



A STUDY TO EXPLORE THE LIVED EXPERIENCES OF PLHIV AT SELECTED ART CENTRES: A PILOT STUDY

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ABSTRACT

Nursing personnel being an important member of health care team, play a very significant role in providing direct as well as indirect care to deal with needs of PLHIV at various hospital settings. The focus of this paper is to present the studies related to lived experiences and stigma discrimination faced by the PLHIV and explore about their psychosocial problems and their coping strategies about their psychosocial problems.

KEYWORDS PLHIV (People living with HIV), lived experiences, Phenomenology

INTRODUCTION

HIV continues to be a major global public health issue, having claimed more than 34 million lives so far. In 2014, 1.2 [980 000–1.6 million] million people died from HIV-related causes globally.

There were approximately 36.9 [34.3–41.4] million people living with HIV at the end of 2014 with 2.0 [1.9–2.2] million people becoming newly infected with HIV in 2014 globally.

Sub-Saharan Africa is the most affected region, with 25.8 [24.0–28.7] million people living with HIV in 2014. Also sub-Saharan Africa accounts for almost 70% of the global total of new HIV infections.

There is no cure for HIV infection. However, effective antiretroviral (ARV) drugs can control the virus and help prevent transmission so that people with HIV, and those at substantial risk, can enjoy healthy and productive lives. Between 2000 and 2015, new HIV infections have fallen by 35%, AIDS-related deaths have fallen by 24% with some 7.8 million lives saved as a result of international efforts that led the global achievement of the HIV targets of the Millennium Development Goals. Expanding ART to all people living with HIV and expanding prevention choices can help avert 21 million AIDS-related deaths and 28 million new infections by 2030.

REVIEW OF LITERATURE

The study used primary data collected through in depth Interview schedule, and periodic visit to the selected ART Centres in Delhi and Secondary data was collected from Government documents, books, journals, available records, bibliographies, unpublished dissertations, and websites visited through internet and by visits to various offices of Health Department and voluntary organizations.

Section 1: Literature related to magnitude of HIV/AIDS.

1. TOI (2014) Reported that 22 million people were tested during 2013-2014 by NACO, of which 2,40,234 people were found HIV positive. Finding revealed that total female sex workers 8.68 lakh and 2.7% are HIV prevalence, total MSM 4.27 lakh and HIV prevalence 4.4%, total IDU 1.77 lakh and among 7.1% HIV prevalence 8.8% prevalence rate among transgender population, total long distance truckers 20 lakh and HIV prevalence rate 2.6%.

It was also found that over 12,000 pregnant women who were positive with HIV.

2. Kihulya Mageda et al (2012) conducted a study noted that after examining the mortality rate and its predictors from a five years retrospective cohort data of HIV patients of the 546 patient records retrieved the mean age was 37 years with median CD4 count of 156 cells. The mortality rate was 4.32/100 person, years at risk with males having three times higher mortality compared to females, starting antiretroviral treatment with advanced disease state, body weight below 45 kg.

3. TOI (Dec 2014) reported that over 22 million people were tested during (2013-14) by NACO and showed 2,40,234 people were found HIV positive and this included over 12,000 pregnant women who were diagnosed with HIV virus.

Further classified report showed that total 8.68 lakh sex workers and HIV prevalence rate 2.7%, total MSM 4.27 lakh and HIV prevalence rate of HIV among transgender 8.8%, total long distance truckers 20 lakh and 2.6% HIV prevalence rate.

4. WHO (2013) stated that 35.3 million people were living with HIV worldwide, including 3.3 million children. The global prevalence rate was 0.8% there were 2.3 million new HIV infections, including 260,000 children from which approximately 95% are in low and middle income countries and about 700 infections are in children under 15 years of age. An estimated 5,500 new HIV infections are in adults aged 15 years and older, of whom almost 47% are among women and about 39% are among young people of age 15-24 years. Since the beginning of epidemic, more than 75 million people have been infected with HIV and approximately 36 million people have died of AIDS related illness. It is estimated that each day 6300 individuals worldwide are infected with HIV.

Section 2: Literature related to the Stigma and Discrimination faced by PLHIV.

1. Kaur, Baldeep. (2014) conducted a cross-sectional descriptive study on HIV related stigma in people living with HIV/AIDS (PLHA): Role of gender differences. Samples were 100 HIV patients (50 Males and 50 Females) who were registered in ART centre, Patiala for HIV treatment. The study revealed that HIV females scored higher on stigma scale as compared to HIV males.

2. Ross, W Michael. (2014) conducted a qualitative Study of HIV Among Seropositive Gay Men in a Southern U.S City. Thematic analysis of 19 gay men's narratives identified six main themes. The study revealed that Encountering HIV stigmatization was common and was linked to the physical stigmata identifying respondents as HIV-positive. Overwhelmingly, they found stigmatization to be most intensely felt within gay communities.

3. Moses Susan, Tomlishon Mark (2012)-stated that stigma and discrimination after being infected with have been the biggest challenge to fight against HIV. Due to such kind of societal

based practices, PLHIV have been forced to experience the trauma of disclosure which in fact has caused a serious problem in providing PLHIV a good positive living.

4. Patel SV, et al (2012) Perceived HIV-associated stigma, fear of discrimination, and fear of family breakdown acted as barriers to HIV disclosure. The focus group participants confirmed similar findings 20 family members, 20 villagers from non-HIV-positive households and 20 health workers, were selected as study subjects by using purposive sampling method and interview schedule in rural areas of Anhui Province. The study revealed that of the 79 subjects who finished the survey, the main forms of stigma and discrimination were expanded stigma[81.0% (64/79)], abandonment and avoidance, stigma and discrimination in healthcare setting[47.4% (28/59)], loss of social support[33.3% (13/39)]. The level of stigma was less in village where were more HIV-positive villagers living and vice-versa. The reasons for stigma and discrimination included: ignorance or misunderstanding of HIV/AIDS [57.5% (23/40)], fear of HIV/AIDS [32.5% (13/40)] and morality judgment toward PLHA

[Source: Strengthening institutional capacity for nursing training on HIV/AIDS (GFATM R7): PLHIV satisfaction Survey Midline Assessment -2011-12

Section 3: Literature related to the Lived experiences of PLHIV.

1. Nagtaetal (2011) conducted a Qualitative study an increase in hunger or appetite since initiating ART; exacerbation of ART-related side effects; non-adherence to ART due to hunger, food insecurity.

2. Ahmad F etal (2004) Mental health (MH) emerged as an overarching health concern with three major themes i.e. appraisal of the mental burden (extent and general susceptibility), stress-inducing factors, and coping strategies. The stress-inducing factors identified by participants included loss of social support, economic uncertainties, downward social mobility, mechanistic lifestyle, barriers in accessing health services, and climatic and food changes.

3. Thiangtham W, Bennett T. (2009)16 HIV positive pregnant women volunteered to participate from June 2005 to June 2006. Data were collected through unstructured multiple in-depth individual interviews, observation, field-note, tape recorded and transcribed, and analyzed thematically.

Two patterns emerged: first was a pattern of suffering, secondly, was a pattern of hope. Suffering was caused by fear of condemnation from their spouses, and by fear of disappointing their larger families.

4. Nagata et al (2011) studied significant determinants of food insecurity include increased age, a greater number of children, and not being married, themes related to food insecurity and ART emerged, including: (1) an increase in hunger or appetite since initiating ART; (2) exacerbation of ART-related side effects; and (3) non-adherence to ART due to hunger, food, insecurity, and agricultural work responsibilities. HIV interventions should address food insecurity and hunger, particularly among at-risk populations, to promote ART adherence and better health outcomes.

5. Patel et al conducted a study on PLHIV selected from the Voluntary Counseling and Testing Centre (VCTC) in Gujarat, conducted two focus group discussions (FGDs) with medical and non-medical providers, respectively. Thirty PLWHA coming to the VCTC participated in one-to-one, in-depth interviews following a semi-structured and culturally sensitive outline of questions after taking written informed consent in local language..

Each in-depth interview took approximately 120 minutes. Non-verbal assessment was also done simultaneously during the interview and noted.

Two FGDs, one each with 7 medical providers and 8 non-medical providers, were conducted after taking written informed consent and were audio recorded.

Findings revealed that PLHIV Travelling and commuting to clinic faced fear of possible physical reactions, high cost of ART from private practitioners, CD4 count being in normal limits and resistance to medication acted as barriers to ART adherence. Initiation of ART was facilitated by family members' suggestion, advice of treating doctors and counselors, appropriate counseling before starting ART, belief that ART would aid in living a better and longer life and due to lowering of the CD4 count.

Section 4: Literature related to psychosocial problems among people living with HIV (PLHIV).

1. JayakumarPalanisamy (2011) Discrimination perceived was 68.8% and mostly in their own house or by neighbors, but most of their children (99.2%) were discriminated as per the clients. Spouse positive rate for married client was 61.5% and unmarried in this population was 4.6%. Major or minor psychological problems in this group were 39.7% attempted suicide was 8.8%.

Drug abuse (alcohol and smoking) while started on ART was 40.4% and the current abusers are 7.6%.

2. Chittiprol S, Kumar AM (2010) stated in India, significant cognitive deficits are reported in advance HIV disease in patients not receiving HAART. IN one study, 56% of PLWHA were demonstrated to have impairment in at least two cognitive domains. Neurocognitive disturbances in asymptomatic HIV infection have been a subject of research interest in view of the implications on its influence on occupational functioning. Between 60-90% of asymptomatic subjects with HIV have been reported to have cognitive deficits.

3. Sun, L,etal (2009)- stated that majority of patients living with HIV/AIDS has moderate to high level of loneliness, may limit their ability or access to social relationship. The findings support that if patients living with HIV/AIDS are better supported &cared, their negative psychosocial consequences might be prevented or at least reduced

4. Mazengera, R Dadirayi. (2008) conducted a study on HIV/AIDS Related Stigma and Discrimination at selected Health Facilities in Chiradzulu District. A purposive sampling technique was used and data for study was obtained from three groups of respondents as follows: 3 local community leaders, namely, a religious leader, 4 health personnel who work with AIDS patients and 12 people living with AIDS. Only those people living with HIV/AIDS who have been utilizing the facility for more than 6 months were included in this study. The study revealed that stigma and discrimination were explored by examining views of people living with HIV/AIDS about the provision of health care services, and the perception of community leaders on the HIV/AIDS services rendered at the health facilities.

5. Ramasubramanion C, (2007) psychiatric morbidity in AIDS patients shows 5% of patients were suffering from depression disorder, 12% had GAD, 10% had drug dependence, 3% had panic disorder, 2% had schizophrenia and 4% had personality disorders.

Section 5: Literature related to Coping Strategies adopted by PLHIV.

1. Michaud PA (2010) conducted a descriptive study to assess the coping strategies of adolescents living with HIV. The aim of the study was to assess specific stressors and coping responses employed by youth with HIV. Data were analyzed from 166 adolescents infected with HIV in three major US cities. The result showed that the youth with moderately advanced disease (CD4 200-500 cells/mm³) used a passive coping style more often than healthier youth

(CD4 > 500 cells/mm³). Additionally, passive coping was associated with greater emotional and behavioral problems. Youth infected with HIV may benefit from interventions promoting adaptive coping responses to HIV-specific stressors, particularly medication adherence.

2. Sun H, Zhang J, Fu X. (2007) investigated on psychological status, coping, social support, and psychosocial factors associated with people living with HIV/AIDS in a highly HIV-infected area. A cross-sectional descriptive correlation study was done on 200 samples. A demographic profile, symptom check list, coping modes and perceived social support scale was used. Participants reported that the most frequently used coping style was confrontation. Both acceptance-resignation and avoidance coping styles were significantly correlated with high distress. This study concluded that health professional may consider further interventions to promote psychological health in HIV/AIDS-positive individuals.

3. Grassi L, Righi R, Sighinolfi L, Makoui, Ghinelli F. (2004) examined a relationship between coping and psychosocial variables among 108 HIV infected patients. The researcher assessed fighting spirit and degree of hopelessness, to assess each patient's individual coping style. The study findings revealed that a coping style based on incapacity to face and confront HIV infection was associated with symptoms of psychological stress, repression of anger and low social support was found in patients who were not adjusting well to their HIV positive status. The data support the hypothesis that coping with the HIV infection is a complex phenomenon involving the interaction of multiple variables. The study concluded that interventions aimed at improving the coping strategies of HIV Patients are needed.

RESEARCH METHODOLOGY

Research Design

The present study uses Phenomenological (Hermeneutic) design because the findings of the study are made by the combination of observing the phenomenon i.e. the participants and the researcher's views thereby producing a meaningful account.

STATEMENT OF THE PROBLEM

A study to explore the lived experiences of PLHIV at selected ART Centre's in Delhi.

Aim of the Study: The primary aim of the study was to gain in-depth understanding of the experiences of PLHIV

Research Question

From the perspective of people with HIV infection, what is the experience of living with HIV infection?

Objectives of the Study

1. To understand the lived experiences of people living with HIV infection.
2. To give participants an opportunity to narrate their HIV experiences.
3. To explore the lived experiences of peoples living with HIV infection.
4. To analyse the meaning of experiences of people living with HIV infection.

Operational Definitions

HIV: The virus that causes AIDS by infecting human lymphocytes called T-lymphocytes

HIV/AIDS: It refers to a disorder caused by the human immunodeficiency virus (HIV) transmitted through direct contact of a mucous membrane or the bloodstream in which there is damage to the human immune system leaving an individual susceptible to opportunistic infections.

PLHIV: -It refers to the people living with HIV above 18 years of age and diagnosed as a case of HIV as per as the records and who are attending selected ART Centres for treatment in Hospitals of Delhi.

Lived Experiences: It refers to the experience which describes the first-hand accounts, impressions and experiences faced by the PLHIV during day to day life as elicited through in depth interview .These lived in experiences may include but not limited to physical, psychological, psychosocial, and financial experiences on account of HIV/AIDS.

ART Centres: -It refers to the centres of selected ART Centre which are involved in the treatment of HIV infected persons with provision of free lifelong supply of antiretroviral drugs, Diagnosis and management of other opportunistic infections Care of HIV patients (Pre-ART care) and giving in high quality counselling by trained counsellor.

Variables under study

The tool has demographic characteristics comprised of gender, age, Marital Status, Religion, Educational Status, occupation ,Economic status, Type of family, Number of siblings, Number of year of diagnosis, Duration of accessing services at the ART Centre, Present chief complaints, past medical and surgical history, history of substance abuse (smoking, alcohol, tobacco chewing, drug abuse),Family h/o HIV, Domicile.

Assumptions

In the present study it is assumed that:

- 1 PLHIV will express their feelings views and needs freely related to HIV.
- 2 HIV/AIDS has some impact on the life of PLHIV and they do experience physical, psychological, psychosocial, financial problems and have special needs.
- 3 In depth interviews with PLHIV can bring out their real experiences on account of HIV/AIDS.

Delimitations

The present study is delimited to:

- PLHIV of age above 18 years of age who are attending selected ART Centre's in Delhi.
- In-depth Interview schedule delimited to one interaction only.

Conceptual Framework

The conceptual framework will emerge after studying the final data phenomenon.

Setting

Setting of the study refers to the physical location and conditions in which data collection takes place in a study. Current study was undertaken at selected ART Centre in Delhi.

Population

People living with HIV above 18 years of age and diagnosed as a case of HIV as per as the records and who are attending ART Centres for treatment.

Sample

People living with HIV above 18 years of age and diagnosed as a case of HIV as per as the records and who are attending ART Centres for treatment in selected hospitals of Delhi and who met inclusion criteria were chosen for the study.

Sampling Technique: Purposive sampling technique was used for selecting the sample.

Inclusion criteria

1. PLHIV attending selected ART Centres for treatment of age above 18 years.
2. PLHIV who can speak and understand Hindi/English.
3. PLHIV who were available and were willing to participate in the study.
4. People who were aware of that they have HIV/AIDS.

Exclusion Criteria

1. PLHIV who were having psychiatric illness.

Sampling Design:-

To select participants for the study, criterion purposive sampling was used. The subjects who met inclusion criteria were enrolled for the study.

Sample Size: Sample size for the pilot study was comprised of 2 PLHIV who were attending ART Centre for treatment.

Ethical Consideration

Prior to commencing this study, obtained permission from the Institutional Review Board, Amity University, Gurgaon. Permission was also taken from the selected ART Centre for conducting the study. Informed written consent was obtained and before writing field notes verbal consent was taken from participants.

Data Collection Tools and Techniques:

Based on the objectives of the study, self-report method was found to be most feasible to collect relevant data. In depth interviews was found to be the most appropriate technique for data collection.

The following tools were used for the study

1. Subject data sheet
2. In-depth interview Schedule.
3. Field notes of Interviews and observation

Content validity and try out: content validity of the data sheet was obtained from nine different experts from various field of psychology, various Nursing specialities, and statistician. The content validity was found to be 0.94. The tool was tried on two samples and found to be feasible.

Pilot Study

Pilot study was conducted on two PLHIV selected from ART Centre. They were enrolled on the basis of inclusion criteria. Data was collected and analyzed based on the objectives. On the basis of the responses made it was found that the study was feasible.

Method of data collection

Interviewing is the predominant mode of data collection in qualitative research. Interviews in a qualitative study may be formal, in that they are prearranged with informants for the purpose of detailed conversations, or they may be informal, in that they are unplanned encounters during periods of participant observation in a setting of importance to the study. Further, interviews may be done on a one-time basis or repeated over-time, either in face-to-face encounters or by telephone follow-up. Interviews may also be done with one or more than one informant at a time (sometimes referred to as "solo" and "conjoint" interviews.)

Trustworthiness of the Data

Credibility: It refers to confidence in the truth of data and interpretations. The credibility was ensured in the present study by:

- Prolonged engagement and persistent observation by the investigator to build trust and rapport.
- Triangulation: means use of multiple referents to draw conclusion.

Data triangulation: is use of multiple data source. In the present study, different sources of data collection were used, e.g. interviews, field notes. Person triangulation: Data was collected from the PLHIV above 18 years of age.

Confirmability: It refers to the objectivity/ neutrality (freedom from bias) of the data. To ensure confirm ability, the collected data was checked by the research advisors.

The researcher utilized field notes throughout the data collection process to capture accounts and records what was observed during the interviews.

Transferability: It is concerned with the issue of generalization. This is the extent to which the research findings can be applied to other situations within the group. Nevertheless it is impossible to generalize in qualitative studies. The findings may not necessarily be transferred to another setting. The researcher may present the data in a completely descriptive way for other researchers to make a comparison of the situation.

Plan for Data Analysis

The analysis is based on the second school of phenomenology i.e. Utrecht school. The phenomenologist using this approach combines characteristics of descriptive and interpretive phenomenology for example Van Manen's (1990) method. In this method the researcher tries to grasp the essential meaning of the experience being studied.

1. .

Steps Used by the Researcher:

Due to the nature of the study data analysis was concurrent with data collection. The interviews were transcribed into text by the researcher shortly after it was conducted. Researcher read the verbatim manuscript many times to understand the interview fully and to analyze the content embedded within each interview. To answer each research question, data was analyzed using Heideggerian Hermeneutic philosophy.

The analysis took place after each interview was complete and transcribed. Firstly each interview was read for overall understanding .The second step involved identifying units and beginning interpretation. The analysis process required ongoing reading and rereading of the transcripts for comparing and contracting interpretation that leads to subthemes, relational themes and eventually metathemes.

It was found that participants reported various psychological disturbances, and perceptions like denial, confusion and social stigma, they were also having worry related to future of their family. It was seen that participants reported about various health problems.

Nursing Implications

Nursing Education Seminars, workshops or in service education can be planned by the nurse educators to update the knowledge of Nursing students and staff nurses about HIV/AIDS. Topics related to HIV/AIDS can be taken for research by the student nurses.

Nursing Practice

Nurses can design and implement psychological support programmes for people having HIV .Keeping in mind the personal and social beliefs in mindhealtheducation programs in ART Clinicscan help PLHIV to findwhen and where to see help in turn will decrease misconceptions and anxiety.

Nursing Administration

Nurse managers and administrators can take the lead to spread the awareness about HIV/AIDS among general public. Nurses must be empowered in HIV/AIDS prevention and care through national and international educational programs.

Community Mental Health Nurse

Community Mental Health can take initiative to provide an integrated, professionally facilitated group support to the people who are having HIV. Education regarding association between sexually transmitted diseases should be disseminated via basic education with help of village health worker.

Recommendations

1. Further research will require other researchers to make a more concerted effort to include participants who are less connected with the community support groups. It is also necessary to explore how people with HIV receive support from their families and how the support affects the value and meanings of their lives
2. A National Nursing Network for HIV/AIDS Research can be built comprising of nurse scientists who would conduct research and educate public for the purpose of improving HIV/AIDS nursing care around the country.
3. A similar qualitative study can be done to measure the level of stigma and its impact on quality of life and coping strategies adopted by PLHIV.

SUMMARY: AIDS is not considered good as far as the societal norms. If a person is having HIV / AIDS they reported to have less social status and prestige in community. Women who suffered with HIV faced difficulties in their in-laws home and to be send back to their parents' home especially in low income group with low education. Some of the women have lost their home because of this disease. some of the participants were unaware about the causes ,sign and symptoms and treatment of HIV AIDS for marriage. In spite of getting disease from their husband and from wrong blood transfusion they suffered lot of discrimination and hatred from their own family members. No one understands them completely. In laws were not helpful even relatives and family members stop talking to them. Even they were not allowing to enter these people to their home. Many participants were unaware about this disease before marriage. All the PLHIV were trying to live their life by following the treatment schedule as prescribed by the

physician and some of them were also adopting strategies to cope up this illness. Some of the women shared using emotional centered and problem centered coping strategies. One of the couple was willing to adopt a child but their family members especially mother was not willing for adoption.

DISCUSSION

Our findings highlight several issues that are consistent with but add to the existing literature regarding cART adherence. Most patients and providers viewed the counsel of doctors and counselors as a crucial emotional support during cART, for starting and staying on cART, coping with diagnosis and illness. As an extreme example of counseling being a barrier to get medication, one individual had such a negative interaction with his counselor that he did not feel safe to start therapy, stressing the importance of proper training of counselors. Meeting other HIV positive persons like them helped in coping and dealing with the stress of being HIV

Study limitations. This study has several important strengths. Qualitative studies are well suited to identifying barriers and facilitators from the perspective of the patients: The use of an in-depth interview approach permitted us to discover a diversity of ideas and practices which most likely would not have been detected using a quantitative approach. All qualitative data were based on this convenience sample of the selected health facility. The study was unable to comment on perceptions among HIV infected individuals who might have stopped treatment or dropped out of the program

CONCLUSION

In-depth data regarding the lived experiences and need of PLHIV at selected ART Centres were collected. These needs were explored with the purpose of informing the development of strategies that will enable those affected to cope with the disease. Data from this study, combined with relevant literature, has identified the lived experiences and needs of PLHIV. This information can serve as the basis for the development of a CBHC programme.

The community needs assistance to build its capacity to provide comprehensive support for PLHIV and their caregivers. Assistance must come from a variety of sectors, including government, non-governmental organizations and businesses. Findings point to a need to expand

health literacy research and interventions to address broader social and structural barriers to health improvement for PLWHA, especially among those living in rural and low HIV prevalence areas. Participants shared barriers to accessing information including stigma, fear, concern about disclosure, and feelings of futility and anger.

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