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# Self-care intervention guidelines on reduction of anxiety among persons living with Human Immunodeficiency Virus

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**Abstract**
*In India, among persons living with human immunodeficiency virus/ acquired immune deficiency syndrome, 88.55% are in the age group of 15-49 years, out of which 27.8% are in the age group of 15-29 years. Comprehensive and diligent self-care is important for the affected people because of the chronic nature of the disease. The aim of this study was to develop and assess the effectiveness of self- care intervention guidelines in reducing the anxiety of persons living with human immunodeficiency virus. Adult subjects on antiretroviral therapy in any clinical stage were selected using systematic random sampling technique. An experimental research design was adopted and State Trait Anxiety Inventory Scale was used to measure the anxiety. A total of 150 subjects were recruited with 75 in the control and 75 in the experimental group using the permuted block randomization. Data collection was done at three time points at the antiretroviral therapy clinic. The mean age of subjects in both the groups was almost similar (control-40.86 ± 8.74, experimental-39.34 ± 7.38) which reflects that subjects are in their productive age group. The subjects' mean score difference on anxiety between the control and experimental group was 4.29, 3.81, and 5.41 in the pre-test, post-test I and post-test II respectively at p<0.001. Based on the above findings, the study concluded that the self- care intervention guidelines is an essential and effective intervention in reducing the anxiety of people affected with human immunodeficiency virus.*
**Keywords:** *Anxiety, Persons Living with Human Immunodeficiency Virus, Self- Care Intervention Guidelines.*

## Introduction

The impact of Human Immunodeficiency Virus (HIV) is very intense on all the domains of life such as physiological, psychological, social and economic domains due to the nature of disease coupled with side effects of Antiretroviral Therapy (ART). HIV/Acquired Immune-deficiency syndrome (AIDS) and anxiety are interrelated. Anxiety is one of the most commonly expressed psychological aftermaths if one is infected with HIV/AIDS because of HIV status and the fear of death and concern regarding the

symptoms related to the disease. An HIV positive diagnosis may trigger symptoms of anxiety and depression, which may result in non-adherence to ART. Anxiety affects the well being of HIV positive individuals when they become preoccupied with the possibility of future helplessness or dependency. A cross sectional study on 220 HIV-positive outpatients assessed the prevalence of common mental health disorders using a standardized questionnaire and found that 15.5% of PLHIV had depression, or mixed anxiety and depression.[1]

Persons living with HIV/ AIDS (PLHIV) need to follow meticulous self- care for life long and it includes compliance to ART, and supportive care such as diet, physical activity, prevention, early detection and management of opportunistic infections and home care management of minor ailments caused by ART or HIV disease.

## Background

Anxiety is prevalent among a majority of PLHIV without any prior anxiety disorders. An HIV positive diagnosis may trigger symptoms of anxiety and depression, which may in turn result in risky sexual behavior and the spread of HIV.[2-4] Miles et al., conducted a study on self-care symptom management intervention for emotional distress such as anxiety and depression. The results showed that subjects in the experimental group reported fewer feelings of anxiety, depression and stigma and higher physical function scores than the subjects in the control group.[5]

It is hoped that knowledge about self-care, especially on common side effects of ART, minor ailments or symptoms due to HIV and opportunistic infections and ways to manage those symptoms at home and prevention of complications will help in reducing their anxiety regarding progression of their HIV status which will further make positive impact on quality of life. Their optimum health and wellness depends largely on their level of understanding about the importance of self- care and the extent to which

they adhere to self- care. There have been no nursing studies reported on effectiveness of self-care interventions in reducing anxiety of PLHIV who take free ART from ART clinics in India.

In view of the aforementioned reasons, the present study was planned to develop and assess the effectiveness of self- care intervention guidelines on PLHIV, in terms of changes in their level of anxiety. In this study, the guidelines on self- care were developed in simple language and designed to be appropriate and acceptable to the South Indian culture. These self-care intervention guidelines provide information for PLHIV regarding various aspects of management and the life style modifications they need to adopt to lead a positive living to improve their quality of life. The objectives of the study were to evaluate the effectiveness of self- care intervention guidelines on reduction of anxiety of PLHIV and to identify the relationships of pre-test scores of anxiety of PLHIV with their selected socio-demographic and clinical variables.

## Methods
### Design and sampling

An experimental design was used. The study was conducted at the ART Clinic of the tertiary level hospital in Tamil Nadu. A total of 150 subjects were randomly allocated to the experimental and control group by permuted block randomization with 75 subjects in each group. Sample size was determined based on the pilot study findings assuming the SD of 10 points with the power of 80% and at 5% level of significance. The calculated number was 63 which was increased to 74 per group (a total of 148) to allow for a predicted drop out of 15% in the follow up. Systematic random sampling technique was used to select the subjects.

Inclusion criteria included PLHIV who were willing to give consent, who could speak and understand Tamil or English, who were in any clinical stage described by the World Health Organization and were above 18years old. PLHIV with dementia, who were on any anti-anxiety

drugs and chronic co-existing debilitating diseases such as COPD, cancer, renal disease were excluded from the study.

## Instrument

A proforma was used to collect socio-demographic and clinical data. The socio-demographic data included age, sex, marital status, education, family income, type of family, and locality. The clinical profile included duration of HIV infection, HIV status of spouse, side effects of ART, and duration of ART.

State-Trait Anxiety Inventory Scale (STAI-Y1) was used to measure the anxiety of PLHIV. It is a standardized scale comprised of 20 items rated on a 4-point scale. The maximum possible total score was 80.[6,7] The score was interpreted as "Low anxiety" (20-34), "Moderate anxiety" (35-49), "High anxiety" (50-64), and "Very high anxiety" (65-80). The tool was translated into Tamil and back translated by language experts. The reliability coefficient of the translated version was 0.97.

## Development of study intervention

Self- Care Intervention Guidelines (SCIG) is the intervention which was developed by the investigator based on the intensive literature review and validated by the clinical experts. SCIG is a manual containing topics on self-care aspects such as "Impact of HIV on immune system; Prevention of re-infection with different types of HIV; Management including Compliance to ART, Nutrition, Personal Hygiene, Physical Activity/ Exercise, Complementary Therapies, Psychological, spiritual and social aspects of management, Prevention of Opportunistic Infections (OIs), early detection and management of OIs and Home care management of minor discomforts."

## Data collection procedure

The data collection was done for a period of six months from March, 2014 to August, 2014. A written consent was obtained from the subjects after explaining about the purpose of the study following which they were allocated into either control or experimental group using permuted block randomization. Interview technique was used to collect the data. Data collection was done at three time points for each subject in both the control and the experimental groups. The subjects were interviewed separately and privately at ART Clinic.

As soon as they were recruited, data on socio-demographic and clinical variables and pre-test anxiety of PLHIV were collected from subjects in both the groups by the investigator. After the pre-test, the subjects in the experimental group were taught about self- care by the investigator privately and individually using discussion, and demonstration as teaching methods. This took approximately 60-90 minutes. Then, each subject was given a copy of the SCIG and asked to read it completely at home and follow the self- care instructions appropriately. The subjects in the control group received the routine care.

The first post-test assessment was done for both the groups at 4-6 weeks followed by the second post-test at 12-14 weeks. The subjects in the experimental group received reinforcement of teaching after the first post-test assessment. At the end of data collection, the subjects in the control group were also given teaching and a copy of the SCIG.

## Results and Discussion

Two subjects from the experimental group and three from the control group were not available for the post-test assessments. Hence, analysis of the data was done for 73 and 72 subjects in the experimental and the control group respectively using Statistical Analysis System (SAS) version 9.2. Frequency and percentages were used to assess the anxiety of PLHIV before and after routine care and SCIG. To assess the changes in anxiety overtime within group, repeated measures ANOVA was used. To evaluate the effectiveness of SCIG in reduction of anxiety between the control and experimental group, independent t test was used. Chi square test, and logistic regression were used to find out the association of pre-test scores of anxiety of PLHIV with their socio-

demographic and clinical characteristics. The statistical significance was defined as p<0.05.

The mean age of the subjects in both the groups was similar (control-40.86 ± 8.74, experimental-39.34 ± 7.38). Majority of the PLHIV (56.94% in control, 60.27% in experimental) were males. Majority of the PLHIV (66.67%) in the control group and 54.79% in the experimental group has completed high school education. Regarding the duration of ART, the majority (56.94%) in the control and 57.53% in the experimental group was on ART for more than three years. Both groups were similar with regard to their socio-demographic and clinical characteristics (p >0.05) except the age (p=0.044).

The findings of the pre-test in the control group revealed that nearly half (48.61%) of the subjects had moderate anxiety. But in the experimental group, 41.10% of PLHIV had high anxiety as shown in table 1. These findings are supported by the studies which reported that more than 30% of PLHIV had anxiety[8-10].

The common factors identified in this study which were associated with anxiety especially among young women PLHIV either separated or widowed were "unpredictable future and discrimination they face in the family particularly with their in-laws." Some of them were even denied of property by their own parents and in-laws. Most of them expressed that they are anxious about their unpredictable health condition and job security. The majority (81.38%) of the PLHIV expressed that they did not feel secure and 58% of them felt very tensed.

Regarding the changes in anxiety overtime within groups, it was noticed that the mean score in the control group reduced from 46.90 in the pre-test to 41.51 in the post-test II and the difference is found to be statistically significant at p<0.001. In the experimental group, the mean score in the pre-test was 51.19 which drastically declined to 36.10 in the post-test II and the difference is statistically significant at p<0.001 (table 2).

With regard to difference in mean score anxiety of PLHIV between control and experimental group, there was a statistically significant difference found at p<0.001. The post-test I mean scores were 44.19 and 40.38 in the control group and experimental group respectively. It shows that there was a marked reduction noted in the anxiety scores (10.81) between pre-test and post-test I among subjects in the experimental group than in the control group (2.71) (p<0.001). This score continued to show a significant reduction in the post-test II in the experimental group (p<0.001). Though both the groups were not homogenous in terms of pre-test anxiety scores, there was a statistically significant difference (p<0.001) after the intervention (as shown in table 3). A few studies found that the anxiety levels of PLHIV were reduced with education on physical exercise, progressive muscle relaxation and mantram recitation[11].

Out of all the socio-demographic and clinical variables, it was found that only gender and duration of ART had an association with pre-test anxiety of PLHIV. It was further observed that the female subjects had 2.24 times, [95% CI (0.95, 5.29)] more chances of very high anxiety as compared to the male subjects and is statistically highly significant (p<0.001). This finding of the present study is supported by the study which also reported that the female gender was associated with a higher anxiety[12]. Subjects who had 6 months to less than one year of duration of ART, had 0.12 times, [95% CI (0.02, 0.59)] more chances of very high anxiety compared to the subjects with < 6 months duration (p<0.01) as shown in table 4 & 5).

**Table 1:** Distribution of subjects based on overall anxiety in control and experimental group during pre-test, post-test I and post-test II

| Group | Categorization of Anxiety | Pre-test | | Post-test I | | Post-test II | |
|---|---|---|---|---|---|---|---|
| | | no | % | no | % | no | % |
| Control (N=72) | Low | 9 | 12.50 | 8 | 11.11 | 11 | 15.28 |
| | Moderate | 35 | 48.61 | 47 | 65.28 | 56 | 77.78 |
| | High | 26 | 36.11 | 17 | 23.61 | 5 | 6.94 |
| | Very high | 2 | 2.78 | 0 | 0 | 0 | 0 |
| Experimental (N=73) | Low | 2 | 2.74 | 8 | 10.96 | 24 | 32.88 |
| | Moderate | 35 | 47.95 | 60 | 82.19 | 49 | 67.12 |
| | High | 30 | 41.10 | 5 | 6.85 | 0 | 0 |
| | Very high | 6 | 8.22 | 0 | 0 | 0 | 0 |

**Table 2** Within group comparison of pre-test, post-test I and post-test II mean scores of PLHIV on overall anxiety in control and experimental groups

| Anxiety | Pre-test | | post -test I | | Post-test II | | F value | P value |
|---|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | Mean | SD | | |
| Control group (N=72) | 46.90 | 8.83 | 44.19 | 6.86 | 41.51 | 5.89 | 54.58 | <0.001*** |
| Experimental group (N=73) | 51.19 | 8.94 | 40.38 | 5.72 | 36.10 | 4.05 | 246.54 | <0.001*** |

***p<0.001

**Table 3** Comparison of mean score differences in the pre-test, post-test I and post-test II measurements of PLHIV on anxiety between control and experimental group

| Anxiety | Control (n=72) | | Experimental (n=73) | | Mean difference | t value | P value |
|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | | | |
| Pre-test | 46.90 | 8.83 | 51.19 | 8.95 | 4.29 | 2.91 | 0.004** |
| Post-test I | 44.19 | 6.86 | 40.38 | 5.72 | 3.81 | 3.63 | <0.001*** |
| Post-test II | 41.51 | 5.89 | 36.10 | 4.05 | 5.41 | 6.45 | <0.001*** |

**p<0.01          ***p<0.001

**Table 4** Association between pre-test anxiety scores of PLHIV and their selected socio-demographic and clinical characteristics (N=145).

| Variables | Anxiety | | | | | | | | $\chi^2$ | df | P value |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Very high | | High | | Moderate | | Low | | | | |
| | n | % | n | % | n | % | n | % | | | |
| **Age (years)** | | | | | | | | | 16.00 | 9 | 0.063 |
| <30 | 2 | 25.00 | 6 | 10.71 | 4 | 5.71 | 1 | 9.09 | | | |
| 30-45 | 6 | 75.00 | 40 | 71.43 | 48 | 68.57 | 4 | 36.36 | | | |
| 46-60 | 0 | 0 | 10 | 17.86 | 15 | 21.43 | 6 | 54.55 | | | |
| >60 | 0 | 0 | 0 | 0 | 3 | 4.29 | 0 | 0 | | | |
| **Gender** | | | | | | | | | 17.69 | 3 | <0.001*** |
| Male | 0 | 0 | 28 | 50.00 | 49 | 70.00 | 8 | 72.73 | | | |
| Female | 8 | 100 | 28 | 50.00 | 21 | 30.00 | 3 | 27.27 | | | |
| **Marital status** | | | | | | | | | 15.35 | 9 | 0.067 |
| Single | 1 | 12.50 | 3 | 5.36 | 6 | 8.57 | 1 | 9.09 | | | |
| Married | 2 | 25.00 | 34 | 60.71 | 51 | 72.86 | 7 | 63.64 | | | |
| Separated/ divorced | 2 | 25.00 | 4 | 7.14 | 1 | 1.43 | 0 | 0 | | | |
| Widowed | 3 | 37.50 | 15 | 26.79 | 12 | 17.14 | 3 | 27.27 | | | |
| **Duration of ART** | | | | | | | | | 22.39 | 9 | 0.005** |
| < 6 months | 1 | 12.50 | 5 | 8.93 | 1 | 1.43 | 0 | 0 | | | |
| 6 months - < I year | 0 | 0 | 4 | 7.14 | 3 | 4.28 | 0 | 0 | | | |
| 1-3 years | 6 | 75.00 | 23 | 41.07 | 17 | 24.29 | 2 | 18.18 | | | |
| > 3 years | 1 | 12.50 | 24 | 42.86 | 49 | 70.00 | 9 | 81.82 | | | |
| P value is obtained from Fisher's Exact test for all the variables. | | | | | | | | | | | |

**p<0.01   ***p<0.001

**Table 5** Results of the proportional odds model using pre-test anxiety as response with ordered categories.

| Variables | Category | Estimate | SE | Odds Ratio | 95%CI | P value |
|---|---|---|---|---|---|---|
| Gender | Female | 0.807 | 0.44 | 2.24 | (0.95,5.29) | <0.001*** |
| | Male | 0[a] | | | | |
| Duration of ART | >3years | -0.669 | 0.85 | 0.51 | (0.09,2.71) | 0.134 |
| | 1-3years | -1.396 | 1.10 | 0.25 | (0.03,2.15) | 0.117 |
| | 6 months-< 1 year | -2.161 | 0.83 | 0.12 | (0.02,0.59) | 0.002** |
| | < 6 months | 0[a] | | | | |

**p<0.01   ***p<0.001

## Implications

The study revealed that the self-care intervention guidelines was effective in reducing the level of anxiety of PLHIV. Hence, nurses and other health care team members working in the ART clinics or in the OPDs can be oriented about all the self-care components using this manual. The learning materials on self-care also can be made available for PLHIV in the ART clinics in vernacular languages which can be used to improve their knowledge regarding self-care which will enhance their self-confidence and self-esteem.

## Conclusion

The findings of this study relied on self-reporting of subjects which is considered to be the limitation. This study recommends one to one education program for PLHIV attending OPD/ ART clinic followed by reinforcement of teaching during each follow-up visit. This study is part of the major Ph.D. research work.

## Acknowledgement

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