

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

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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.
- HIV infection is often diagnosed through rapid diagnostic tests (RDTs), which detect the presence or absence of HIV antibodies. Most often these tests provide same day test results; essential for same day diagnosis and early treatment and care.
- 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.
- It is estimated that currently only 54% of people with HIV know their status. In 2014, approximately 150 million children and adults in 129 low- and middle-income countries received HIV testing services.
- By mid-2015, 15.8 million people living with HIV were receiving antiretroviral therapy (ART) globally.

- 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.

### MATERIAL AND METHODS

#### Phenomenological (Hermeneutic) Research Design and the Present study

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 were attending selected ART Centre's in Delhi.
- In-depth Interview schedule delimited to one interaction only.

### Conceptual Framework

The conceptual framework emerged after studying the final data phenomenon was based on Roys's adaptation model.

### 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.

A main criterion to choose the particular setting was administrative approval and approachability.

### Sample and Sampling Technique

#### 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 chronically ill and were having psychiatric illness as per as records.

#### Sampling Design

To select participants for the study, criterion purposive sampling was used and screening sheet was used to screen the subjects who met inclusion criteria.

**Sample Size:** Data saturation occurs after 10 PLHIV patients and two more patients were taken to identify any new information about PLHIV, who were attending ART Centre for treatment.

#### Ethical Consideration

1. Prior to commencing this study, obtained permission from the Institutional Review Board, Amity University, Gurgaon
2. Permission was also taken from the selected ART Centre for conducting the study.
3. Prior to enrolling the participants, a meeting was held so that the researcher could give information of the study to participants through participant's information sheet and allowing to ask questions during the meeting or any time they want.
4. It was explained that confidentiality will be maintained by replacing the participant's name by an encoded number.
5. 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 fields 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.

#### 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 confirmability, 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.

#### 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 analyse the content embedded within each interview. To answer each research question, data was analysed 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 on-going 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.

**RESULTS AND DISCUSSION**

**Table 1: Personal Variables of PLHIV under study N=12.**

Patient No.	Age	Sex	Marital Status	Religion	Education	Occupation	Economic Status	Type of Family	Number of siblings
P1	32	Female	Widowed	Hindu	Primary	Self-Employed (Stitching)	Upto Rs. 5000	Nuclear	2
P2	28	Female	Married	Muslim	Secondary	Private Service (Cook, Maid)	Rs 5,000 to 10,000	Joint	1
P3	26	Female	Married	Muslim	Secondary	Self-Employed (Beauty parlor)	Rs 5,000 to 10,000	Joint	2
P4	21	Female	Unmarried	Hindu	Graduation	Self-Employed (Tuition)	Upto Rs 5,000	Nuclear	0
P5	36	Female	Married	Hindu	Primary	Self-employed (Ironing)	Upto Rs 5,000	Nuclear	2
P6	28	Female	Widowed	Hindu	Primary	Self-Employed (Maid)	Rs 5,000 to 10,000	Nuclear	2
P7	25	Male	Married	Hindu	Senior Secondary	Self-Employed (Photgraphy)	Rs 5,000 to 10,000	Joint	4
P8	38	Male	Married	Hindu	Primary	Self-Employed (Riksha)	Upto Rs 5,000	Nuclear	4
P9	23	Male	Unmarried	Hindu	Secondary	Self-Employed (Painter)	Rs 5,000 to 10,000	Joint	3
P10	37	Male	Married	Hindu	Primary	Private Service (GateKeeper)	Rs 5,000 to 10,000	Nuclear	3
P11	32	Male	Married	Hindu	Graduate marketing	Private Service (Marketing)	More than Rs 10,000	Nuclear	2
P12	26	Male	Married	Muslim	Middle	Self-Employed (Fabricator)	Rs. 5000 to 10,000	Nuclear	5

Number of years of Diagnosis	Duration of accessing services at the ART center	Past Medical /Surgical History	Past history of smoking/Alcohol/tobacco chewing/drug abuse	If yes then mode	Family history of HIV	Domicile
6 years	More than 5 years	Tuberculosis of lungs	No	NA	Yes, Husband	Urban
3	1 – 3 years	None	No	NA	Husband	Urban
2	1 – 3 years	None	No	NA	Husband	Urban
2	1 – 3 years	None	No	NA	None	Rural
5	3 – 5 years	Dengue	No	NA	None	Rural
4 Years	3 – 5 years	None	No	NA	Husband	Rural
6 Years	3 – 5 years	Tuberculosis (ATT Category II)	No	NA	No	Urban
6	More than 5 years	Kalaazar, Tuberculosis, HCV Reactive	Tobacco chewing	Oral	1, Wife	Rural
4 years	3-5 years	TB/Tattooing on Hand	No	NA	No	Rural
6	3 – 5 years	None	IV Drug abuser, Smoking, Alcoholic, Opium	Parentral	None	Urban
3	1 – 3 years	None	Smoking, Alcohol	Oral	No	Urban
3 Years	1 – 3 years	Dengue	Tobacco chewing	Oral	No	Urban

**Section II**

This section give details about the metathemes, themes and subthemes as emerged about the phenomenon with the help of verbatim of participants collected and

categorized from in depth interview with participants. Table 2 gives summary of derived metathemes, themes and subthemes.

**Table 2: Summary of Themes and Sub Themes.**

S. No.	Meta Theme	Theme	Sub Theme
1	MT1 Psychological Factors	A) T1 Emotional Disturbances	ST1 Anger
			ST2 Guilt
			ST3 Behavioural/Crying
			ST4 Escapism/Suicidal Thoughts
			ST5 Fear of Dying/Death
		B) T2 Perceptions	ST1 Panicked/Stunned
			ST2 Denial
			ST3 Confusion
2	MT2 Environmental Factors	A) T1 Influence of Society	ST1 Social Discrimination/Stigma
			ST2 Non-Disclosure Of HIV Status
			ST3 Loss of Job
			ST4 Loss of Home
		B) T2 Life	ST1 Shattered Dreams
			ST2 Worry about Future
			ST3 Life is Not Good/ Has No Meaning
			ST4 Marital Life
3	MT3 Health Factors	A) T1 Health Problems	ST1 Loss of Appetite
			ST2 Other Problems
4	MT4 Hindrance Factors	A) T1 Inadequate Social System	ST1 Lack of Family Support
		B) T2 Inadequate Facility	ST2 Lack of Support From Staff
			ST1 Lack of Proper Free Food
		C) T3 Financial	ST2 Lack of Proper Sitting Facility
			ST1 Financial Problems
5	MT5 Helpful Factors	A) T1 Hospital Policy	ST1 Guidance & Counselling Related to Treatment
		B) T2 Self Strength	ST1 We have to Live
		C) T3 Social Support	ST1 Support From Relatives
			ST2 Support From Friends
			ST3 Support From Hospital Staff
			ST4 Support from NGO
		D) T4 Faith/ Hope	ST1 Hope for Future
			ST2 Hope for Any New Treatment For Curing of HIV
6	MT6 Treatment Seeking Factors	A) T1 Modalities Adopted	ST1 Experience Related to Modalities Adopted
		B) T2 Burden of Treatment	ST1 Lack of Money
		C) T3 Knowledge Related to HIV	ST1 Lack of Knowledge Related to ART/ HIV
7	MT7 Expectation of Facility	A) T1 Physical And Other Comfort Facilities For Patients	ST1 Need of Waiting Room/ Sitting Arrangement/Free Food
			ST1 Stressful Day of Visit
		B) T2 Expectation From Health Professionals & Society	ST2 Expectation from Healthcare Professional
			ST3 Expectation from Society

**7 meta themes, 17 themes and 39 subthemes emerged from the expressions of participants describing lived in experiences of PLHIV**

**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 counsellors as a crucial emotional support during cART, for starting and staying on cART, coping with diagnosis and illness. As an extreme example of counselling being a barrier to get medication, one individual had such a negative interaction with his counsellor that he did not feel safe to start therapy, stressing the importance of proper training of counsellors. Meeting other HIV positive persons like them helped in coping and dealing with the stress of



being HIV 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 PL HIV 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 centred and problem centred coping strategies. One of the couple was willing to adopt a child but their family members especially mother was not willing for adoption.

## 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.

People to cope with HIV/AIDS and its complex psychological and social challenges.

Ann P. Zukoskiaet al People living with HIV/AIDS in rural and low HIV prevalence areas faces a number of challenges including stigma, limited access to specialized medical care, and lack of an HIV/AIDS specialist and fear which may interfere with their ability to find and use information to manage their health. This study examined how 16 individuals living with HIV sought out information to meet their health needs. In qualitative semi-structured interviews, explored participants' primary sources of information, types of information

sought, and barriers to accessing information. The sample was comprised of people living with HIV/AIDS (PLWHA) who resided in a predominantly rural area with low HIV prevalence. The majority of participants relied on a combination of sources including their HIV/AIDS physician, the Internet.

Participants shared barriers to accessing information including stigma, fear, concern about disclosure, and feelings of futility and anger.

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