Anxiety and Anxiety Management of People Living with HIV/AIDS in Bangladesh

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Abstract

Background: Anxiety is one of the dominant psychological symptoms occurring in both symptomatic and asymptomatic HIV patient group. Although previous work has described the prevalence of HIV-related anxiety and self-care strategies, but most of the studies till date reported were conducted in developed countries. Little is known about the anxiety experiences and the ways in which people living with HIV/AIDS (PLWHA) manage and tackles anxiety in Bangladesh.

Objective: This study aims to describe anxiety experiences and anxiety management of people living with HIV/AIDS in Bangladesh.

Methods: The study was conducted using the descriptive research. The subjects were a minimum of 75 people living with HIV/AIDS recruited from the outpatient department at Infectious Diseases Hospital/NGO in Bangladesh. Data were collected using a selected questionnaire including: the Demographic Data Assessment Form (DDAF), the Anxiety Experience Questionnaire (AEQ), and the Anxiety Management Strategies Questionnaire (AMSQ). The contents of the questionnaire were validated by three experts. The AEQ and the AMSQ were tested for reliability using test-retest coefficient yielding of .87 to 1.00. Data were analyzed using frequency, percentage, range, mean, and standard deviation.

Results: The finding revealed that the majority of the subjects (76.0%) reported a high level of overall anxiety experiences (M = 6.62, SD = 2.69) and used several strategies to manage. Although pharmacological and non-pharmacological anxiety management activities were perform. The anti-depressant and anti-anxiety drugs were reported as helpful (M = 7.69, SD = .72, and M=6.99, SD=.51 respectively). Regarding non-pharmacological methods, using ventilation, avoidance coping and religious practice was reported to be most helpful. The research findings could guide nurses to promote better advice and services in reducing anxiety problems of PLWHA in Bangladesh.

Key word: Anxiety, Anxiety experiences, Anxiety management, and HIV/AIDS.
Background and significance of the problem

Human Immunodeficiency Virus (HIV) causes Acquired Immune Deficiency Syndrome (AIDS), an incurable disease, and progression of the disease is uncertain and unpredictable (Eller et al., 2001). Although advances in treatment have resulted in increasing longevity, coping with chronic disease often involves a series of psychological and physical symptoms (Lorenz, Shapiro, Asch, Bozzette, & Hays, 2001). As a consequence, the body’s immune function and people’s life day by day are deteriorated (Sukati et al., 2005). Anxiety is one of the dominant psychological symptoms occurring in both symptomatic and asymptomatic HIV patient group (Sanjay, Chwastiak, & Bruce, 2005). The main causes of anxiety are fear of death and fear of the unexpected future about the disclosure of HIV/AIDS and discrimination by the society (Kemppainen et al., 2003). In addition, the level of anxiety and fear changes from time to time depending on how people living with HIV/AIDS (PLWHA) respond, anxiety management strategies (Flaskerud & Miller, 1999).

To relieve anxiety, people generally use several symptom management strategies related to their perception of symptoms. Based on the symptom management model, Dodd et al. (2001) identified that several self-care strategies that have been effective will be used to relieve symptoms depending on the individual’s perceptions of symptoms, and the expected symptoms outcome. In a review of self-care management of anxiety in HIV disease, both pharmacological and non-pharmacological methods were used. In addition, people may perceive the anxiety experience and perform anxiety management strategies in different way included using activities for distraction, talking to others, using complementary/alternative therapies, taking medications, using self-talk, using substances, and using avoidance behaviors (Kemppainen et al., 2003).

Self-care practice used to manage anxiety symptoms may be determined by several factors. Dodd et al. (2001) has explained that some factors are related to the response of symptoms. These factors are: (i) the person, such as age, gender (ii) health and illness such as physical symptoms, treatment access & outcomes, and (iii) the environment, such as social support. However, those factors may require further explored in some cultural context as the findings remain inconsistency.

Although previous work has described the prevalence of HIV-related anxiety and self-care strategies, most of the studies till date reported were conducted in developed countries, only self-care strategies used for HIV-related anxiety without any measures of frequency and overall effectiveness (Kemppainen et al., 2003). The anxiety level of HIV/AIDS infected people are related to anxiety symptom and anxiety management strategies which might be
different (Henry, Holzemer, Weaver, & Stotts, 1999). It was found that self-management of anxiety plays an important role in determining symptom outcomes in HIV/AIDS (Campsmith, Nakashima, & Davidson, 2003).

In Bangladesh, Infectious Diseases Hospital in Dhaka is one of the biggest hospitals for treatment of HIV/AIDS disease. Hospital was equipped with both indoor as well as outdoor facilities to meet the demands of subjects. The prevalence of HIV in the general population of Bangladesh appears to be low; at under 0.1 percent but high prevalence of HIV/AIDS in neighboring India, it is major problem for Bangladesh. Previous study also reported that care and support provisions for PLWHA in Bangladesh are limited (Azim et al., 2008).

Anxiety is one of the most prevalent symptoms of HIV-infected people, little is known about the anxiety experiences and the ways in which PLWHA manage and tackle anxiety in Bangladesh. Hence, a study on anxiety management strategies in PLWHA is necessary. The outcomes of this study can assist nurses and other health care providers to provide better advice and services for PLWHA.

Objectives of the study

1. To describe anxiety experiences of PLWHA in Bangladesh.
2. To describe anxiety management strategies used by PLWHA in Bangladesh.

Technical of terms

Anxiety experience refers to feeling of anxiety symptom which occurred over the last week perceived by PLWHA. Anxiety experience included perception, evaluation and response. Perception of anxiety experience refers to an expression or feeling of an individual behavior towards the symptoms of anxiety. Evaluation refers to the symptom severity and symptom distressful of anxiety which the patient characterizes from their perception. Response was the way that the patient describes its impacts to daily life. Anxiety experience was measured by the Anxiety Experiences Questionnaire which modified from Tangkawanich, Yunibhand, Thanasilp, & Magilvy (2008).

Anxiety management strategy refers to the activity of an individual initiated and performed towards his/her ability to manage anxiety over the last week. Anxiety management report had obtained from the individual’s self report/ performance using the Anxiety Management Strategies Questionnaire, modified from Tangkawanich et al. (2008). The content comprises of both pharmacological and non-pharmacological strategies in dealing
with what strategies an individual uses, how often he/she does that particular strategy, and how well he/she perceives their strategies used to relieve their anxiety were assessed.

**Framework of the Study**

The conceptual framework of this study was derived from Symptom Management Model (SMM) developed by Dodd et al. (2001) which specific to anxiety symptom. The SMM focused on interrelationship among the three domains of symptom experience, symptom management and outcomes. There is a bidirectional relationship among the symptom experience, symptom management and outcomes. In this study, the domain of symptom experience and symptom management will be explored. Firstly, symptom experience is a dynamic, involving the interaction of three sub-concepts including an individual’s perception of symptoms, evaluation of symptoms and response to symptoms. Perception of symptoms refers to the perception of an individual towards a change from the way that the individual usually feels to behave. Evaluation of symptoms refers to the judgment of the individual to characterize the symptom experiences. Response to symptoms refers to the individual’s effects from the symptom. In this study, the symptom experience by in terms of perception, evaluation, and response were focused. Secondly, symptom management strategies refers to an individual symptom management process encompasses the components of what, how to manage that specific symptom or a cluster of symptoms. In this study, symptom management was focus on the individual’s self-management of the anxiety symptoms to reduce or relieve anxiety experience perceived by PLWHA in terms of what strategies they use, how often they do that particular strategy, and how well they perceive of their effectiveness used to relieve their anxiety.

**Research methodology**

**Research Design**

A descriptive study was used to describe the anxiety experiences and anxiety management strategies in people living with HIV/AIDS.

**Sample and Setting**

The study setting was outpatient departments at the Infectious Diseases Hospital (IDH), Dhaka in Bangladesh. It was one of the biggest hospitals for treatment of HIV/AIDS disease and collaborated with NGOs in the medical management of HIV/AIDS patient. By monthly medical record, about 25 to 26 PLWHA have received treatment from
hospital. The sample consisted of 75 people living with HIV/AIDS which estimated by Kirk (1995), who proposed that sample size of 50 – 100 were a good representation of the population for the descriptive studies. Purposive sampling was used for recruiting subjects using the inclusion criteria as follows: 1) had been diagnosed with HIV/AIDS by the doctor at least one month; 2) were alert and able to communicate in Bengali language; and 3) had experienced of anxiety in the last 2 weeks using a screening question “Have you ever felt anxious in the last 2 weeks?”.

**Instruments**

The instruments in this study composed of Demographic Data Assessment Form (DDAF), Anxiety Experiences Questionnaire (AEQ), and Anxiety Management Strategies Questionnaire (AMSQ). AEQ consisted of 4 items to assess anxiety perception, response and evaluation. Anxiety perception was consisted of anxiety occurrence assessed during past week until present (day 1- 7). The number of day would indicate rarely or low (1-3 days), sometimes or moderate (4-5 days), and often or high (6-7 days). Anxiety evaluation consisted of the severity of anxiety experiences and how much distressful of anxiety people living with HIV/AIDS have been using numerical rating scale from 1 to 10. Anxiety response consisted of the impact of anxiety on daily life of participants using numerical rating scale from 1 to 10. “1” indicated very low and “10” indicated very high. The higher total score indicated the higher anxiety. In order to determine the level of anxiety, the score of each item was divided into three levels as low (1-3), moderate (4-6) and high (7-10). AMSQ was composed of the statement relating to the anxiety management strategies in people living with HIV/AIDS including what to do (using a checklist with yes/no format), how often (using a checklist with daily, weekly), and how well each strategy used to relieve anxiety (using numerical rating scale from 1 (not at all) to 10 (very well). The higher score indicated the most helpful of the strategy.

**Content validity of instruments**

The content validity of the instruments was judged by three experts. One was a HIV/AIDS experts/consultant from the Infectious Diseases Hospital, Dhaka and two expert nursing instructors from Faculty of Nursing, Prince of Songkla University. Recommendations from the experts were used to modify the instruments to be appropriate for this study.
Reliability of the instruments

The reliability of the instruments was tested by using test-retest procedure with a one-week elapse time. The test-retest coefficients of the anxiety intensity, anxiety distressful, and impact of anxiety on daily life were 1.00, .87, and 1.00, respectively. For the AMSQ, the test-retest reliability coefficients ranged from .87 to 1.00.

Translation of Instruments

The instruments were translated with a back translation method by bilingual English expert. This method was preceded in three phases (Sperder & DeVellis, 1994). Firstly, the instrument of English version was translated into Bengali version by bilingual translator. Secondly, the Bengali version was translated back into English version by bilingual translator. Thirdly, the original instruments and the English back translated instruments were evaluated by bilingual English expert for discrepancies.

Data collection procedure

Permissions were obtained from Institutional Review Board of the Faculty of Nursing, Prince of Songkla University, Thailand and director of the Infectious Diseases Hospital. Researcher introduced himself and briefly explained the purpose of the study to the heads of outpatient department and medical department. The subjects who met the inclusion criteria were approached and informed about the study. Subjects were assured of their confidentiality and anonymity. Neither their name nor any identifying information was revealed in the reports of the study; their names were coded by number, and they had freedom of withdrawal from the study at any time. The questionnaires were checked the completion before leaving the subjects and entering data. Responses were coded, translated, and analyzed by the researcher.

Data analysis

Data were processed with computer program. The subjects’ demographic characteristics, health related data, anxiety experiences, and anxiety management strategies were analyzed using descriptive statistics, i.e., frequency, percentage, range, mean, and standard deviation.
Results

Demographic Characteristics

The majority of the subjects ranged in age from 20-40 years old (80.0%) with a mean age 35.47 years (SD = 7.26). The majority of the subjects were male (65.3%). Most of the subjects were Muslim (82.7%) and were married (94.7%). More than half of subjects completed primary school (54.7%). Thirty-seven subjects were migrants. Regarding medical payment, all subjects have got supports from Non-Government Organization (NGO). The majority of the subjects were married (94.7%) but most of them stayed alone. Twenty-four subjects (32.0%) lived in Dhaka divisions. Regarding health related data, majority of the subjects knew of HIV positive for an average of 3.77 years (SD = 2.60), half of the subjects (52.0%) reported their anxiety caused by fear of social discrimination and stigma after knowing of HIV/AIDS. They currently received anti-retroviral drugs (64.0%) and treatment with others medications such as antituberculosis and other symptoms. The most common symptoms reported by all subjects (100%) were itching and dry mouth followed by muscle weakness (98.7%), and loss of appetite (98.7%).

Anxiety experiences

Of 75 subjects, the majority of them reported a high level (M= 6.62, SD= 2.69) of overall anxiety experiences. Most subjects perceived their anxiety occurred almost of the time (90.7%). More than half of subjects evaluated their anxiety at a high level of both severity (M= 6.53, SD= .94) and distressful (M= 6.56, SD= 1.00). More than half of subjects reported a high level of responses (M= 6.77, SD= 1.13). (See Table 1)

Table 1
Mean, Standard Deviation and Level of Anxiety Experiences In terms of Perception, Evaluation and Response Reported by Subject’s (N = 75)

<table>
<thead>
<tr>
<th>Anxiety Experiences</th>
<th>M</th>
<th>SD</th>
<th>Low n (%)</th>
<th>Moderate n (%)</th>
<th>High n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety Experiences (1-10)</td>
<td>6.62</td>
<td>2.69</td>
<td>---</td>
<td>18(24.0)</td>
<td>57(76.0)</td>
</tr>
<tr>
<td>Perception</td>
<td>--</td>
<td>--</td>
<td>1(1.3)</td>
<td>6(8.0)</td>
<td>68(90.7)</td>
</tr>
<tr>
<td>Evaluation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Severity (1-10)</td>
<td>6.53</td>
<td>.94</td>
<td>1(1.3)</td>
<td>32(42.7)</td>
<td>42(56.0)</td>
</tr>
<tr>
<td>- Distressful (1-10)</td>
<td>6.56</td>
<td>1.00</td>
<td>---</td>
<td>30(40.0)</td>
<td>5(60.0)</td>
</tr>
<tr>
<td>Response (1-10)</td>
<td>6.77</td>
<td>1.13</td>
<td>---</td>
<td>34(45.3)</td>
<td>41(54.7)</td>
</tr>
</tbody>
</table>

Anxiety management strategies

Based on symptom management model that guided the study, subjects identified 26 strategies for anxiety symptoms under 6 categories. All subjects reported that they used both
pharmacological and non-pharmacological anxiety management strategies. Almost subjects used anti-anxiety agent (97.3%) and anti-depressant (90.7%). For non-pharmacological strategies, several strategies were used. The common strategies used by all subjects were talking with family and friends, health care provider, others with HIV, counselor, denial or try not to think, crying, stay alone, sleeping, talk myself through it, watch television, walking, prayer, and meditation. Moreover, most of the subjects with equal number (98.7%) attended support groups, read book and relaxation technique, and going mosque/temple. Using cigarettes (82.7%), alcohol (73.3%), and marijuana (52.0%) were also reported. Regarding the frequent use of those strategies, all subjects reported their daily used by talking with family and friends, denial or try not to think, prayer, and almost reported of using antidepressant drug (89.3%). Besides, the majority of the subjects reported their weekly strategies performed with swimming (76%), jogging (78.7%), talking with health care provider (81.3%), talking to HIV counselor (84.0%), relaxation technique (72.0%), swimming (85.3%), and alcohol (84.0%).

Effectiveness of anxiety management strategies

To assess the degree to which each strategy used to relieve anxiety (using numerical rating scale from 1 (not at all) to 10 (very well), subjects reported in various levels. For pharmacological management, the anti-depressant and anti-anxiety drugs were reported as helpful or high level (M = 7.69, SD = .72 and M = 6.99, SD = .51 respectively). In non-pharmacological anxiety management, the top 5 items with the highest score of helpful strategies were talking with family and friend (M = 7.23, SD = .48), watch TV (M = 7.21, SD = 1.06), attend support groups (M = 7.17, SD = 1.17), talking to HIV counselor (M = 7.04, SD = 1.10), and prayer (M = 6.99, SD = 1.18) were reported. While the 5 items of the least helpful strategies were jogging (M = 5.67, SD = 1.93), cigarettes (M = 5.59, SD = 1.77), marijuana (M = 5.48, SD = 1.81), alcohol (M = 5.03, SD = 1.99), and intravenous drug (M = 4.28, SD = 1.70) were reported (Table 2).
Table 2
Frequency, Percentage, mean and Standard Deviation of the highest and the lowest 5 items in Effectiveness of Anxiety Management Strategies Reported by the subjects (N = 75)

<table>
<thead>
<tr>
<th>Anxiety management strategies</th>
<th>Effectiveness Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
</tr>
<tr>
<td>Pharmacological: Medications</td>
<td></td>
</tr>
<tr>
<td>Use anti-depressant</td>
<td>68(90.7)</td>
</tr>
<tr>
<td>Use anti-anxiety agent</td>
<td>73(97.3)</td>
</tr>
<tr>
<td>Non-pharmacological:</td>
<td></td>
</tr>
<tr>
<td>The 5 items of the highest score</td>
<td></td>
</tr>
<tr>
<td>Talk with family &amp; friend</td>
<td>75(100.0)</td>
</tr>
<tr>
<td>Watch TV</td>
<td>75(100.0)</td>
</tr>
<tr>
<td>Attend support groups</td>
<td>74(98.7)</td>
</tr>
<tr>
<td>Talking to HIV counselor</td>
<td>75(100.0)</td>
</tr>
<tr>
<td>Prayer</td>
<td>75(100.0)</td>
</tr>
<tr>
<td>The 5 items of the lowest score</td>
<td></td>
</tr>
<tr>
<td>Jogging</td>
<td>64(85.3)</td>
</tr>
<tr>
<td>Cigarettes</td>
<td>62(82.7)</td>
</tr>
<tr>
<td>Marijuana</td>
<td>39(52.0)</td>
</tr>
<tr>
<td>Alcohol</td>
<td>55(73.3)</td>
</tr>
<tr>
<td>Intravenous drug</td>
<td>36(48.0)</td>
</tr>
</tbody>
</table>

Discussions

Demographic characteristics

Seventy five subjects who had experiences of anxiety in past two week were included in the study. The majority of the subjects were in the reproductive age (20-40 years old), and the higher proportion of male to female which was congruent with the national statistics (Government of the People’s Republic of Bangladesh, 2007). Most of the subjects were married (94.7%) which may reflect the high number of HIV transmission in the household as reported of the increased HIV prevalence in pregnant women (Panuwatsuk, 1998). It is interesting that those who had anxiety symptoms were migrants who having less income which may be because of unemployment, given reports as other studies in terms of psychological symptoms are the primary cause of unemployment among migrants living with HIV (Sanjay et al., 2005). Previous study by Azim et al. (2008) also reported that care and
support provisions for PLWHA in Bangladesh are limited. For medical payment, all subjects received supports from Non-Government Organization (NGO).

*Health related data*

The finding revealed that more than half of subjects currently received anti-retroviral drugs and other medications related to HIV-related symptoms. All regimens of ART and medications were free, but some who did not receive ART partly because their immune (CD4 count) had higher than 350 (T cells/cubic mm) and some reported that they were afraid of many complications particularly hair loss. Regarding current physical symptom, it was assessed by the researcher during interview. People living with HIV/AIDS often have multiple symptoms. Of 21 symptoms check list, most common HIV-related symptoms were itching, dry mouth, muscle weakness and loss of appetite, muscle aches, cramps, headache, rash and trouble sleeping, numbness, tingling or burning. The symptom prevalence was congruent with other studies (Holzemer, 2002; Kemppainen et al., 2003). However, some symptoms would be reduced after taking ART as the most subjects reported their current health status better than before.

*Level of anxiety experiences*

In this study most subjects had a high level of anxiety experienced (76.0%) with a high level of evaluation of symptom severity (56.0%) and distressful (60.0%). This may be because of several reasons. The most frequent causes of anxiety were fear of death, isolation, and social discrimination and stigma. The previous study also supported that the two most frequently reported sources of anxiety and fear of HIV diseases include fear of death and fear of future (Douaihy & Singh, 2001). These are all negative emotions and might contribute to a generally negative stress response. Fear in particular elicits the mood-congruent effects and associated with anxiety disorders (Kemppainen et al., 2003). Anxiety may be also caused by suffering from multiple physical symptoms. Due to several physical symptoms and past experiences of hospital admission, the anxiety experiences were at high level. This is supported by a study on self care management of anxiety and fear in HIV diseases which indicated that the levels of anxiety were higher among those who had physical symptoms compared to those who lacked physical symptoms (Kemppainen et al.). Not only the number of symptoms, but also the frequency reported by patients would indicate the severity of symptom burden and lead to the higher anxiety level (Kemppainen et al., 2006). For instance, when the symptoms are severe, the physical nature of symptom would stimulate the patients to seek help (Tsai, Hsiung, & Holzemer, 2003).
Effectiveness of Anxiety management strategies

Overall effectiveness of anxiety management strategies was measured by two main dimensions including pharmacological and non-pharmacological anxiety management strategies. The finding indicated that the majority of the subjects reported several strategies were effectiveness to reduce their anxiety particularly when used anti-depressant and anti-anxiety agent (Table 2). This finding was similar to the previous study (Tangkawanich et al., 2008) in terms of the strategies used. In this study, several non-pharmacological strategies were reported as effectiveness in an effort to alleviate the symptoms of anxiety. Using ventilation was the highest mean of effectiveness score (M =6.95, SD = .61) followed by using religious practice (M = 6.72, SD =1.10). Using ventilation can emphasize the importance of self care by seeking advice from supportive family, friends, providers and others with HIV/AIDS which remain the main sources of support in daily life of people living with HIV/AIDS. The subjects reported using religious practice as the second mean effectiveness which apparently played an important role in daily practice of most Muslim population. This finding suggested that the self healing method by praying could be one alternative intervention for managing of anxiety in Bangladesh. Similar to the previous study those self management strategies for anxiety should be encouraged by health care providers (Kemppainen et al., 2003).

Conclusion

It is clear from this research that anxiety symptoms continue to exist among people living with HIV/AIDS although ART is available. Anxiety management strategies are imperative in the management of these symptoms. Moreover, non-pharmacological activities performed by most of the subjects are common reported particularly the religious practice and family support.

Limitations

The limitations of the study are: 1) this study assessed anxiety experiences and self-management of anxiety in people living with HIV/AIDS in a single point of time which may not include all anxiety experiences and management strategies which are dynamic; 2) most of the people living with HIV/AIDS in this study were living of migrants or in other divisions of Bangladesh, having a burden of environment/ economic and social condition from others, especially those living in poorer areas. So findings are limited and may not be generalized to all people living with HIV/AIDS in Bangladesh; 3) reliabilities of some sub-scales in the
Anxiety Management Strategies Questionnaire were rather low, indicating a need to adjust some items in future study.

**Recommendations**

The findings could emphasize the importance of assessment of anxiety symptom in a clinical setting. Due to limited access to resources in a country, some effectiveness of self management strategies particularly non-pharmacological methods should be encouraged to enable people living with HIV/AIDS to relieve their anxiety and maintain daily life function. Religious practice and family support should be contributed as the main sources in managing anxiety symptoms. However, the comprehensive intervention is required to test its effectiveness as the anxiety is caused by several factors and partly under recognized and under reported.

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References


