



## LIVED EXPERIENCES OF PLHIV AT SELECTED ART CENTRES: A SYSTEMIC REVIEW

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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

### 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.

## **RESEARCH METHODOLOGY:**

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.

To supplement data obtained from secondary sources, a few case studies were obtained and incorporated in the report.

## **REVIEW OF LITERATURE:**

In the present study, the researcher did an extensive and systematic review of the relevant publications. The reviewed literature for the present study is divided into the following sections:

- Section 1: Literature related to magnitude of HIV/AIDS.
- Section 2: Literature related to the Stigma and Discrimination faced by PLHIV.
- Section 3: Literature related to the Lived experiences of PLHIV. (Physical problems, financial problems)
- Section 4: Literature related to psychosocial problems among PLHIV.
- Section 5: Literature related to Coping Strategies adopted by PLHIV.

### **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, WHO stages 4 diseases and CD4 cells below 50 were main predictors of mortality. Promoting early voluntary counseling and testing should be given prior to facilitate timely start of treatment.

HIV related mortality especially among men was high and mean survival time was relatively low in this population. Majority of patients started ART at a late disease stage characterized by wasting syndrome, lower CD4 cells and these were associated with higher mortality.

**3. Mukhopadhyay, S. Tadulkar, A. et al. (2010)** conducted a study to determine the pattern of PLHIV in attending voluntary confidential counseling and testing centre (VCCTC) and prevention of parent to child transmission(PPTCT) centre of a low prevalence district of eastern India. To find out high-risk group and interventional strategy for prevention cross-sectional exploratory secondary data analysis from the VCCTC and PPTCT register was used of the 1348 participants, 160 adult were PLHIV seropositive, prevalence in males and females was 9.8% and 20.7% respectively. Among 22 seropositive children, transmission was vertical in 18 children and there were 71 positive adult males who were migratory goldsmiths working in Mumbai and other big cities. They were clustered in a particular locality (Daspur). Goldsmiths migrated from Daspur to big cities are the bridge populations who are responsible for higher prevalence of HIV in their families and locality.

**4. Mwanga, A Jamilla.(2012)** conducted a study on HIV sero status disclosure and associated factors among people living with HIV/AIDS attending a care and treatment centre in Kisarawe District hospital, Tanzania. A cross sectional study of PLHWA attending care and treatment centre at Kisarawe District Hospital was conducted using both quantitative and qualitative methods in data collection. A total of 402 PLWHA from Kisarawe District Hospital were enrolled. The study was conducted from May 2012 to August 2012. A systematic random sampling was used in the recruitment of patients. The study revealed that overall, the prevalence of HIV status disclosure to at least one person was 98%(394). The disclosure status did not differ by gender(male 97.0% versus female 98.5%,  $p=0.296$ ). Majority of study participants 173 (43%) told five people and above, followed by two to four people 172 (42.8%). Participants who disclosed their status at least to one person were 49 (12.2%) while only 8 (2%) participants did not disclose to anyone.

**5. 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.

**6. 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. A total of 1.6 million people died from AIDS related illness. Although the testing capacity has increased overtime, the majority of people with HIV are still unaware that they are infected.

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.

**7. UNAIDS/WHO. (2007)** stated that the existence and rapid spread of HIV/AIDS possess a serious challenge to every nation across the globe. HIV and AIDS have the potential to undermine the massive improvements that have been made in global health over years. Apart from being a serious health problem, multilayered effects of the epidemic on the socioeconomic fabric of whole nations, make HIV and AIDS a potential development threat worldwide. The estimated number of persons living with HIV worldwide in 2007 was 33 million, a reduction of 16% compared with the estimate published in 2006.

## **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 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. Wanchu, Ajay. (2012)** conducted a study on HIV Stigma and Specified Correlates in North India. 100 samples were taken. The subjects self-administered ‘Tanzania Stigma Indicator and Community Endline-Individual Questionnaire’. Psychiatric morbidity was screened with General Health Questionnaire and diagnosed with Structured Clinical Interview for DSM-IV. The study revealed that only 35 subjects could differentiate between HIV and AIDS, only 24 were aware of antiretroviral therapy. Unprotected sex, sharing injections, and blood transfusions were reported as possible source of transmission by 79% subjects each, 80% of subjects reported no fear in touching HIV-positive subjects or their objects. Avoiding injections, being faithful to uninfected partner, avoiding blood transfusions, using condoms, and avoiding sharing razors/blades were reported as HIV preventive measures by 40 to 26 subjects each. Half of the subjects blamed self for contracting HIV. Only 38 subjects reported others behaving differently with HIV-positive subjects. HIV status disclosure was reported by 98 subjects. It has been reported higher primary stigma and shame or blame. Psychiatric disorders, present in 45 subjects, showed no association with stigma items.

**4. Moses Susan, Tomlishon Mark (2012)-** stated that stigma and discrimination after being infected with HIV 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.

**5. 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

**6. Srales, Math (2011)** conducted a study on stigma, discrimination experience and coping mechanism: A case study of people living with HIV/AIDS in urban and rural Cambodia. 100 samples were taken. The study revealed that stigma and discrimination was high among patients living in Cambodia.

**7. HB, Zhang. (2009)** conducted a study of HIV/AIDS-related stigma and discrimination among former plasma donors in rural areas. Eighty local residents, including 20 HIV-positive villagers, 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. The majority of HIV positive participants were unwilling to disclose their positive status to others in order to protect their family members and children. 25% of clients felt discrimination or isolation at some point during their visits to the facilities and 39% of them reported having been denied of services.

[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. Nagta et al (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 et al (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.

Moreover; the suffering was exacerbated by feelings of uncertainty for the sickness in the future, worry about the discrimination and stigmatization of their children, self-blaming and a feeling desperation. Within the pattern of hope, these women hoped for their unborn babies to be healthy and free.

**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.

A phenomenological approach was used. Sixteen HIV positive pregnant women volunteered to participate from June 2005 to June 2006 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, the suffering was exacerbated by feelings of uncertainty for the sickness in the future, worry about the discrimination and stigmatization of their children, self-blaming and a feeling desperation. Within free from HIV infection:

### **5. Perceptions regarding barriers and facilitators to combination antiretroviral therapy adherence among people living with HIV/AIDS in Gujarat, India: A qualitative study**

**Sangita Patel, Rajendra K. Baxi, and Kedar Mehta Sangita 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..

HIV-infected patients were eligible to participate in the study if they were English or Gujarati speaking, more than 18 years age and diagnosed with HIV for at least 3 months.

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. Health care providers were eligible to participate if they had experience of working with PLWHA for more than 1 year.

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.

This study suggested that several issues need to be considered when providing ART. Further research is needed to study interactions between patients and their health care providers.

A widowed female, thankfully described the support of the cART counselor, "I felt like dying, but then the ART counselor explained, 'several people like you are still living. You just have to take care of yourself and you can live till 60 years.' After that I started medication".

An illiterate married female, recalled, "They had explained me the importance of timely medication and said that there should be no lapse in medication as that would lead to an increase in the severity of the infection"

The family members also helped the patients in adhering to medication. This often happened by the family reminding the patients to take their medicines on time.

A married male aged 55 years appreciated his family's support, "My wife and my children remind me to take my medicines regularly."

The other significant reason cited by patients was that they felt better after starting medication and had the notion that regular medication would help them live a longer life and hence they preferred to continue with it.

A married male from an urban slum reported, "I feel good after taking these medicines. My appetite increased. I don't suffer from diarrhea and don't fall sick again and again."

Regular visits to the ART center aided in obtaining peer support.

A married female aged 35 years, discussed her coping mechanism, “When I come to the ART center for medicines, I talk to other patients. We share our feelings and counsel each other”.

Proper counseling before starting ART was also one of the factors that motivated patients to start and continue taking their cart.

**Medications barriers:** - Patients agreed that ART was beneficial to them though there were some factors that acted as barriers in accessing and maintaining adherence to ART, especially when the patients had to commute long distances to other cities as the ART center had not started in their local city. Having to wait for a long time in the government hospital and being called again and again for medication was also cited as an obstacle to accessing medication.

A married male aged 32 years recollected the inconvenience he had to bear initially, “Earlier when I used to go to the government hospital in another city, a whole day would be spent plus I had to bear the travel costs”.

The other factor that acted as a barrier was the fear of possible physical reactions to the medication which made the patients a doubtful starter.

A married male living in an urban slum, expressed his doubts, “We both are not taking cART. I fear that it might not suit me and I will have ulcers. What if something happens to me due to cART?”

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

**1. Jayakumar Palanisamy (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 psycho-social 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.

**6. Premilla D (2007)** A study conducted to assess psychosocial problems, stigma and attitudes towards people living with HIV/AIDS. They took 40 families and were studied for a period of 18 months. The study was done by observation, questionnaires and interviews. The study illustrates that the AIDS is still secrete issue a taboo family members do not discuss it openly. There psychosocial reactions range from blaming, bewilderment, anger, confusion and resentment towards patients. This concludes into depression, self-blame to understand, acceptance and support of the people living with HIV/AIDS.

**7. Chandra PS, (2005)** HIV infection and psychiatric disorders present a complex relationship and have received special attention in the last decade, considering their impact in the personal, sexual, social and occupational lives of people living with HIV/AIDS.

**8. Malik D Schoenherr (2003)** conducted a study among AIDS patients with anxiety, to discover whether they manifest common attitudes, behaviours and health concern. Qualitative methodology was used to generate substantive theory. Case study method was used to collect data over a period of one year. This study recommends that health professionals should focus on providing education and counseling for patients with AIDS.

### **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/mm<sup>3</sup>) used a passive coping style more often than healthier youth (CD4 > 500 cells/mm<sup>3</sup>). 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.

## **SUMMARY:**

Reviewing of relevant literature for the present study was at all steps a very interesting and thought provoking task, each time unfolding some newer dimensions of the phenomenon under study. Each review provided base for a better insight and comprehension of the impact of HIV among PLHIV .It was such an interest grabbing task that at times it was even difficult to keep oneself on track.

The review of Literature reveals that more in depth work needs to be done on exploring the feelings, experiences and apprehensions of PLHIV.This review has also helped the investigator to select the study design for the present study i.e. qualitative method of data collection by using in-depth interview and give insight into the analysis and presentation of data into themes.

## **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

## **CONCLUSIONS:**

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. Zukoskia et 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.

## **ACKNOWLEDGEMENT:**

The author is highly thankful to her research Guide Dr. Mrs. Molly Babu for timely guidance and Mr. S.S Kaushik for his constant support throughout the study and special thanks to all the participants of selected ART Centres their cooperation in this study was highly appreciated.

Source of Funding:-The author declares that no funds were received from anyone.

Ethical Clearance:-No ethical issue exists in this article.

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