Thus, the research questions were: (a) What were their thoughts about the moment when patients learned that they were infected? (b) To whom and when did patients disclose that they were infected? (c) How did they disclose the information? (d) How much or what information did they disclose, and what were the reactions of those who were informed? (e) Why did they reveal the information? The descriptive study was done using a convenience sample of 45 patients with HIV/AIDS at a hospital clinic in northeastern Thailand. The results showed that 67% told a family member, usually their mother, within a day of being told about their HIV diagnosis from a medical staff. Most patients (65%) communicated the diagnosis face to face; only 4% used the telephone. Most patients disclosed the cause and source of infection; some also disclosed the location and time of infection and the current treatment. About half chose to tell family because family would likely take care of them when their symptoms became worse. About one fourth said they informed family because family would more readily accept their condition. Study findings may be useful to those who assist AIDS patients, including the development of effective methods or a system or network of persons who may help patients seek medical and other assistance sooner.

Key words: HIV/AIDS-infected patients, disclosure, information.

INTRODUCTION

The first AIDS patient in Thailand was identified in 1984. In 1988, when the number increased to 4,326 patients (UNAIDS and WHO, 2009), the Ministry of Public Health began to initiate various measures to suppress the spread of the disease and to cure patients (Pongpan et al., 2009). Nevertheless, a recent report (28 February, 2011, Bureau of Epidemiology) showed that there were 370,074 AIDS cases, with 97,952 deaths. The highest rate is in the age group 30 to 34 years (24.96%), followed by age groups 25 to 29 years (21.76 %), 35 to 39 years (18.06%) and 40 to 44 years (10.56%). The illness rate in

the age group 10 to 14 years old is (0.43%). Reported infection causes were sexual intercourse which was 84.25%, syringe use 4.45%, maternal-to-child transmission 3.63%, blood transfusion 0.02%, other 0.10% and not known 7.55% (Ministry of Public Health Thailand, 2011).

Countries differ in the methods used to notify persons of their HIV status (Seki et al., 2009; Oosterhoff et al., 2008; Choudhury and Tetali, 2007). The Thai protocol of disclosure typically is done by medical staff trained in HIV counseling: patients are informed directly by a process that is similar to the USA (Hult et al., 2009).

Bairan et al. (2007) have described a model of HIV disclosure with three themes: Social relations (sexual and non sexual), fear, and stigma. A social relationship was

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a major variable in patients' decision to disclose or not.

Pervasive stigma has surrounded HIV/AIDS since the beginning of the pandemic. In Southeast Asia, as elsewhere, it has been accompanied by discrimination, affecting transmission patterns and access to care and support (Busza, 2001). Learning that one is infected with HIV/AIDS often causes an emotional crisis in patients; responses vary from acceptance to denial. The study of Herek et al. (2003) had shown that more than one third of all respondents reported that concerns about AIDS stigma would affect their own decision to be tested for HIV in the future. Concealment from their social milieu is used as a tactic (Rassin, 2011), some due to fear of being rejected, abandoned, or stigmatized as a bad, promiscuous person. Stigma can also affect health, directly threaten physical wellbeing (Balfe and Brugha, 2010; Link et al., 2001) and mental health (De Santis, 2009; Hasanah et al., 2011), and negatively related to quality of life (Deribew et al., 2009; Dasgupta et al., 2011; Cao et al., 2010; Rahmati-Najarkolaei et al., 2010). Families also avoid disclosure of HIV infection to protect the patient from emotional pain and shock (Seki et al., 2009) and community stigma and discrimination (Ishikawa et al., 2011). Patients who choose to reveal do so only with a few trusted persons such as family members or close friends (Bairan et al., 2007; Ding et al., 2011; Simoni et al., 2000). Many visited a doctor only when symptoms were serious and needed treatment.

Purpose and research questions

Much of the literature has focused on communication and disclosure of information from the medical staff to the persons infected with HIV, and the social stigma related to the condition. However, given the stigma, few studies have focused on the processes in which patients reveal their HIV infection to others. This study sought to understand these processes. Thus, the research questions were: (a) What were their thoughts about the moment when patients learned that they were infected?

(b) To whom and when did patients disclose that they were infected? (c) How did they disclose the information? (d) How much or what information did they disclose, and what were the reactions of those who were informed? (e) Why did they reveal the information? Study findings may be useful to those who assist AIDS patients, including the development of effective methods of persons who may help patients seek medical and other assistance sooner.

METHODS

Design

This descriptive study was done at a general hospital of a medium size city in Northeastern Thailand. The sample consisted of 45 persons who met the selection criteria.

Participants

Convenience sampling was used. Those who were included met the following criteria: (a) Diagnosed with HIV/AIDS infection and sought services at the infection department of the hospital, (b) Able to talk, hear, and communicate and (c) Agreed to participate in the study.

Data collection procedure

The ethical issues of research in humans had been approved by the Faculty of Nursing, Mahasarakham University, Thailand. Following approval, enrollment of participants took place at the AIDS clinic of the hospital every Tuesday (June to August 2009). Each in-depth interview was done in a private room, and took 1-2 h to complete.

Instruments

Two instruments were used: A questionnaire that included demographic items and patient-report items regarding the source and cause of infection, and so forth. An interview outline of open-ended questions also was developed to allow participants to respond to items in their own words. The process of revealing information to others was the focus. Sample questions included "to whom did you first reveal information that were HIV infected?" "why did you decide to do so?" and so forth. The items were based on the research questions, experts in HIV/AIDS, and the literature. The researchers discussed the order or sequence and appropriateness of the items in the interview guide, and role played the administration of each item.

Data analysis

The demographic and other data were analyzed descriptively using frequency distributions and percentages. The processes of revealing information to others also were described. Content analysis was done of the responses to the interviews to identify themes that emerged (Krippendorff, 2004).

RESULTS

Sample characteristics

Table 1 show that most of the infected persons were in the age group 31 to 40 years (64.5%). Most had a secondary school level or equivalent education (49%), and had low incomes of 3,000 to 5,000 baht (38 %). The table also show the marital status of respondents who were to be single (31%); married (22%), or living together without registration of marriage (29%). At the time of the study, most lived with their spouse (40%), or their parents (38%). Table 2 shows that most participants reported that they were infected from sexual relationships (87%); a few reported the cause of infection was from drug use with others using a syringe (7%), the rest stated the cause of infection was not known (7%). The table also shows that among those infected sexually (33%), reported that their spouse or partner was the source, while 44% stated that they did not know or were not sure of the source since they were sexually active with many people.

Table 1. Sample characteristics (N=45).

Data	Number	Percent
Age (years)		
20-30	6	13.3
31-40	26	64.5
41-50	8	17.8
51-60	1	2.2
Above 60 years	1	2.2
Education		
None	3	6.7
Primary education	17	37.8
Secondary education or equivalent	22	48.9
Bachelor's Degree or equivalent	2	4.4
No response	1	2.2
Income (Thai baht:30 baht= 1 dollar)		
Less than 3,000 baht	14	31.1
3,000 – 5,000 baht	14	37.8
5,001 – 7,000 baht	7	15.6
7,001 – 9,000 baht	1	2.2
Above 9,000 baht	2	4.4
No response	4	8.9
Marital status		
Single	14	31.1
Live together without marriage registration	13	28.9
Live together with marriage registration	10	22.2
Widow/widower	5	11.1
Divorce	3	6.7
Live with whom*		
Spouse	18	40
Parent	17	37.8
Children	11	24.4
Relatives	6	13.3
Brother/ sister	5	11.1
Friend	1	2.2
Live alone	1	2.2
*Can answer more than 1 Item		

Table 2. Infection causes and sources (N=45)

Data	Number	Percent
Cause of infection		
Sexual relationship	39	86.6
Through syringe	3	6.7
Not known/ not sure	3	6.7
Infection source		
Spouse	15	33.4
Female/ male prostitute	5	11.1
Friend	5	11.1
Not known/ not sure	20	44.4

Table 3. When was infection disclosed/revealed (N=45).

Data	Number	Percent
Immediately after learning	30	66.7
Tell when symptoms appear	9	20.0
Not tell anyone	6	13.3

Table 4. Method of revealing information (N=45).

Data	Number	Percent
Tell face-to-face	29	64.5
Tell by phone	2	4.4
Others know themselves	7	15.6
Did not tell	6	13.3
No reply	1	2.2

Research questions addressed

What were their thoughts about the moment when patients learned that they were infected?

Upon learning that they were infected, patients thought about the cause and source of the infection. The responses show that those who readily knew the answer were those who either lived with one partner or did not change sexual partners, or those who used prostitutes. The rest did not know the exact source because they were sexually active with many persons.

Examples of responses from the interviews

"I think I got infected from my first wife. She did not tell me; although, I noticed that she became weaker, thinner, and took some medicines. Also, when we were going to have a baby, she went for an illegal abortion without telling me. I was confused that she did not allow me to visit her. After that, I went to have my blood checked. Then the doctor told me that I was infected, too." (A 39-year-old man)

"I injected drugs with my friends. Then one was in accident; so, the doctor checked his blood and told him that the blood was abnormal. I thought then that if he was infected, then I would be infected, too. My friends who took drugs and I were musicians and played music in pubs and bars. There were three of us. I was pretty sure that I was infected from syringes, because whenever I had sexual intercourse, I always wore condoms. Once I had a sexual encounter when I was a student; however, the woman I had sexual intercourse with had a husband and children and she is fine currently. So, I am sure that I was infected from the syringes." (A 35-year-old man)

"I thought I was infected from my close friend. He is a man. He is infected; how can I not be infected as we had had sexual intercourse? The symptoms have appeared already". (A 24-year-old man)

"Initially, I did not tell anyone, but the symptom appeared by itself: I had chronic diarrhea for about 3 months, lost weight, and had abscesses. I visited the doctor, and the doctor checked my blood and found that I was infected with AIDS. I did not tell anyone for many years." (A 34-year-old male)

To whom and when did patients disclose that they were infected

Table 3 show that upon learning that one was infected; most patients (66.7%) made a decision to tell their family immediately, within a day. The first person informed by the patient was the patient's own mother, and secondly, the spouse or partner (Table 4), however, that 20% did not tell about the infection until the symptoms began to show, while 13.3% did not tell anyone at all.

Examples of responses, from the interviews

"The doctor checked my blood, and found that I had AIDS. After knowing, I told my mother and my boyfriend that same day". (35-year-old woman)

"I went to stay in "upcountry" for one year and my symptoms were worse. My parents then suspected and told me to go for a checkup". (A 34-year-old man)

"I did not tell anyone, I was shy, and could not accept it..."

(A 24-year-old homosexual man)

"I told my father, and later my brother, the head of the village, then friends". (A 36-year-old man)

How did they disclose the information

Table 4 shows that 64.5% revealed the infection directly to those with whom he/she lived, while 4.4% did so by phone since they lived far or did not want face to face disclosure. The table shows also that family members knew the patient was ill; took medicines for worsening symptom; or, that the patient lived with someone who had died of AIDS. The rest did not want to reveal their infection to others.

Examples of responses, from the interviews

"I told my mother face to face, "Mom, I have AIDS". My mother was shocked and sad and asked me why. Later, my younger brother could not accept it and expressed disgust. He was afraid that his wife and children would be infected. So, he did not allow them to stay near me. After that, he told the community president as he wanted to get funds for the patient (500 baht a month); then the neighbors (about 5 to 6 households) knew, too. It took 2 years to be accepted by neighbors as they saw me strong; I kept taking the medicines". (A 36-year-old man)

"When I had a symptom, my father told me to go for a checkup. I thought I was infected with AIDS. My father said that if I am really infected, I must not be sad. Just let the doctor treat me". (A 37-year-old man).

How much and what information did they disclose, and what were the reactions of those who were informed

The amount of information that AIDS patients told others: 13% said that they were infected but did not give the details, 9% told the cause/source of infection and when they got infected, 58% told where and when they got infected, and the treatment; while 20% did not say AIDS, but mentioned another disease, such as pneumonia, skin disease, or "weak body".

Examples of responses, from the interviews

"After knowing about the infection, I wanted to die at home so I returned home and told my elder brother and my mother that I was infected and had sought treatment. I was cured in the temple and I got herbs and I felt better".

(A 39-year-old man)

"When the blood test result came, I told my mother that I was infected and that the source was my friend who was addicted to drugs".(A 35-year-old woman)

I did not tell anyone; I concealed it for as long as possible-but my parents and family members knew. I hope I could stay alive longer for many years as I am young and there may be a medicine in the future to cure it. I heard that now there is research on the use of stem cells with AIDS patients. I hope I would recover". (A 24-year-old homosexual man)

"I told my mother about the symptoms, the treatment, and everything. She helped by setting the alarm clock to remind me of taking my medicines on time at 9 am and at 9 pm.". (A 35-year-old woman)

Why did they reveal the information

The main reasons why participants decided to tell others were: "so they would accept it" (22%), "so they would help take care of me, when symptoms appear or get worse"... , or "...my child, if I died" (49%), or, "My family "knew" themselves (16%).

Examples of responses, from interviews

"I told my Mom because I trust her. In case I died, she would help take care of my child". (A 35-year-old woman)

"I told my Mom so that she would help take care of me when my symptoms become serious" (A 36-year-old man)

"I told my mother and sister so that they could prepare their minds." ...

"I did not intend to tell them, but they suspected. After staying home for about one year, they suspected that I was infected with AIDS: my symptoms became worse. When I went for a check up, it really was AIDS". (A 37-year-old man)

DISCUSSION

The study findings are consistent with the UNAIDS report that AIDS infected persons are in the working/reproductive age group, and the risk factor of infection from sexual intercourse is most common (UNAIDS and WHO, 2009). Most persons in this study also had low incomes, and needed money for daily needs and for health care (Frank et al., 1995). The study showed that some participants who were recently diagnosed and did not show symptoms did not reveal their infection to

others, while those with symptom often returned home in “upcountry” (Northeast Thailand) and revealed their infection to family.

Disclosure of information about AIDS infection to others

Findings showed that most patients made a decision to tell the family within a day after knowing their diagnosis. The first to be told was the most trusted person, their mother, and secondly, their spouse. About a third disclosed only after symptoms of AIDS appeared; although some never told anyone. Most patients communicated the diagnosis face to face; only a few used the telephone. Some patients stated they told family, but chose to not tell friends, neighbors, colleagues and distant relatives. This result is consistent with other studies including one done in India (Bairan et al., 2007; Sahasrabuddhe et al., 2002; Simoni et al., 2000).

Most Thai people are close to their mothers whom they believed would take care of them when their illness became serious, or (if they died) their child. These were major reasons for the decision to disclose in this study. Similar or related reasons for disclosure were reported in other studies, including the following: Trust, close relationships, it is the right thing to do to protect others, reaffirmation of self, increased social support, catharsis, desire to educate others, seeking and needing help, desire to test someone’s reaction, being in a close or supportive relationship and mechanism for dealing with the disease (Derlega et al., 2002; Ding et al., 2011; Holt et al., 1998; Parsons et al., 2004; Serovich and Mosack, 2003; Wolitski et al., 2003)

Most patients in the study chose to tell immediately when the doctor informed them of the diagnosis, based on the blood test. In many cases, a family member (who often had observed the symptoms already) accompanied the patient to the clinic; therefore, the doctor tended to inform them as well. The accompanying person may be a parent or a spouse; and the doctor would test the spouse as well. Those who chose (and were able to) to conceal did not have symptoms yet. Patients often changed their workplace also after being infected and could not accept the diagnosis; or they were unemployed due to poor health. Patients thought they would be stigmatized by Thai society (Boonmongkon, 1993). Stigma was associated with a poor quality of life in the psychological domain (Deribew et al., 2009), and patients experienced difficulties with disclosing their HIV status in society (Gebrekristos et al., 2009). Stigma and fear are major disclosure concerns of HIV+ persons (Bairan et al., 2007). Other studies found similar or related reasons for not disclosing, including the following: stigma, need for privacy, fear of rejection, threats to person’s well-being potential loss of income, difficulty in communicating, and denial (Carr and Gramling, 2004; Derlega et al., 2002;

Parson et al., 2004; Serovich and Mosack, 2003).

As mentioned, the study findings are consistent with others in Thailand that the family is an important institution. The family provides assistance to members in various ways, including financial, physical, social and emotional aspects. A study of Rassin (2011) showed that assistance from family members helped to sustain the concealment also. Nevertheless, the support and encouragement given to patients help make them feel worthy and hopeful. This would assist patients in their fight with the problem of HIV/AIDS in many ways, especially emotional and physical (Kusuma-Na-Ayuddhaya and Somenarin, 1998; Kownaklai et al., 2009).

When they became infected, many patients stated that they returned home to “upcountry”, especially those who had symptoms. Consistent with another study, the patients expected that the family could be trusted, and would accept their diagnosis. The study of 14 families of HIV/AIDS infected patients in Tawat Buri District, Roi-et Province, Thailand, found that the families took care of the patients. Mothers, and every family member, showed acceptance of the patient by: allowing him/her to stay with the family, and providing quality care; those who took care of the patients consulted and mutually agreed on the appropriateness of treatments (Bootchon et al., 2003).

Nevertheless, needs, stresses and quality of life of family members of people living with HIV/AIDS were affected by the disclosure, too. Family caregivers felt mostly stressed by the disclosure and stigma issues, and most worried about patients’ interpersonal relationships. Their most important needs were care-related needs including knowledge of the disease progression, methods of examination and treatment, and the related side effects. Others have reported that the level of stress significantly positively correlated with needs, and negatively correlated with quality of life (Feng et al., 2009). Ding et al. (2011) found that HIV disclosure was a significant predictor for access to care. Another study showed that AIDS patients who have a source of income and family support had a better quality of life (Deribew et al., 2009). Life stressors also were found to be significantly and inversely associated with both physical and mental health-related quality of life (Gibson et al., 2011)

Conclusions

Most participants reported that they were infected from sexual relationships. Regarding the process of disclosure, the decision to tell someone was based on health status. That is, if patients felt healthy or showed no symptoms, they often decided to conceal the information. Disclosure to other people often was done by patients with symptoms of AIDS whose health was worse, and they felt that they needed to return home to their families

for end-stage care. Most told a family member, usually their mother, within a day after knowing of the HIV diagnosis from a medical staff. Most patients communicated the diagnosis face to face; only 4% used the telephone. Most patients disclosed the cause and source of infection; some also disclosed the location and time of infection and the current treatment. About half chose to tell family because family would likely take care of them when their symptoms became worse. About one fourth said they informed family because family would more readily accept their condition.

IMPLICATIONS AND RECOMMENDATIONS

Study findings may be useful to those who assist HIV/AIDS patients, including the development of effective methods of persons who may help patients seek medical and other assistance sooner. A larger study in other parts of Thailand, and inclusion of a more varied socioeconomic group needs to be done; and a study that focuses on quality of life of people living with HIV/AIDS, including children, and their caregivers. Also, a comparative study on the advantages and disadvantages of disclosing or revealing information to others, including various groups of people such as family, village leader, village volunteer and health staff will also be beneficial for public health awareness and education.

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