



# ASSESSMENT OF CONTEXTUAL BARRIERS AFFECTING ART (ANTIRETROVIRAL THERAPY) ENROLMENT AMONG PLHA (PEOPLE LIVING WITH HIV AIDS) IN A SELECTED DISTRICT

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## INTRODUCTION

Human immunodeficiency virus (HIV) continues to be one of the deadliest infectious diseases in the world. HIV kills or damages the cells of the body's immune system, destroying CD4 positive (CD4+) T cells. HIV positive people are vulnerable to many infections, diseases, and its complication. AIDS is diagnosed when a person has one or more opportunistic infections, such as pneumonia or tuberculosis, and has a dangerously low number of CD4+ T cells (less than 200 cells per cubic millimetre of blood)<sup>1</sup>. In the last 28 years, HIV-1, the retrovirus responsible for the Acquired Immunodeficiency Syndrome (AIDS), has moved from a state of an “**inherently untreatable**”<sup>2</sup> infectious agent to a chronically manageable disease.<sup>3</sup>

According to UNAIDS 2017 statistics, about 36.7 million are people are living worldwide with HIV/AIDS (PLHA)<sup>4</sup>, and of which, 2.1 million are children<sup>5</sup>. Since the start of the epidemic AIDS related illness has killed around 35.0 million people According to the current statistics only 60% of people with HIV know their status. The remaining 40% (over 14 million people) are yet to access HIV testing services.

The introduction of highly active antiretroviral therapy (HAART) has its potential to decrease both viral and non viral related commodities as well as HIV transmission. Antiretroviral therapy has changed the “inherently untreatable” devastating epidemic to **a manageable chronic disease**<sup>2</sup>. ART hinders replication of the HIV virus inside a person infected with HIV, and thereby improving the body’s immune system to recover and rebuild itself. It’s not curative, but these medicines are dramatically powerful, with studies suggesting that HIV-positive patients in resource limited settings also can lead near-normal life expectancies when taking ART<sup>6</sup>. As of July 2017, 20.9 million people living with HIV were accessing antiretroviral therapy (ART) globally, from 15.8 million in June 2015, 7.5 million in 2010, and less than one million in 2000.<sup>7</sup>

With about 21 lakh HIV infected people, India is estimated to have the third highest number of people living with HIV and AIDS (PLHA) among all the countries in the world<sup>8</sup>. India has an adult (18-49 age group) HIV prevalence of approximately 0.26 % with the prevalence among Males as 0.30% and among Females 0.22%.<sup>5</sup>

The free Antiretroviral Therapy (ART) initiative was launched on 1<sup>st</sup> April, 2004 by National AIDS Control Programme which brought hopes to lives of PLHA in the country. The programme adopted a public health approach for provision of ART and provided comprehensive prevention, care and treatment services, with a standardized, simplified combination of ART regimen, a regular secure supply of good quality ARV drugs, and a robust monitoring and evaluation system. Through efficient planning and rapid up scaling over the years, the number of ART centres has expanded, 528 ART centres and 1108 Link ART centres (LACs) are functioning in India since 2004. These centres provide ART to over 9.97 lakh

PLHIV, which is the second highest number anywhere in the world. Wider access to ART has led to 29% reduction in estimated annual AIDS related deaths between 2007 and 2011. It's estimated that the scale up of free ART has averted over 150,000 HIV/AIDS related deaths<sup>9</sup>.

The cascade of HIV care include HIV testing and counselling (HTC) and linkage to care, clinical staging through CD4 testing, pre- ART care, ART initiation and lifelong ART adherence and retention in care<sup>10</sup> Though the UNAIDS has at present the global targets in the global response to HIV that by 2020 30 million people should initiate ART. Considerable losses were noted in each stage of this continuum; however, factors contributing to these continuums are poorly understood.

## **BACKGROUND OF THE STUDY**

Timely initiation of antiretroviral therapy (ART) for patients with HIV disease is critical for achieving optimal treatment outcomes<sup>11</sup>. Late initiation of ART, after reaching advanced clinical and immunological disease status, is associated with the risk and severity of opportunistic infections, as well as higher mortality<sup>12</sup>. In 2016, the WHO updated its guideline and recommended that all PLHA should initiate ART as soon as they are diagnosed with HIV. WHO thus announces "treat-all"<sup>13</sup> recommendation which removes all limitations on eligibility for antiretroviral therapy (ART) among people living with HIV and thus all the people are eligible for ART irrespective of their CD4 count. 50% of people living with HIV AIDS (PLHA) in resource limited setting (RLS) enroll in care when they are in advanced stage of disease<sup>13</sup>. In 2012, 9.7 million people in low- and middle-income countries were on treatment representing 65% of the global targets. Half of all patients in resource limited setting (RLS) enroll in care, when they are at advanced stage of disease, often when the CD4<sup>+</sup> cell count (CD4<sup>+</sup>) threshold is below the for ART initiation and enrolment in care<sup>11</sup>.

HIV transmission takes place when there is High plasma concentration of HIV-1 RNA. Antiretroviral therapy (ART) can lower viremia as well as transmission of HIV to sexual partners.<sup>14, 15</sup> Expanded use of ART may lower incidence and eventually, prevalence of HIV on a community or population level.<sup>16</sup> Thus, making it as a secondary goal of ART is to reduce the risk of HIV transmission.

Historically, individuals with HIV with low CD4 counts have enrolled to care. Concrete efforts are taken to increase testing of individuals at-risk and to link individuals with HIV to medical care before they have advanced HIV disease<sup>17</sup>. The magnitude of CD4 recovery is directly correlated to the CD4 count at the time of ART initiation. Many individuals who start treatment with CD4 counts  $<350$  cells/mm<sup>3</sup> never achieve CD4 counts  $>500$  cells/mm<sup>3</sup> and above after 10 years on ART<sup>18,19</sup> and they have a shorter life expectancy than those initiating therapy at higher CD4 count thresholds.<sup>20</sup>

ART research studies demonstrated the optimal time to initiate ART Approximately a 50% reduction in morbidity and mortality among individuals with HIV who had CD4 counts  $>500$  cells/mm<sup>3</sup> and who were randomized to receive ART immediately versus delaying initiation of ART were described. Therefore the panel on Antiretroviral Guidelines for Adults and Adolescents recommended immediate initiation of ART for all<sup>21,22</sup>

The decision to initiate ART includes consideration of patient's comorbid conditions, their willingness and readiness to initiate therapy. Without antiretroviral therapy (ART), most individuals with HIV will eventually develop progressive immunodeficiency marked by CD4 T lymphocyte (CD4) cell depletion and leading to AIDS-defining illnesses and premature death.

According to the HIV statistics 2017 in India there are about 80000 new HIV infection reported. AIDS related death peaked to 62000 and 77 % (1,600,000) of the subjects knew their HIV status whereas 33% yet to be screened. At present there are about 100,000 people who are on treatment, among these 992000 are adults. There is a decrease in the incidence of HIV among children and 41% are on treatment<sup>5</sup>

According to Times of India Maharashtra detected the highest number of new infection in 2017. Accounting for 16% of the country's 1.84 lakh fresh cases. Among the infected were 1,560 new-borns who probably didn't receive ART on time. 200 adults got the disease due to transfusion of blood? <sup>23</sup>. Some of those who are not in care have deliberately opted not to seek it, while others lack the resources, information and some needed to be motivated. Understanding why patients opt out of care, or are unable to opt in, is important to achieving the goal of universal access. Currently, little is known about what inhibits uptake of antiretroviral (ARV) treatment even when it is available to them. In resource-limited settings, the barriers for accessing care likely differ. Reasons for not seeking available care in resource-limited settings are likely related to the cost of seeking treatment, the time and large travel distanced to reach the setting, stigma, fear of violence, and there has also supportive statements suggesting that PLHA take ART from private practitioner not even revealing the actual number of HIV cases. Some PLHA rely on traditional medicine for cure because of the myths. <sup>24:32</sup> Substantial proportion of patients eligible for ART enrolment do not have timely initiation (defined variously as within 2 weeks to 6 months) and few patients are lost as LFUs (lost to follow up) before initiating to ART<sup>33</sup>.

ART is also recommended for individuals with HIV to prevent HIV transmission as it decreases the viral load. Even though, ART does not cure HIV, ART help to improve and maintain immunologic function and maintain viral suppression and so ART should be continued indefinitely. Observational studies define the optimal time to initiate ART, whereas randomized controlled trials demonstrated that ART should be initiated to all patients with HIV, regardless of disease stage. The urgency to initiate ART is greatest for patients at lower CD4 counts, where the absolute risk of OIs (Opportunistic Infections), non-AIDS morbidity, and death is highest. ART improves survival and delays disease progression in patients with CD4 counts  $<200$  cells/mm<sup>3</sup> and/or history of AIDS-defining conditions. Low CD4 counts, abnormally high levels of immune activation and inflammation, despite suppressive ART, predict an increased risk of not only AIDS events, but also Non-AIDS events including kidney disease, liver disease, cardiovascular disease, neurologic complications, and malignancies. <sup>34</sup> Early ART initiation increases the probability of restoring normal CD4 counts, a normal CD4/CD8 ratio, and lower levels of immune activation and inflammation. Low CD4 count, increased viral load in

absence of ART pose a risk of HIV transmission. Biological, ecological, and epidemiological studies and randomized clinical trial provide strong evidence that treatment of individuals with HIV can significantly reduce sexual transmission of HIV<sup>35</sup>. Study results has shown that there is 93% reduction of HIV transmission and viral load was also suppressed among HIV serodiscordant couples when the partner with HIV was taking ART as prescribed.<sup>36</sup> The most dramatic and well-established example of this effect is the use of ART in pregnant women to prevent perinatal transmission of HIV. Effective suppression of HIV replication is a key determinant in reducing perinatal transmission. Use of combination ART during pregnancy has reduced the rate of perinatal transmission and ART is thus recommended for all pregnant women with HIV, for both maternal health and for prevention of HIV transmission to the newborn. The key to successful ART in maintaining viral suppression is initiating ART at the correct time and getting adherent to the prescribed regimen.<sup>37</sup>

Recent studies on ART have revealed that patients on ART have long lifespan than those not ART in the last two decades<sup>38</sup>.

A team of British and Spanish researchers conducted a meta-analysis, and that compared the rates of high-risk HPV (Human Papiloma Virus) and high-grade cervical lesions among women living with HIV. The analysis showed that ART treatment was associated with lower rates of high-risk HPV and invasive cervical cancer. ART also appeared to curb squamous intraepithelial lesions (SIL) and cervical intraepithelial neoplasia (CIN), both of which can lead to cancer.<sup>39</sup>

A mixed survey conducted among HIV-infected people not started on antiretroviral therapy in India revealed that Sociodemographic and clinical characteristics are associated with non-initiation of ART among ART-eligible PLHIV in India<sup>40</sup>

Researches have been conducted to identify the barriers, but there is no quantitative data published on the actual and perceived barriers to access ART. As there are limited reviews available it is difficult to identify the factors which have the strongest influence on treatment seeking and could be targeted to improve uptake.

## NEED FOR THE STUDY

The 90-90-90 initiative was launched by India paving way for an AIDS free India for attaining universal coverage of HIV prevention, treatment to care continuum of services that are effective, inclusive, equitable and adapted to needs. As on March 2017, 1.05 million PLHA were alive and were accessing ART. Still there was a gap of almost 7, 00,000 PLHA who are yet to be put on treatment.<sup>41</sup>

ART is recommended for all individuals with HIV, regardless of CD4 cell count, to reduce the morbidity and mortality associated with HIV infection. Though the evidence supports benefits of Antiretroviral Therapy so as to prevent morbidity and mortality, viral suppression, restoring normal CD4 counts, lowering the risk of HIV transmission (vertical and horizontal). It is found that patient who have not been initiated on ART as well as those not adherent have a high mortality rate<sup>42</sup>.

In India until 2015-2016 1.52 million cases was identified and registered to ART centres considering the estimated total number of people living with HIV at 2.12 million. Among 1.52 million PLHA identified and 1.04 million are on ART. There is thus a coverage gap of 0.48 million<sup>41</sup>. According to the NACO guidelines average number of days for initiation on ART is 60 days.<sup>43</sup>

The government of India has announced free ART services. Studies from India have confirmed that about 20–26% of diagnosed PLHA are lost before being registered at the ART centres<sup>44</sup>. Despite the ever-increasing availability universal access to comprehensive, equitable, stigma free, quality care, and support and treatment services to all PLHA there is a loss in the cascade of care and there<sup>5</sup> There is no published evidence in India as to what proportion of ART-eligible PLHA is lost before initiating ART and what are barriers for not enrolment and hence there is a need to study on the barriers of enrolment.<sup>10</sup>

## PROBLEM STATEMENT

Assessment of contextual barriers affecting ART enrolment among PLHA in a selected district.

## OBJECTIVES

1. Identify the barriers leading to non-enrolment of PLHA for ART initiation.
2. Explore the contextual factors regarding the identified barriers of non-enrolment of PLHA for ART initiation.

## RESEARCH QUESTION

What are the barriers faced by the PLHA leading to delayed enrolment to ART?

## OPERATIONAL DEFINITION

- a. Assessment:** The action or an instance of making a judgment about something, the act of assessing something<sup>44</sup>.

In this study assessment refers to the act of finding out the barriers of ART initiation among PLHAs.

- b. Barriers:** A fence or other obstacle that prevents movement or access.<sup>45</sup>

In this study barrier refers to those circumstances that put an obstacle for a person from enrolling ART. The barriers may be related to the stigma, lack of knowledge, ignorance, and lack of seriousness of disease, poor family support, geographical location, poor transport facilities, financial crisis, lack of confidence on HIV test report, distance, long waiting time and lack of care givers.

- c. Enrolment:** It is the act of registering a member of to an official registry<sup>44</sup>.



In this study enrolment refers to the act of registering of PLHA for ART initiation in ART centres.

**d. PLHA:** People living with HIV and AIDS (PLHA) are men and women who are alive and are diagnosed with human immunodeficiency virus and AIDS<sup>1</sup>.

In this study PLHA are people living with HIV not enrolled for ART.

**e. ART:** ART is a combination of drug that slow down the rate of HIV virus in HIV infected patients<sup>46</sup>. In this study ART is a combination of three drugs that has to be initiated by the study subjects.

### SCOPE OF THE STUDY

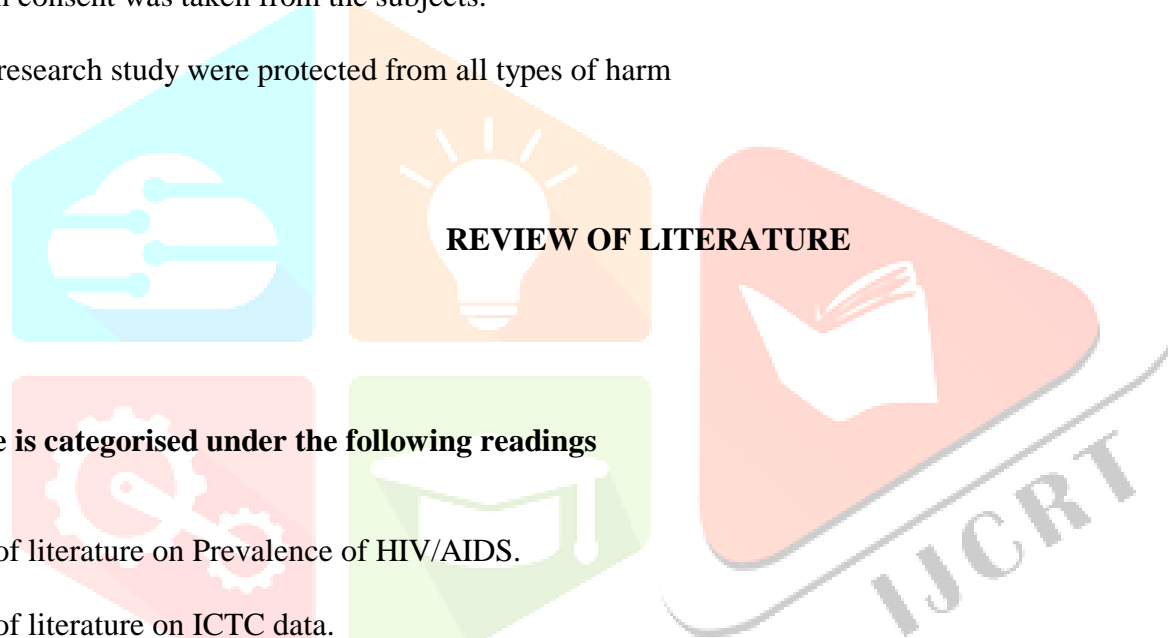
1. This study will help to identify the barriers to ART enrolment and help in enrolment of the patient to nearest ART centres.
2. This study will enhance the knowledge of PLHA regarding ART and will ultimately help them to enrol themselves for ART.

### ASSUMPTION

1. There may be a number of factors that prevent PLHA from enrolling to ART
2. The various barriers which may lead to non-enrolment are preventable and measures can be taken for enrolling PLHA for ART.
3. PLHA will be sincere in giving responses to questions asked and will share their data.

**ETHICAL CONSIDERATION**

1. The study proposal was sanctioned by the Ethics committee of the institution.
2. A prior permission and consent was obtained from the higher authority before extracting details of the patient.
3. Confidentiality of patient details was maintained.
4. Informed written consent was taken from the subjects.
5. Subjects in this research study were protected from all types of harm

**Review of literature is categorised under the following readings**

1. Review of literature on Prevalence of HIV/AIDS.
2. Review of literature on ICTC data.
3. Review of literature on ART and enrolment to ART.
4. Review of literature on barriers of enrolment to ART.

## 1. Review of literature on the Prevalence of HIV/AIDS.

UNAIDS in the year 2016 reported that there is a new trend in HIV prevalence. New HIV infection among adults remained static. In 2017, new adult infections were estimated to have declined by 8% between 2010 and 2015, and by 11% between 2010 and 2016.<sup>51</sup>

There is a decline in new HIV infection by about 46% and in HIV related death by 2% in India. The statistics reported that new HIV infections has declined from 1, 50,000 in 2005 to 80,000 in 2016. HIV related death has declined from 150000 to 62000 in 2016.<sup>52</sup>

In high-prevalence settings, young women remain at unacceptably high risk of HIV infection. In eastern and southern Africa, young women (aged 15–24 years) accounted for 26% of new HIV infections in 2016 despite making up just 10% of the population. Young women (aged 15–24 years) in Western and Central Africa and the Caribbean respectively accounted for 22% and 17% of new HIV infections in 2016.<sup>53</sup>

In lower prevalence settings, the majority of HIV infections occur among key populations were those who inject drugs, sex workers, transgender, prisoners, and gay men and other men who have sex with men and their sexual partners. Outside of sub-Saharan Africa, key populations and their sexual partners accounted for 80% of new HIV infections in 2015. Even in sub-Saharan Africa, key populations and their sexual partners are an important part of the HIV epidemic: in 2015, 25% of new infections occurred among this group, underlining the importance of reaching them with services.<sup>54</sup>

Globally, gay men and other men who have sex with men accounted for 12% of new infections in 2015, while sex workers and people who inject drugs accounted for 5% and 8% of new infections. Data reported by countries across the world show that HIV prevalence among key populations often is substantially higher than it is among than the general population<sup>55</sup>

India is one of the largest HIV epidemic country in the world. In 2016, HIV prevalence in India was an estimated 0.3. Overall, India's HIV epidemic is slowing down, with a 32% decline in new HIV infections (80,000 in 2016), and a 54% decline in AIDS-related deaths between 2007 and 2015. The AIDS Data suggest that the key populations most affected by HIV in India are sex workers (HIV prevalence of 2.2%), gay men and other men who have sex with men (HIV prevalence of 4.3%), people who inject drugs (HIV prevalence of 9.9%) and transgender people (HIV prevalence of 7.2%). The vulnerabilities that drive the epidemic are different in different parts of the country. The three states with the highest HIV prevalence Manipur, Mizoram, and Nagaland. Some states in the north and northeast of the country have also reported rising HIV prevalence.<sup>56</sup>

Studies in India reported that among patients attending in an ART centre 25 cases (12.9%) were co infected with pulmonary tuberculosis. However, prevalence of HIV/TB co infections have been reported varying from 0.4% to 20.1% from different regions of northern part of India.

## **2. Review of literature on Integrated testing and counselling**

In 1997, there were just 67 HIV testing and counselling (HTC) sites in India. By August 2016, there were more than 20,000 HTC facilities. Between April and September 2015, NACO reported that 6.85 million general users accessed HTC, suggesting that India is on its course to meet its annual testing target of 12.4 million. A total of 5.32 million pregnant women received HTC over the same period against a yearly target of 9 million. Despite this progress, around one quarter of people living with HIV in India (23%) are unaware of their status. During the year 2016-2017 around 88.8 lakh individual had undergone HIV testing. Of which 96,468 (1.09%) were diagnosed positive. In the year 2016-2017 76.2 lakh women were tested for HIV and among these 5233 were positive. And among them 4935 (94.3%) initiated on ART and among these 86.7% 4651 babies received ART. There is a HIV trend in positivity declined from 5% in 2008-9 to 1.09% in 2016-2017.<sup>57</sup>

The NACO has established the PLHIV ART linkage system to link the PLHIV to ART centres. At present 23 state and union territories are following this system for early initiation of ART.

Retrospective hospital record based descriptive study has reported that ICTC can provide comprehensive, family centred clinical and supportive services. Thereby estimating sero prevalence in pregnancy thus helping for effective and timely intervention that could be undertaken<sup>58</sup>.

Researchers reported that ICTC (Integrated Testing and Counselling Centre) is the place where HIV symptomatic patients first come in contact with government health facility. Their seropositivity status depends on the services which they will be provided within ICTC.

Researcher's reports that through effective counselling services people are ready to engage themselves for HIV care. Study finding also suggest that people are ready for voluntary HIV services.

A systematic review proved that HIV testing and counselling is the first crucial step for linkage to HIV treatment and prevention. Community-based HIV testing and counselling (testing outside of health facilities) has the potential to reduce coverage gaps. Community HIV testing and counselling had high coverage and uptake and identified HIV-positive people at higher CD4 counts than facility testing. Mobile HIV testing reached the highest proportion of men of all modalities examined and home with self-testing reached the highest proportion of young adults. Community testing with facilitated linkage achieved high linkage to care and antiretroviral initiation. Expanding home and mobile testing, self-testing and outreach to key populations with facilitated linkage can increase the proportion of men, young adults and high-risk individuals linked to HIV treatment and prevention, and decrease HIV burden.

Data collected from December 2009 to February 2011 researchers reviewed electronic medical records to identify uptake of care in individuals with previously known (self-reported) infection and new HIV diagnoses as of June 1, 2014. Result suggested that of 3482 adults with HIV identified at HBCT (Home Based HIV Testing and Counseling), 2122 (61%) had previously been diagnosed with HIV. 993 (73%) of the 1360 individuals with new diagnoses at HBCT were registered in the electronic medical records, only 209 (15%) had seen a clinician over a median of 3.4 years since diagnosis. The median time to engagement in the newly diagnosed individuals was 60 days. The study suggested that creative and innovative strategies are needed to support people to engage with care when they are newly diagnosed with HIV through population-based case-finding initiatives.

### 3. Review of literature on ART and on ART enrolment

A multicenter hospital-based cohort study of HIV-infected patients attending 10 hospitals was used to differentiate differences in the uptake and time to initiation of highly active antiretroviral therapy. Among ART naive patients, IDUs had a 33% lower risk of initiating HAART compared to men who have sex with men. No differences by transmission categories were seen among patients with prior non-HAART (Highly Active Antiretroviral Therapy). Patient not on ART had worst effect. There is a need to extend the programs in order to enhance IDUs to access HAART.

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A study was conducted to identify the areas for improvement towards achieving global 90-90-90 targets. Over 3.9 million CD4 cell count and 2.7 million viral load measurements reported in 2012 in the public sector were extracted from the national laboratory electronic database. The number of persons living with HIV (PLHA), number and proportion in HIV care, on antiretroviral therapy (ART) and with viral suppression (viral load <400 copies/ml) were estimated and stratified by sex and age group. Result suggested that among 6511000 PLHA in South Africa in 2012, 33,00,000 individuals (50.7%) accessed care and 32.9% received ART. Although viral suppression was 73.7% among the treated population in 2012, the overall percentage of persons with viral suppression among all PLHA was 23.8%. Linkage to HIV care was lower among men (38.5%) compared to women (57.2%). Overall, 47.1% of those aged 0-14 years and 47.0% of those aged 15-49 years were linked to care compared with 56.2% among those aged above 50 years. The study concluded that around a quarter of all PLHA have achieved viral suppression in South Africa. Men and younger persons have poorer linkage to HIV care. Expanding HIV testing, strengthening prompt linkage to care and further expansion of ART are needed for South Africa to reach the 90-90-90 target. Focus on these areas will reduce the transmission of new HIV infections and mortality in the general population.<sup>60</sup>

A group of researcher conducted a study on retention of PLHA registered in HIV care program. A total of 689 adult PLHIVs were registered between January 2011 and March 2012 at the Pune ART Centre. The study pointed that out of 689 patients only 492 patients enrolled in ART and

of the total patients 106 had tuberculosis and the mean CD4 count was 245. 489 patients had CD4 count  $\leq 350$  cells/mm<sup>3</sup> and 450 were initiated on ART after performing their baseline investigations, clinical evaluation, and counselling as per the national guidelines. 9 patients died, 8 were transferred to other ART center and 22 were LFU. ART was initiated subsequently to 53 patients as their CD4 count dropped. 75 patients were under regular follow-up. Baseline demographic and biological characteristics associated with loss to follow-up in patients registered for HIV showed that females, age <25 years, illiterate, unmarried, being employed and baseline CD4 count >350 cells/mm<sup>3</sup> had a higher risk of loss to follow-up and illiteracy was also significantly associated with loss to follow-up among patients in HIV care (pre-ART). And of LFU, 22 were males, and 54 were females. The study also led to a conclusion that the female sex workers are mostly lost in care.<sup>61</sup>

A study was done on providing, immediate report for initiating patient with ART. CD4 count results were typically available within a week of testing. However, 35%-55% of newly diagnosed HIV-positive patients did not return for their CD4 results and therefore, do the researcher evaluated the impact of a CD4 count result. A total of 344 patients were recruited, of which 64.5% were females with a median age of 30 years. The study proved that early initiation prevents delay into care.<sup>62</sup>

A community-based CD4 services on facilitating pre-ART care in rural South Africa. The study suggested that diagnosis must be followed by determination of treatment eligibility and referral to care prior to initiation of antiretroviral treatment (ART). Between 2010 and 2013, 7213 individuals accessed CBVCT (Community Based Voluntary Testing and Counseling) services; of these, 620 (8.6 %) individuals were HIV-positive, 205 (33.1 %) were eligible for ART according to South African national CD4 count criteria, and 78 (38.0 % of those eligible) initiated ART. During the periods when a professional nurse was available to provide CD4 phlebotomy services, HIV-positive clients were significantly more likely to complete CD4 testing than during periods when these services were not available. Additionally, when nurses were present, individuals were significantly more likely to be notified of CD4 result. These findings indicate that in addition to CBVCT, availability of onsite CD4 phlebotomy may reduce loss along the pre-ART care cascade and facilitate timely entry into HIV care.<sup>63</sup>

Two parallel analyses were done among 17,517 asymptomatic patients with HIV infection. None of the patients were on antiretroviral therapy. The baseline CD4 count of the patients were 351 to 500 cells per cubic millimeter or >500 cells per cubic millimetre. The researcher compared the relative risk of death for patients who initiated therapy when the CD4+ count was above each of the two thresholds of interest (early-therapy group) with that of patients who deferred therapy until the CD4+ count fell below these thresholds (deferred-therapy group). In the analysis, 8362 patients were involved out of which , 2084 (25%) were initiated on therapy at a CD4+ count of 351 - 500 cells per cubic millimeter, and 6278 (75%) deferred therapy. There was 69% risk of transmission as well as disease related death in patients were in deferred group. In another study which involved 9155 patients, 2220 (24%) initiated therapy at a CD4+ count of more than 500 cells per cubic millimeter and 6935 (76%) deferred therapy. Among patients in the deferred-therapy group, there was an increase in the risk of death by 94%. The study proves that there is a need for early initiation of ART before the CD4+ count fell below.<sup>21</sup>

4685 patients were followed for a mean of 3.0 years. The median HIV viral load was 12,759 copies per milliliter, and the median CD4+ count was 651 cells per cubic millimeter. 96 patients in the deferred group got ART initiated late where as 42 patients had immediate initiation of ART. Hazard ratios for serious AIDS-related and serious non-AIDS-related events were 0.28 and 0.61, respectively. More than two thirds of the primary end points (68%) occurred in patients with a CD4+ count of more than 500 cells per cubic millimeter. The risks of a grade 4 event were similar in the two groups, as were the risks of unscheduled hospital admissions. The study concluded that the initiation of antiretroviral therapy in HIV-positive adults with a CD4+ count of more than 500 cells per cubic millimeter provided net benefits over starting such therapy in patients after the CD4+ count had declined to 350 cells per cubic millimeter.<sup>22</sup>

researchers assessed the linkage and retention in HIV care among people living with HIV (PLHIV) enrolled at a private HIV care clinic in Pune, India out of 1220 patients, 341 PLHIV delayed in linkage within 24 months after HIV testing. Younger people, women, low socioeconomic status, and those diagnosed at facilities other than the study clinic delayed in engaging to HIV care. The study reported that those patients who were sick



enrolled in HIV care within a short span of time. Whereas, patients who were eligible for ART initiated ART within a span of 3 months. The study reported that those PLHIVs whose CD4 count was more than 500 did not report back and those patients whose CD4 were less than 500 enrolled themselves in care and had done further follow up. The study also led to the idea that those patients who were educated enrolled in care and had timely uptake of subsequent CD4 count compared to unskilled labourers. The study highlighted that there is a long delay occurring between HIV diagnosis to linkage and further attrition during pre-ART and ART phases which led to further delay in ART initiation.<sup>64</sup>

Review was done among 233 public HIV testing centres in Karnataka. A total of 2291 HIV-positive persons diagnosed, 1829 reached ART center. Of the latter, 1166 were eligible for ART, and 959 were initiated on treatment. Overall attrition on the road between HIV diagnosis and ART initiation were 669 (29%). Deaths, migration and not willing to go to the ART center were cited as the main known reasons for not reaching ART center. The study proved that in Karnataka, eight in ten HIV-positive persons reached ART centres, and of those found ART eligible 82% started treatment. Although this is an encouraging achievement, the programme needs to take further steps to improve the current performance by further reducing pre-ART attrition. They recommended online registration to track the path.<sup>65</sup>

A before-and-after observational study was conducted using routinely collected data by researchers on ART initiation of point-of-care (POC) among Youth PLHIV in South Africa. The data was collected on patients from May 2010 to April 2011 (Group A) when baseline CD4 count testing was performed in a laboratory and results were returned to the clinic within two weeks. Same-day POC CD4 testing was implemented in June 2011, and data were collected on patients from August 2011 to July 2012 (Group B). A total of 272 and 304 youth tested HIV positive. More patients were in World Health Organization (WHO) Stage 1 disease with CD4 counts  $\geq 350$  cells/ $\mu$ l and more males were detected in Group. The study proved that point to initiate ART Strategies can improve management of youth infected with HIV.<sup>66</sup>

A meta analysis was conducted in sub-Saharan Africa between 2000 and June 2011 on losses along the continuum of care for people living with HIV infection. Among patients who know their HIV-positive status, just 57% completed assessment of ART eligibility. Among the eligible

individuals, 66% were started on ART and others were lost. The study focused on reducing losses at HIV testing and during ART care, the researchers found that losses occur throughout the care pathway, especially prior to ART initiation, and for some patients this is a transient event, as they may re-engage in care at a later time.<sup>67</sup>

A 5-year (2004-2008) prospective evaluation study was among 40,140 registered pregnant women. 23,812 were counselled out of which 19,794 were agreed to undergo HIV testing and 111 were found HIV positive with a prevalence of 0.56%. Overall HIV counseling and testing rates were 59.32% and 83.13%, respectively. The nevirapine (NVP) dispensing rate of the mother and newborn were 29.72% and 85.4%, respectively. At 18 months of age, 85% babies were found HIV negative in the mother baby pair who received NVP with absolutely formula feeding but it was 42.8% without such intervention.<sup>68</sup>

A review of the peer-reviewed scientific and grey literature to determine the proportion of HIV-infected Men sex with men and transgenders in Peru who were diagnosed, linked to and retained in care and were taking antiretroviral therapy (ART), and also attained virologic suppression. Approximately 63,981 MSM and TW were HIV infected out of 613,080 HIV-infected. Only 24.0% of HIV-infected MSM and TW are aware of their diagnosis, 15.6% were retained in care, 13.6% were on ART, and 12.0% had achieved adequate virologic control. The largest drop-off in the HIV care continuum occurs at the first step: diagnosis of HIV. Improving HIV serostatus awareness among MSM and TW was crucial to control occurrences of HIV epidemic in Peru. In the era of 'treatment as prevention', understanding the full HIV care continuum may help guide efforts to curb transmission and reduce HIV-related morbidity and mortality.<sup>69</sup>

Globally, there are around 2.3 million new HIV infections annually, 80% of which occur in sub-Saharan Africa. Despite the high burden, only one-third of adults in sub-Saharan Africa have been tested for HIV in the past year and less than 50% of HIV-positive individuals know their status.<sup>70</sup>

A group of researcher studied on the combined effect of modern HAART regimens and adherence on mortality over time among randomly assigned HIV-positive adults who had a CD4+ count of more than 500 cells per cubic millimeter to start antiretroviral therapy immediately (immediate-initiation group) or to defer it until the CD4+ count decreased to 350 cells per cubic millimeter or until the development of the acquired immunodeficiency syndrome (AIDS) or another condition that dictated the use of antiretroviral therapy (deferred-initiation group). The primary composite end point was any serious AIDS-related event, serious non–AIDS-related event, or death from any cause. The study proved that initiation of antiretroviral therapy in HIV-positive adults with a CD4+ count of more than 500 cells per cubic millimeter provided net benefits over starting such therapy in patients after the CD4+ count had declined to 350 cells per cubic millimetre<sup>71</sup>

#### 4. **Review of literature on barriers of enrolment to ART.**

A cross-sectional survey was among 163 HIV-infected women in (ANC) centres in Swaziland. 163 pregnant women were eligible for ART, 110 initiated on ART. Some females responded that long term initiation of ART is a barrier for them. The need for partner support for ART initiation was the main reason for PLHA not on ART. The study concluded that ART initiation among ART-eligible pregnant women in Swaziland was associated with the presence of partner support and favourable perceptions of the benefits of ART. Stronger counselling and education for pregnant women and male involvement strategies need to be implemented as universal life-long ART for all HIV-infected pregnant women is implemented.<sup>72</sup>

A cohort study on HIV infected children. The study concluded that the major reasons for non enrolment was structural factor, including time between sample collection and return of DNA PCR results, which is done centrally in all countries.<sup>73</sup>

A study on the barriers to ART. The study concluded that the major barriers to ART enrolment are mental health disorders or substance abuse, and social problems, eg, homelessness.<sup>74</sup>

A survey results among adult 18 years and older attending a mobile health clinic in South Africa indicated that post-test counselling was needed to be provided for essential health care to the patients to enrol and initiate in HIV care.<sup>75, 76</sup>

A study conducted on effect of age and HAART Regimen the study has proved that age is a barrier for initiation of ART among the PLHIV.<sup>77</sup>

A study among people living with HIV AIDS in Africa. The study concluded that Persons living with HIV infection rely on Traditional Healers instead of ART.<sup>78</sup>

A group of researcher interviewed 35 participants recruited using snowball sampling for identifying the barriers to ART. The study reported that the major impediments to ART uptake included inadequate preparation for a positive diagnosis and the dual stigmatization of homosexuality and HIV and its consequences, leading to fear of disclosure of HIV status. Health system barriers included lack of clarity and consistency about how to register for and access ART, failure to protect patient confidentiality and a reticence by providers to discuss sexual identity and same-sex issues.<sup>79</sup>

Evidences from the study founded that PLHIV travelled further for care even if the nearest facility supplies ART services.<sup>80</sup>

A cross-sectional qualitative study was conducted among 28 HIV positive Female Sex Workers (FSWs) from May to July 2014. The result provided the idea that facilitators for linkage to HIV care included the perceived good quality of health services with same-day results and immediate initiation of treatment, community peer support systems, and individual's need to remain healthy and have alternative sources of income. Major barriers

included perceived stigma, fear to be seen at outreach HIV clinics, fear and myths about antiretroviral therapy, lack of time to attend clinic, and financial constraints, misconception. They concluded that Linkage to HIV care among FSWs is influenced by good quality friendly services and peer support.<sup>81</sup>

A study was conducted among PLHIV to understand the unique barriers PLHIV faced when accessing healthcare compared with those not living with HIV in a rural area of sub-Saharan Africa with limited availability of healthcare infrastructure. In comparison to non HIV people PLHIV travelled an additional 1.9 km to access healthcare compared with those not living with HIV, and they were 56% accessed healthcare at the nearest health facility to their residence, so long as that facility lacked antiretroviral therapy (ART) services.<sup>82</sup>

Researchers have proved that dissatisfaction with the public health services, as a result of being asked for bribes, being badly attended by some care providers, stigmatization and breaches of confidentiality as the major reason for non enrolment to HIV care.<sup>83</sup>

A study on Lost to follow up among 182 patients who missed follow-up appointments at the clinic was identified financial difficulty as the major obstacle to obtaining treatment.<sup>84</sup>

A cohort study was conducted on Factors associated with delayed entry into HIV medical care after HIV the study reported that the Factors associated with delayed entry into care were homelessness, and illiteracy. They also found that non enrolment is most commonly seen in females. Younger age, poverty, and being diagnosed with HIV due to having an HIV positive partner were associated with delayed entry into care only in men. Women belonging to disadvantaged communities or living far from a town were less likely to engage in HIV care within three months. They also came to a conclusion that widows and unmarried men were more likely to enter into care within three months than married people<sup>85</sup>

A study on Social Support among 168 persons were newly diagnosed with HIV out of which 129 were successfully followed for more than 12 months with the help of social support. The study discussed on the importance of higher social support.<sup>86</sup>

A study in South Africa suggested that strengthened personal or social motivation can result from individual and/or group opportunities to build positive attitudes, clinic-level intervention to promote more positive interactions with the care team and system of care, and community-level campaigns of continuing efforts to decrease community-level HIV stigma. All these factors would help in better retention of patients<sup>87</sup>

A case-control cohort study was conducted on HIV stigma as a barrier to retention in HIV. A previously validated HIV stigma scale with four domains was used. Stigma scores were highest for disclosure concerns. Which lead to non enrolment.<sup>88</sup>

A Systematic literature review to identify Risk factors, barriers and facilitators for linkage to antiretroviral therapy Seven hundred and sixty-eight citations were identified. Forty-two studies from 12 countries were included for review. The most commonly cited category of factors was transport costs and distance. Stigma and fear of disclosure comprised the second most commonly cited category of factors followed by staff shortages, long waiting times, fear of drug side effects, male sex, younger age and the need to take time off work<sup>89</sup>

A study on retention in care among HIV infected patients suggested that retention in care within the decentralizing network of services is likely higher than existing estimates, socio-structural factors such as program characteristics, transportation, poverty, work/child care responsibilities, and social relations are the major determinants of retention in care.<sup>90</sup>

A study was conducted to find out Factors associated with antiretroviral treatment initiation amongst HIV-positive individuals. HIV-positive individuals were offered immediate ART in the intervention. The findings suggest good ART uptake within a setting, even among individuals with high CD4 count. However, inadequate staffing and healthcare professional practices could result in prioritizing ART initiation in patients with the lowest CD4 counts.<sup>95</sup>

HIV Cohort Study in India was conducted to describe the attrition before engagement in HIV medical care in 523 CLHIV from 2007 to 2012.

Factors associated with delayed entry into care were being identified as after mother's HIV diagnosis, belonging to scheduled castes, age <18

months, female gender, and living >90 minutes from the HIV centre. Children whose parents were alive and were living in a rented house were at a higher risk of delayed entry into care than those who were living in an owned house.<sup>92</sup>

A group of researchers assessed the linkages from HIV testing to enrolment and retention in HIV care. They found that disengagement from care by people living with HIV (PLHA) remains high. A series of three longitudinal, semi-structured interviews with 14 PLHA who had disengaged from ART programs for a total of 37 interviews. Narrative analysis was used to identify key themes. Findings indicated that an individual's decision to disengage from care often resulted from harsh and disrespectful treatment from providers following missed appointments. Once disengaged, participants reported a strong desire to re-engage in care but also exhibited reluctance to return due to fear of further mistreatment. Participants who successfully re-engaged in care during the course of this study leveraged social support networks to facilitate this process, but often felt guilt and shame for breaking clinic rules and believed themselves to be at fault for disengagement. Developing strategies to minimize disengagement and facilitate re-engagement through more flexible attendance policies, improved client-provider interactions, and outreach and support for disengaged clients could increase retention and re-engagement in HIV care and treatment programs.<sup>93</sup>

A group of researcher conducted a study on identifying perceived barriers along the HIV care. A structured interview were done for the patient where, providers and peer educators demonstrated empathy non acceptance of HIV status, anticipated stigma from unintended disclosure, and fear of antiretroviral therapy were identified as patient barriers, whereas brusque counselling and insufficient counselling at provider-initiated testing sites were identified as service delivery-related are the major cause for non-enrolment.<sup>94</sup>

A group of researcher explored that delayed initiation of ART can increased risk of death. Reasons for failure of linkage are poorly understood. Progression through the HIV care pathway is strongly influenced by socio-cultural norms, particularly around the perceived need to regain respect lost during a period of visibly declining health. Capacity to call upon the support of networks of families, friends and employers was a key determinant of successful progression. Over-busy clinics, non-functioning laboratories and unsuitable tools used for ART eligibility assessment (WHO clinical

staging system and centralized CD4 count measurement) were important health systems determinants of drop-out. They concluded by noting that Key interventions that could rapidly improve linkage include guarantee of same-day, same-clinic ART eligibility assessments; utilization of the support offered by peer-groups and community health workers; and integration of HTC and ART programmes<sup>95</sup>

Study sighted that proper counselling can lead to initiation of ART and its due poor counselling that PLHA do not enroll to ART.<sup>96</sup>

A study was conducted among PLHA who were on ART from either private or public private or a public sector. A total of 471 individuals were included in the study among these 263 from the public facility, 149 from the public-private facility and 59 from the private center. Private facility patients were male, with higher education levels and incomes. Even with all the facilities including low waiting time in private sector hospitals, there was poor adherence to ART compared to from a public sector. The study suggested that Adherence and treatment success was significantly higher among patients from public and public-private settings compared with patients from private facilities.<sup>97</sup>

Cross-sectional analysis was conducted among the HIV-infected children seeking care rural southern Zambia. Information was collected from caretakers and medical records. 192 HIV-infected children were enrolled from September 2007 through September 2008, 28% of whom were receiving antiretroviral therapy (ART) at enrollment. The median age was 3.3 years for children not receiving ART and 4.5 years for children receiving ART 91% travelled more than one hour to the clinic and 26% travelled more than 5 hours. Most participants reported difficulties accessing the clinic, including insufficient money, lack of transportation and roads in poor condition.<sup>98</sup>

A cross-sectional study of cost, stigma, and perceptions about ART the study concluded that reasons for not seeking available care in resource-limited settings are related to the cost of seeking treatment, the time and distance needed to travel to access care ,stigma , fear of violence, and reliance on traditional medicine.<sup>99</sup>



Mary KT, Heidi M C, Kenneth A. conducted a study on the effect of mental illness, substance use, and treatment for depression on the initiation of highly active Antiretroviral Therapy among HIV-Infected Individual. The study reported that there is a strong association between ART initiation and alcohol use and mental health illness.<sup>100</sup>

Researcher conducted an One focus group discussion with lay HIV counsellors and observations in the community they reported that the major barrier for PLHA doesn't enrol to care were people's health and treatment beliefs, changing perceptions about effectiveness of herbal remedies and faith healing, improving ART delivery to attenuate social and economic costs and allaying concerns about future non-availability of treatment.<sup>101</sup>



## RESEARCH METHODOLOGY

Research methodology is a way to structure a study and to gather and analyse information in a systematic fashion. Research methodology describes actions to be taken to investigate a research problem and the rationale for the application of specific procedures or techniques used to identify, select, process, and analyse information applied to understanding the problem, thereby, allowing the reader to critically evaluate a study's overall validity and reliability.<sup>48</sup> The methodology section of a research paper answers two main questions: How was the data collected or generated? And, how was it analysed?

This chapter describes the methodology adopted by the investigator to assess the barriers of ART enrolment among PLHA. It includes the description of the research approach, research design, schematic representation of study, variables of the study, setting of the study, population, sample, sampling technique, sample size, inclusion and exclusion criteria, data collection technique and tool, pilot study, feasibility of the study, validity, reliability, data collection method and plan for data analysis.

## RESEARCH APPROACH

Research approach refers to the way in which the investigator plans the research process. Research approach indicates the procedure for conduction the study in order to accomplish the objectives of the study. It is a systematic, objective method of discovery with empirical evidence. The research approach spells out the basic strategies that the investigator adopts to develop information that is accurate and interpretable. It is the backbone or the structure of the study to provide a framework that supports the study and holds it together. Research approach helps the investigator to determine what data to collect and how to analyze it. Research approach helps the investigator in the selection of subject, manipulation, of independently variables, observation to be made and the type of statistical analysis to be used to interpret the data.<sup>50</sup> It refers to the way in which the investigator plans and constructs the research processes.

The present study is based on a Quantitative Descriptive research approach.

## RESEARCH DESIGN

Research design is a broader plan of study and research approach is an important aspect of research design which governs it. A research design is a framework of the guide used for the planning implementing, and analysis of a study. Polit and Hungler stated that a research design incorporates the most important methodological decisions that a researcher makes in conducting a research study.<sup>48</sup> It is the researchers overall plan for answering the research questions or testing the research hypothesis.

In this study Non Experim

## VARIABLES

Variables are the concepts used in a quantitative study. A variable implies something that varies. It is any entity that can take on different values.<sup>50</sup>

**Research Variable:** Research variables are those variables that are measured and observed in natural setting as they exists, without manipulating and no effect on intervention or treatment.

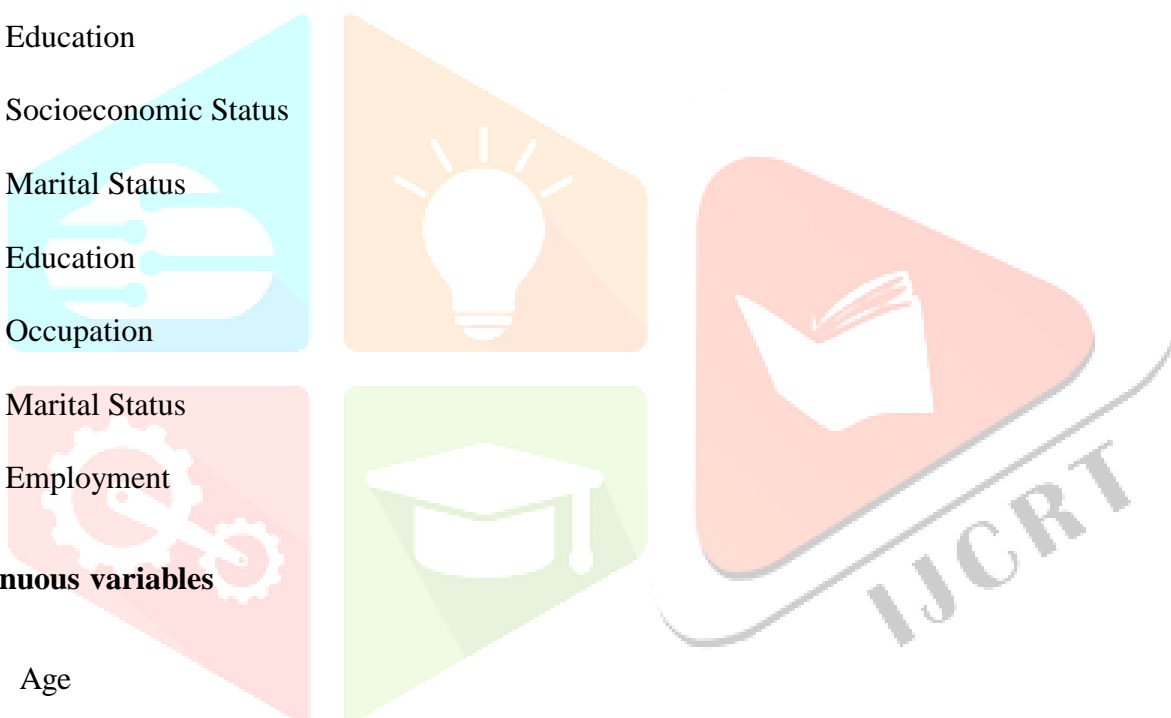
In this study research variable is barriers of ART enrolment

### Demographic Variables

1. Gender
2. Education
3. Socioeconomic Status
4. Marital Status
5. Education
6. Occupation
7. Marital Status
8. Employment

### Continuous variables

1. Age
2. Family type
3. HIV test year
4. HIV first screening
5. CD4 count
6. Distance to ART centre
7. Amount spend on travel



## Categorical variables

1. Educational status
2. Family Type
3. Land acres
4. Earning members
5. Income
6. HIV test place
7. HIV first screening
8. Mode of transport
9. Health care facility

## SETTING OF THE STUDY

Setting refers to the specific area where the research information is collected. The research site is the overall location of the research is conducted. The setting of the study is important as it can have an influence on research process. Setting of the study refers to “the specific place where information is gathered”<sup>49</sup>

In this study setting of the study refers to selected district where PLHIV are residing.

## IDENTIFICATION OF POPULATION

The population is the entire set of individuals or objects having some common characteristics selected for a research study. The population is also referring to be the universe of the study. Population is the total number of all the units in which a researcher is interested. In other it is set of people or entities to which the results words population is the set of people or entities to which the results of a researcher are to be generalised.<sup>48</sup>

### Target Population:

Target population refers to the entire population in which the researchers are interested and to which they would like to generalize the research findings<sup>48</sup>. It consists of the total number of objects which are meeting the designated set of criteria. It includes the all the aggregates of all the cases with a certain phenomenon to about which the researcher would like to make a generalization.

In this study, the target population comprised of the PLHA who are not enrolled for ART.

### Accessible population

The accessible population is the aggregate of cases that conform to designated inclusion or exclusion criteria and that are accessible as the subjects of the study<sup>48</sup>. The accessible population for the present study was People living with HIV but not enrolled for ART in a selected district.

## SAMPLING TECHNIQUE

According to **Polit & Hungler** “Sampling is the process of selecting a portion to represent the entire population.”<sup>49</sup>.

Non-probability Convenient sampling technique was adopted for the present study. Non-probability sampling is done in which samples are selected by non-random methods. This is selected based on the purposes of this study, which is to identify the barriers of ART enrolment.

## SAMPLE

The sample is the subset of the population to participate in the study. It is the representative unit of a target population, which is to be worked upon by a researcher during their study.<sup>50</sup> It consists of a subset of units which comprise the population selected by the investigators or researchers to participate in their researcher project. In this study, the sample consisted of the people living with HIV and not enrolled for ART and who fulfilled the criteria that were laid down for the selection of samples.

### Estimated Sample Size

Sample Size: The sample size was estimated using G\*Power 3 a statistical power analysis program designed to analyze different types of power and compute size with graphic options. Based on the estimates from the pilot study and from the previous studies, inherent variances in given stratum i.e. different scales (Zelaya and BACE) were used with  $\alpha$  error probability = 0.05, power  $(1-\beta) = 0.8$  and the data from AVERT India 2016 ( $q = 50\%$  of adults on antiretroviral treatment and subsequently  $p = 50\%$  not on antiretroviral treatment) the estimated sample size was ~ 90. The internal consistencies for each scale were checked using Cronbach's Alpha which was found to be  $> 0.7$ .

## SAMPLE SIZ

According to Polit and Beck (2009), sample size is the numerical value assigned to a subset of population selected to participate in a study. Sampling is the process of selecting a representative part of a population.<sup>48</sup>

The present study consisted of 50 PLHA residing in a selected district.

## • CRITERIA FOR SAMPLE COLLECTION

**Inclusion criteria;** PLHA who are

1. Registered for HIV Testing and Counselling (HTC) and not enrolled to ART.
2. Not enrolled for ART within 6 months of HIV Testing.

**Exclusion criteria;** PLHA who are

1. Registered for ART.
2. Newly diagnosed.
3. Having Visual and Hearing impairment

## TOOL PREPARATION

According to Polit and Beck, “Tool is an instrument or a device used to collect the data e.g. questionnaire, test, observation schedule, etc.”<sup>49</sup>

The present study is aimed at identifying the barriers of enrolment of patient to initiate ART among people living with HIV. Thus, data was collected using semi structured questionnaires. The tool consisted of three sections.

## DATA COLLECTION

According to Polit and Hungler “data collection is the gathering of information needed to address a research problem”<sup>49</sup>

A formal written permission was obtained for the study. Permission was obtained from the management and the administrator of the selected hospital to conduct the main study.

After verifying the records, patients who fulfilled the inclusion criteria were selected as samples. The purpose of the study, the method of data collection and time duration were explained to the subjects for getting true responses. Subjects were selected using Convenient sampling method. Informed consent was obtained from the subjects indicating their willingness to participate in the study before the collection of data. Assurance was given to the subjects regarding the confidentiality of the information. Demographic variables were identified using semi-structured interview schedule.

## FEASIBILITY OF THE STUDY

Feasibility helps the researcher to determine, if the samples understand the items and if the directions given are clear. The purpose is to reveal problems selected to be answered and to point out weakness in the administration, organization and distribution of the instrument.<sup>48</sup>

It was feasible to conduct study in the selected area.

## DATA COLLECTION AND ANALYSIS.

Data collection was carried out in the month of November and January. A sample of 50 PLHA with the use of Non probability convenient sampling was selected. The reliable tool was used for the data collection. Semi structured interview was used in to collect the necessary information. Data analysis is the systematic organization and synthesis of research data and testing of research hypothesis using the data. It is a systematic approach to investigations during which numerical data is collected and/or the researcher transforms what is collected or observed into numerical data. It often describes a situation or event; answering the 'what' and 'how many' questions you may have about something. This is research which involves measuring or counting attributes<sup>103</sup>

## PLAN FOR DATA ANALYSIS

The data obtained was analysed using both descriptive and inferential statistics based on the objectives and research question of the study under the following headings:

- Preparation of master sheet
- Description of subjects with regard to demographic variables in terms of frequency and percentage
- Analysis of data related to non-enrolment of people living with HIV to ART
- Analysis of data to find relationship between Zelaya scale and selected demographic variables.
- Analysis of data to find relationship between BACE scale and selected demographic variables



## ANALYSIS AND INTERPRETATION OF DATA

Analysis and interpretation of data is the most important phase of the research process. The collected data, which is known as raw data is meaningless unless it is analysed using some statistical tests. Data analysis means to make the raw data meaningful after proper statistical treatment.<sup>105</sup> Data analysis is the systematic organization and synthesis of research data and testing of research hypothesis using the data. The interpretation of data refers to the critical examination of the analysed study results to draw inferences and conclusions. It is considered as one of the most essential task in the research process to frame the recommendations.<sup>48</sup> It involves the process of sifting, assimilating, modelling and transforming of data collected by the researcher. In the form of tabulation or presentation of data or in some other form and is done with the purpose of suggesting conclusions and supporting the hypothesis presented in the dissertation. This chapter presents the analysis and interpretation of the data collected to assess the barriers to ART enrolment among PLHA in a selected district. The data analysis was carried out based on the objectives set by the investigator.

### OBJECTIVES OF THE STUDY

1. Identify the barriers leading to non-enrolment of PLHA for ART initiation.
2. Explore the contextual factors regarding the identified barriers of non-enrolment of PLHA for ART initiation.

Analysis is the process of organizing and synthesizing data so as to answer research questions and test hypothesis. The purpose of the analysis is to reduce data to eligible and interpretable form so that the relation of the research problems can be studied and tested. Interpretation of data refers to the critical examination of the analysed study results to draw inferences and conclusions. This is done carefully through brainstorming to infer condensed and statistically computed data; so that research questions can be answered and hypothesis can be tested Interpretation is the process of making sense of study results and of examining their implications.<sup>49</sup>

## ORGANIZATION OF STUDY FINDINGS

The collected data is tabulated, analysed, organized and presented as following sections.

**SECTION I:** Description of subjects with regard to demographic information in terms of frequency and percentage.

**SECTION II:** Analysis of data with regards to each barriers of ART

**SECTION III:** Analysis of data to find Association between ZELAYA SCALE and demographic variables.

**SECTION III:** Analysis of data to find relationship between BACE SCALE and demographic variables.

### SECTION I: DISTRIBUTION OF STUDY SUBJECTS WITH REGARD TO DEMOGRAPHIC INFORMATION IN TERMS OF FREQUENCY AND PERCENTAGE

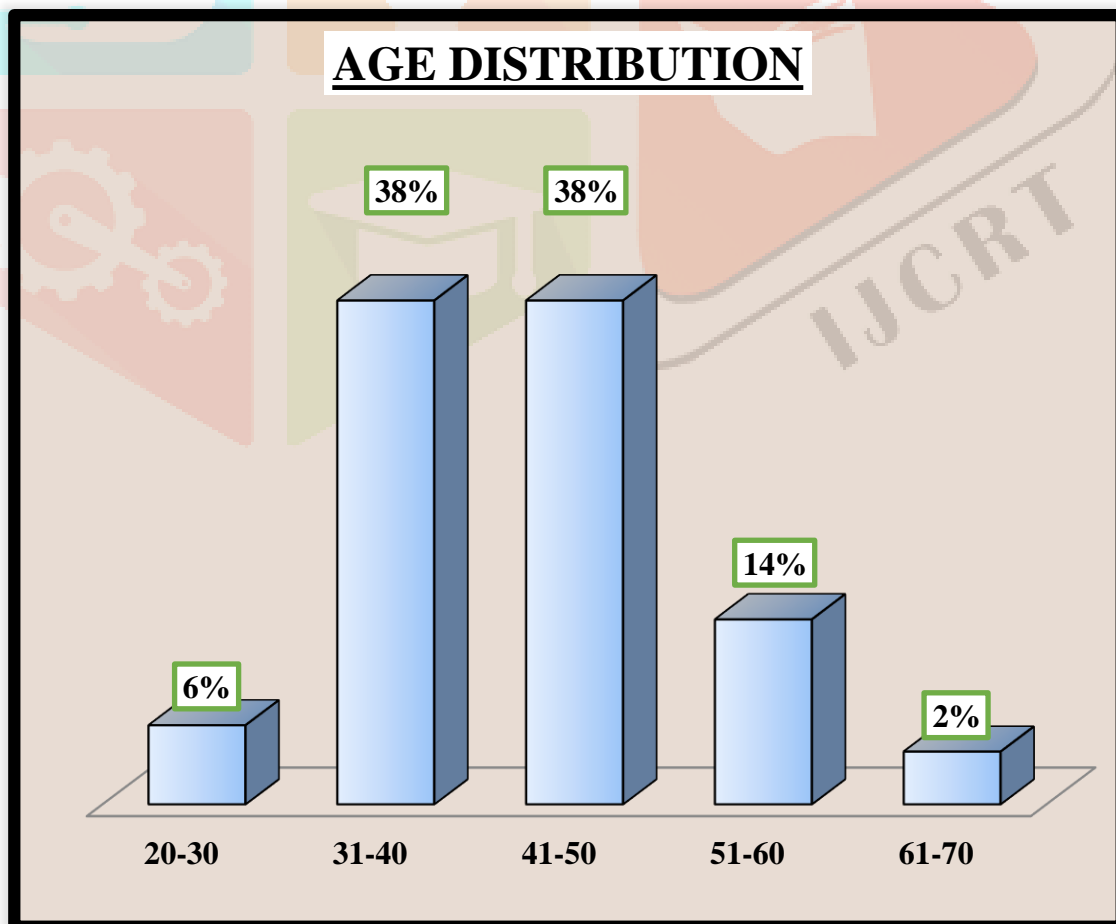
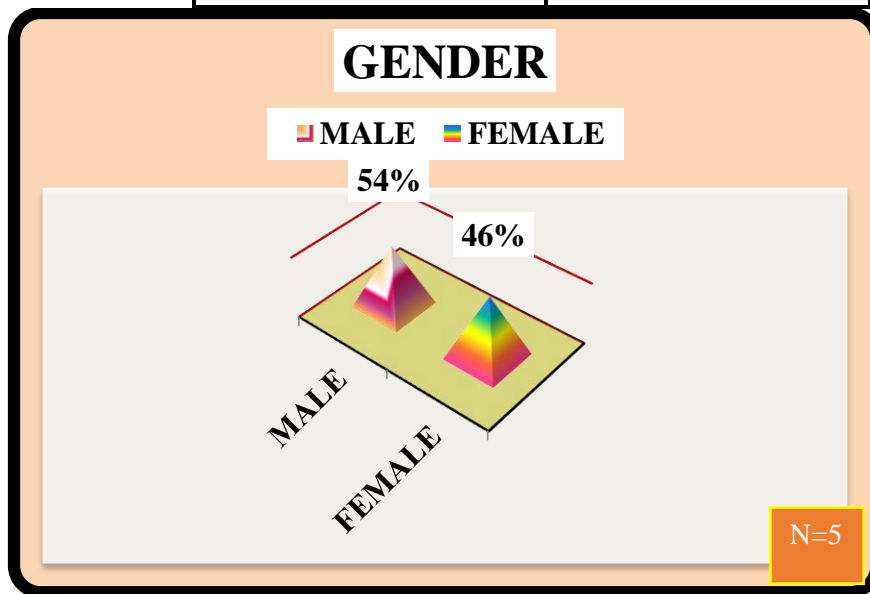


Figure no; 3 Bar diagram representing Frequency and percentage distribution of subjects according to their age

**Figure3:** depicts distribution of subjects according to age. Majority of the subject 38% (19) of the subjects belonged to the age group 31-50 and 38% (19) subjects belonged to the age group 41-50 years. 6% (3) of the subjects were of the age category 20-30 years, 7 subjects (14%) belonged to the age group of 51- 60 and 2 subjects (4%) belonged to the age group 61-70 years

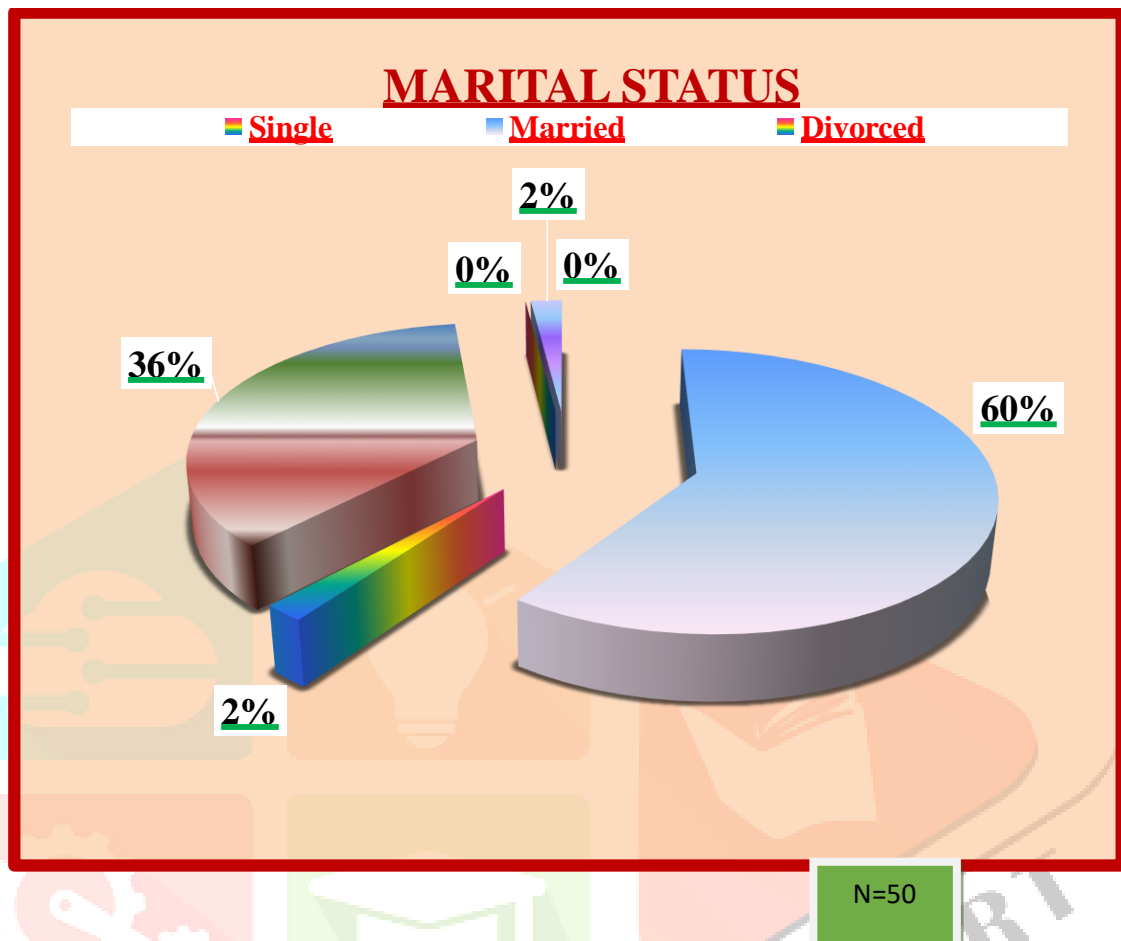
**Table No: 3 Frequency and percentage distribution of subjects according to their gender.**

CATEGORY	FREQUENCY	PERCENTAGE
Male	27	54%
Female	23	46%



Pyramid diagram showing distribution of subjects on the basis of their gender.

**Table 3 and Figure 4:** shows the distribution of subjects according to Gender. 27 (54%) were males and 23 (46%) of the subjects were females

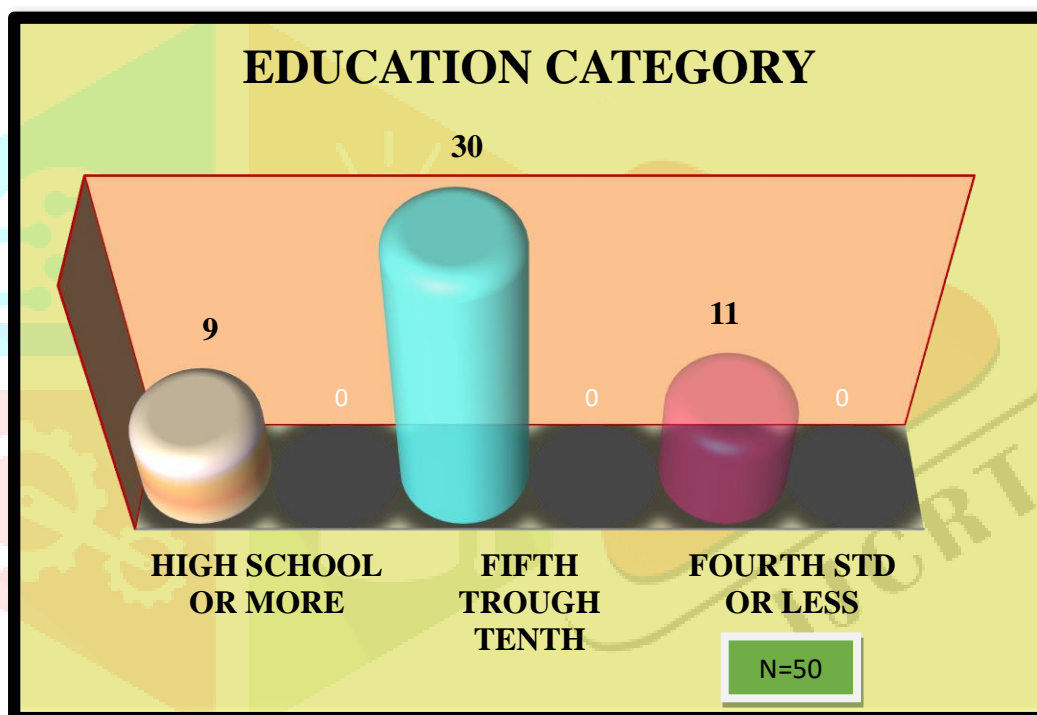


**Figure 5 :** Pie diagram representing the marital status of the subjects

**Figure 5** deals with the distribution of marital status among the subjects. Majority of the subjects 30 (60%) were married, 18 (36%) subjects were widow /widower, 1 (2%) of the subjects was separated, 1 (2%) was divorced.

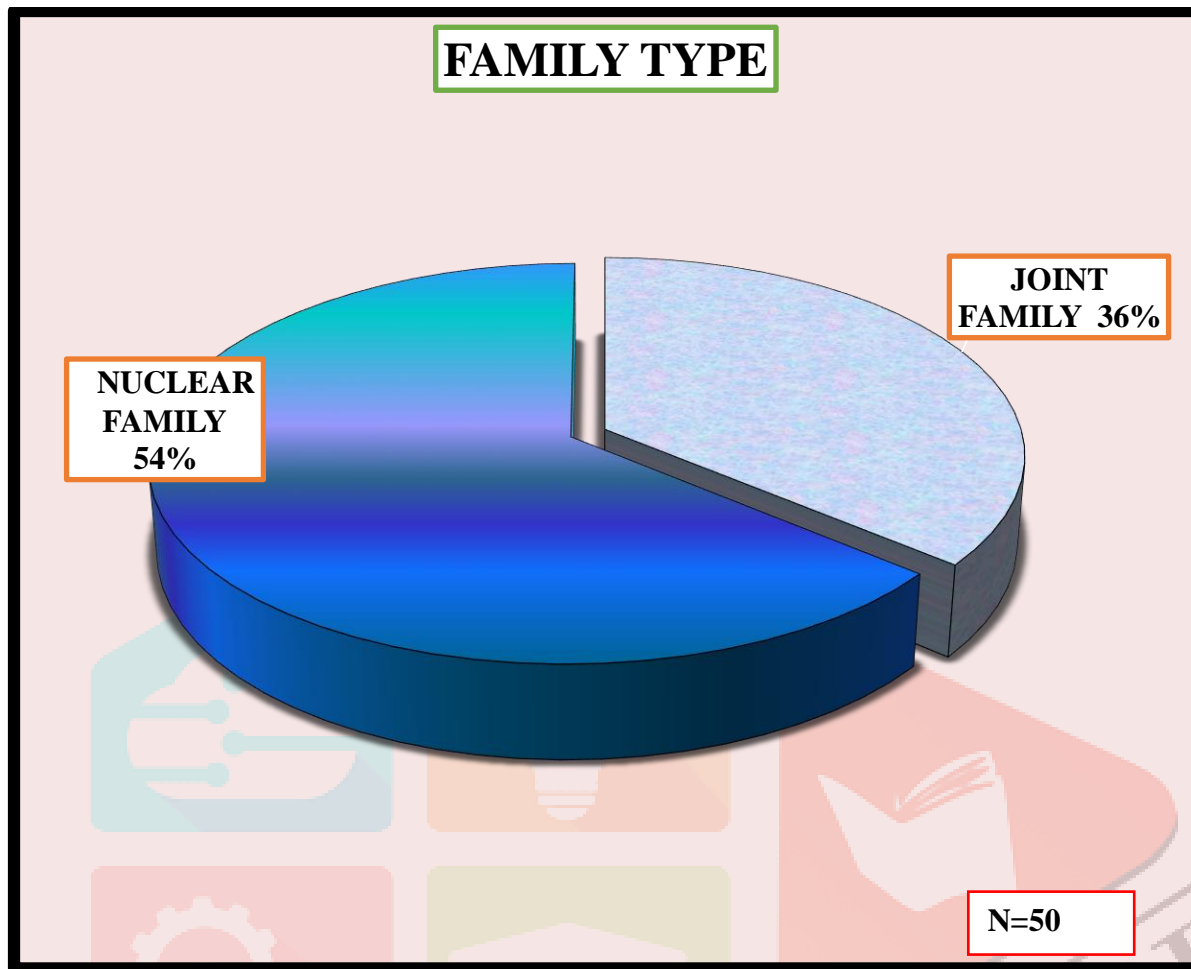
**Table no: 4** Frequency and percentage distribution of subjects according to their educational qualification

Category	Frequency	Percent	Cum.Percent
<b>Fourth std or less</b>	11	22%	22%
<b>Fifth trough tenth</b>	30	60%	82%
<b>High school or more</b>	9	18%	100%



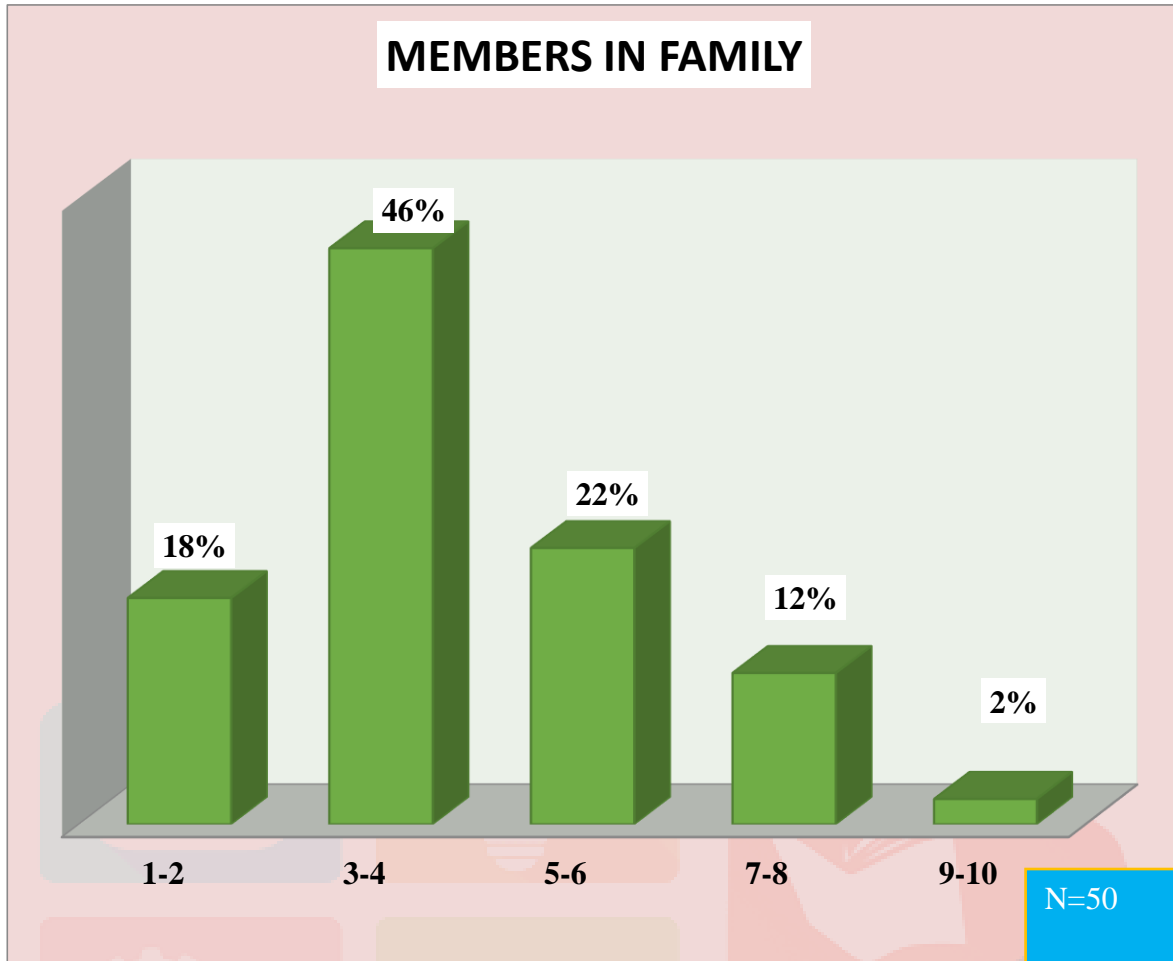
**Figure 6** cylindrical diagram representing educational of the subjects.

**Table 6 and Figure 6** represents educational qualification of the sample. 30 (60%) subjects had a educational qualification from fifth through tenth, 22% ( 11 ) had their basic education and 9 (18%) of the subjects had a bacctularate degree.



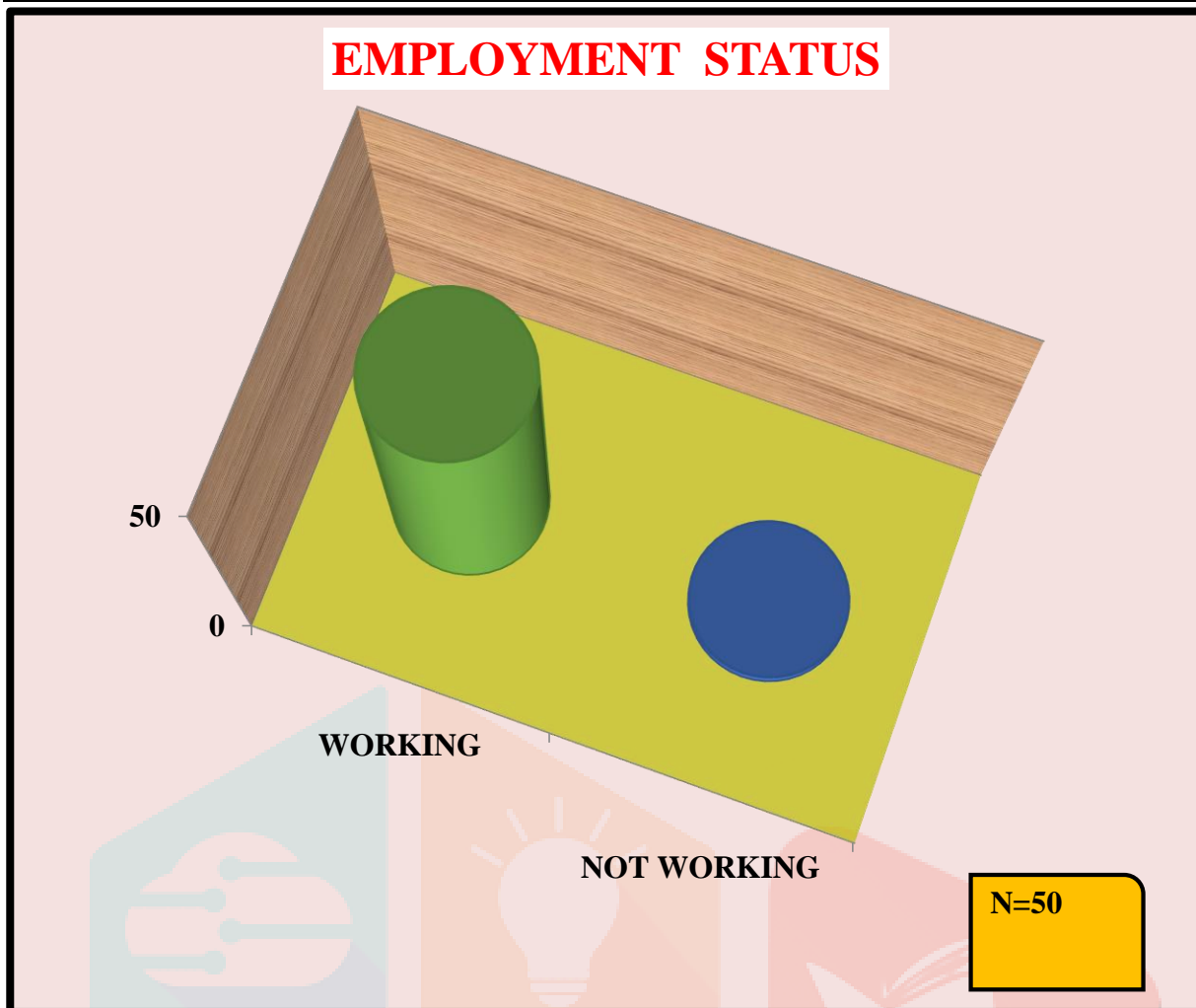
**Figure 7; pie diagram Frequency and percentage distribution of subjects according to their family type.**

**Figure 7** represents family type of the subject. 32 (64%) subjects belonged to a nuclear family. 18 (36%) belonged to a joint family.



**Figure 8** Column diagram representing frequency and percentage distribution of subjects according to the number of family members.

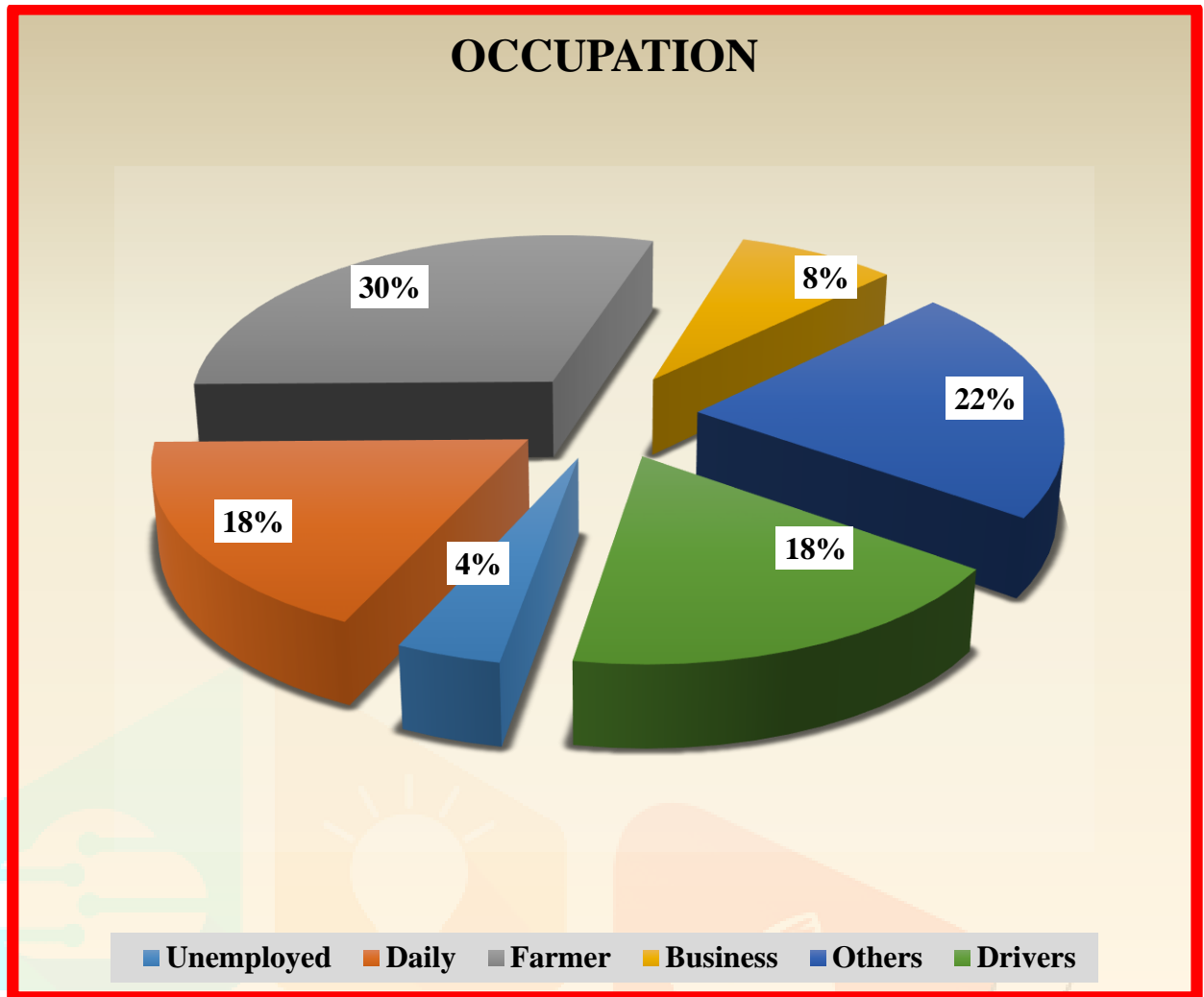
**Figure 8** shows the members in the family. Majority of the family 23 (46%) had around 3-4 members their family, 9 (18%) family consisted of 1-2 whereas 11 (22%) of the families had around 5-6 family members 6 (12%) family consisted of 7-8 members in 1(2%) their family.



**Figure 9:** Pie diagram representing frequency and percentage distribution of employment status

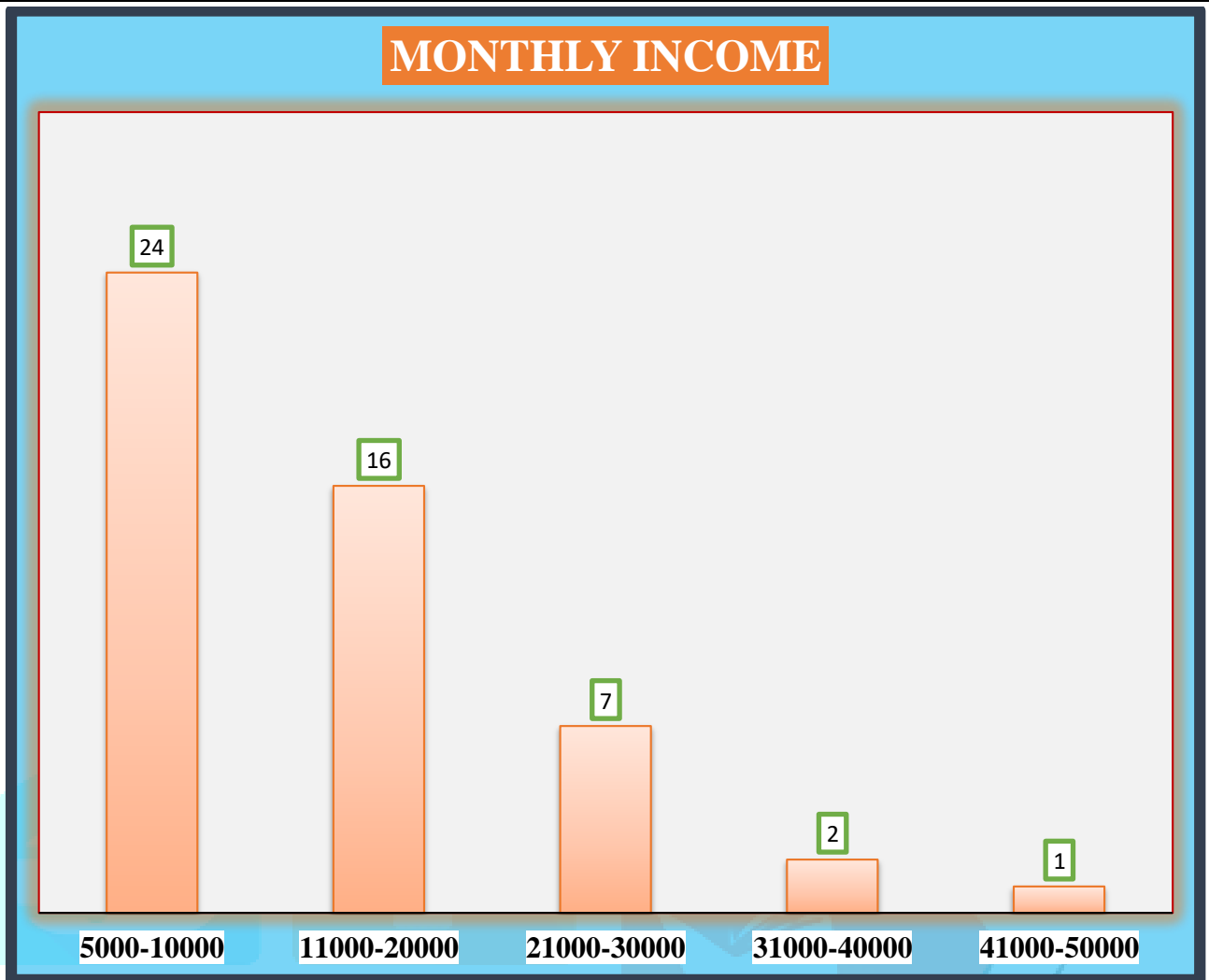
**Figure 9** represents the employment status of the family. 96% of the subjects were employed and only 4% were unemployed





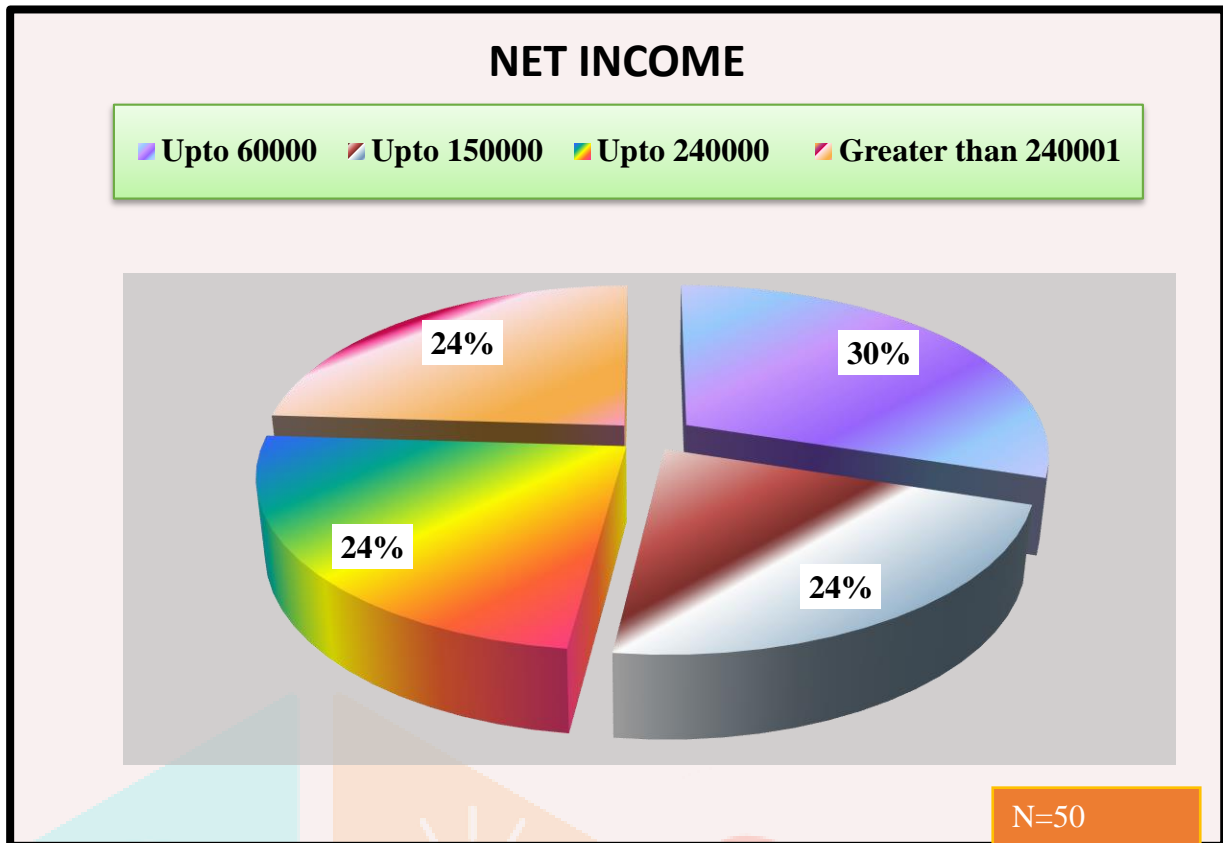
**Figure 10** Pie Diagram frequency and percentage distribution of occupational status.

**Figure 10** represents the occupation of the subjects. 30% (15) of the subjects were farmers. 18% (9) were daily wagers, 18% (9) were drivers, 8% (4) were businessman, 22% (11) of the subjects were occupied in other category, 4% (2) were unemployed



**Figure 11 bar diagram representing monthly income of the subjects.**

**Figure 11 represents the economic status of the sample.** Majority 24 (48%) of the sample had monthly income of 5000 to 10000 Rs. 16 (32%) people had 11000 to 20000 Rs per month. 7 (14%) people had monthly income of Rs. 21000-30000. 2 (4%) people had monthly income around 31000-40000 and 1 (2%) person had a monthly income of above 40000 Rs.



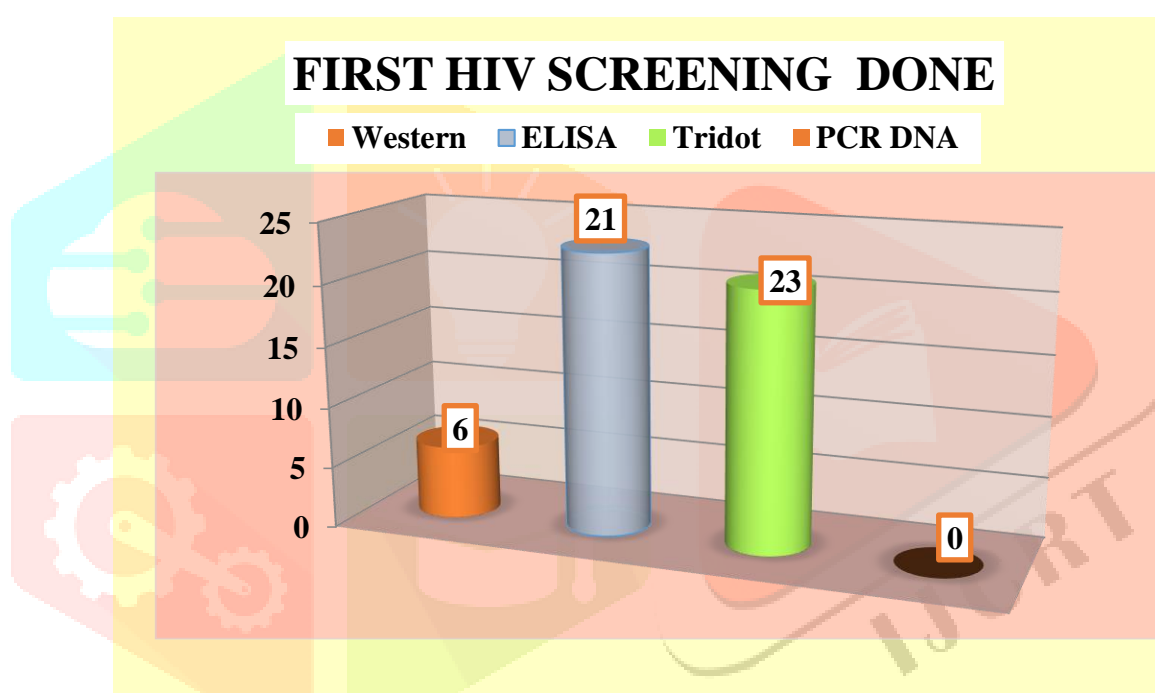
**Figure 12** Pie diagram on Frequency and percentage distribution of subjects according to their monthly income

**Figure 12** pie diagram representing the net income of the subject.

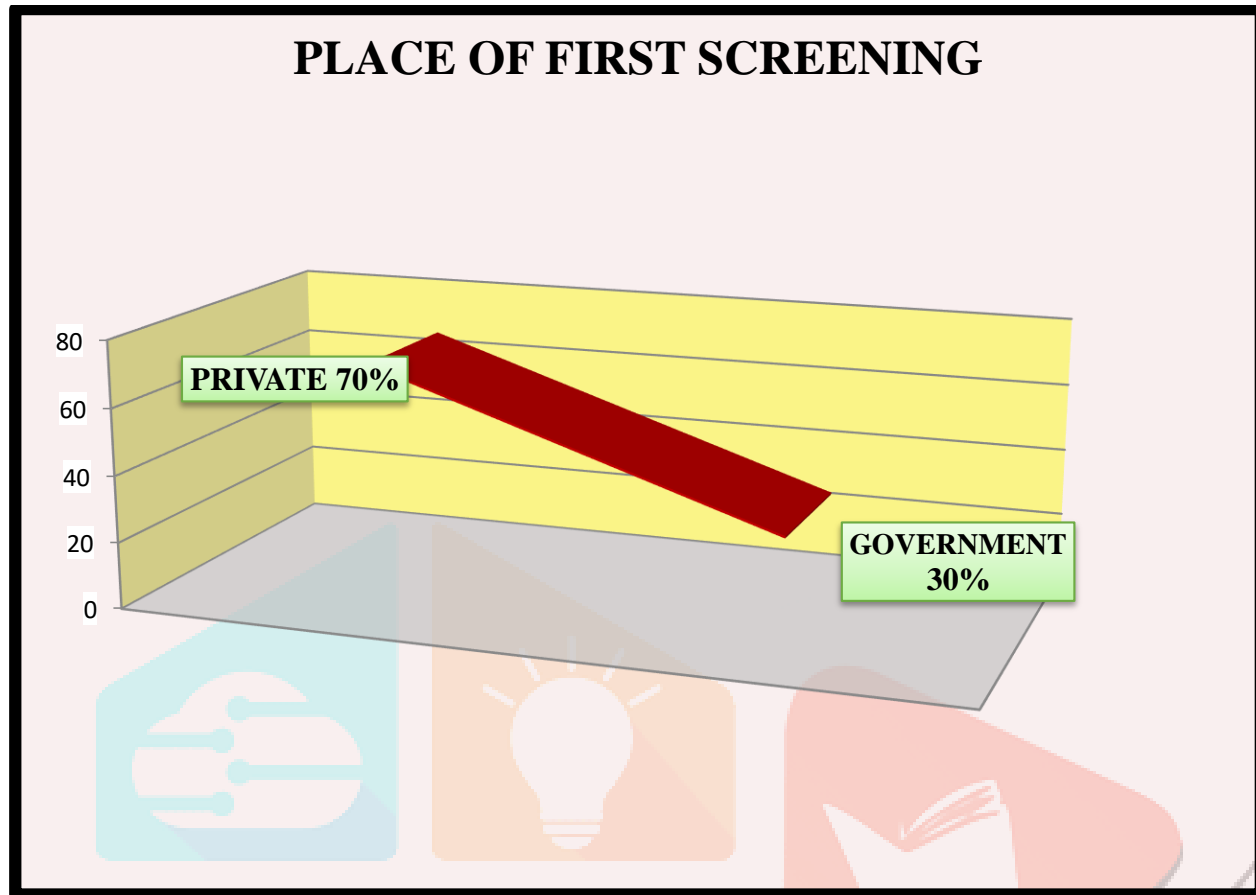
Figure 12, represents the net income of the family on the basis of their quartile 30% (15) of the subjects had an income more than 60000 Rs. Per year. 22% (11) of the subjects had net income above 1.5 lakh, 22% (11) had amount up to 2.4 lakh. 22% (11) of the subjects had a net income above 2.4 lakh per year.

5. Table: 5 Frequency and percentage distribution of subjects according to First screening done.

Parameters	Freq	Percent
WESTERN BLOT	6	12%
ELISA	23	46%
TRIDOT	21	42%
PCR DNA	0	0%

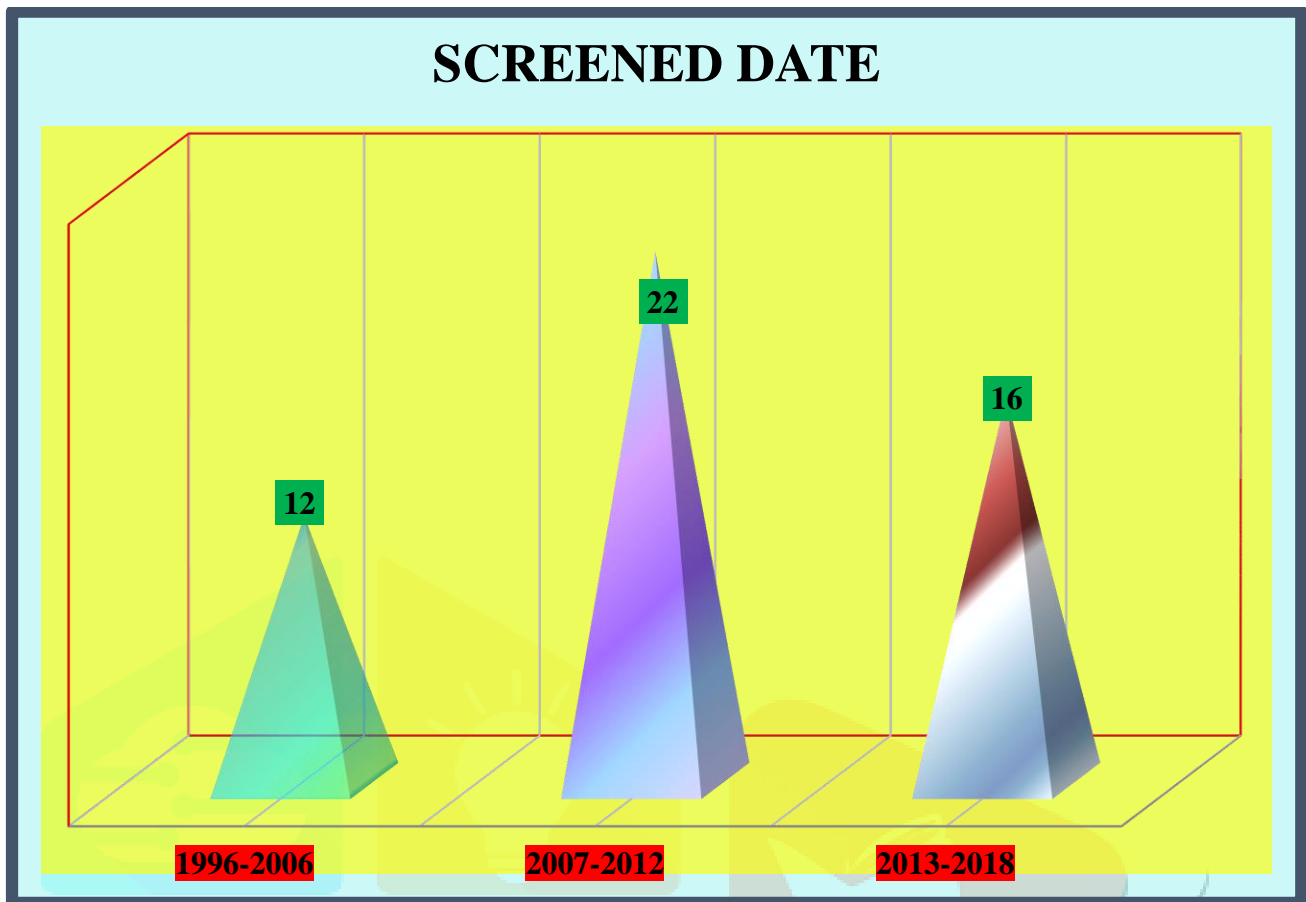


**Figure 13** Stacked cylinder diagram representing the first screening undergone by the subjects . 46% of the subjects had undergone ELISA testing. 42% had undergone a Tridot and 12% undergone a western blot test.



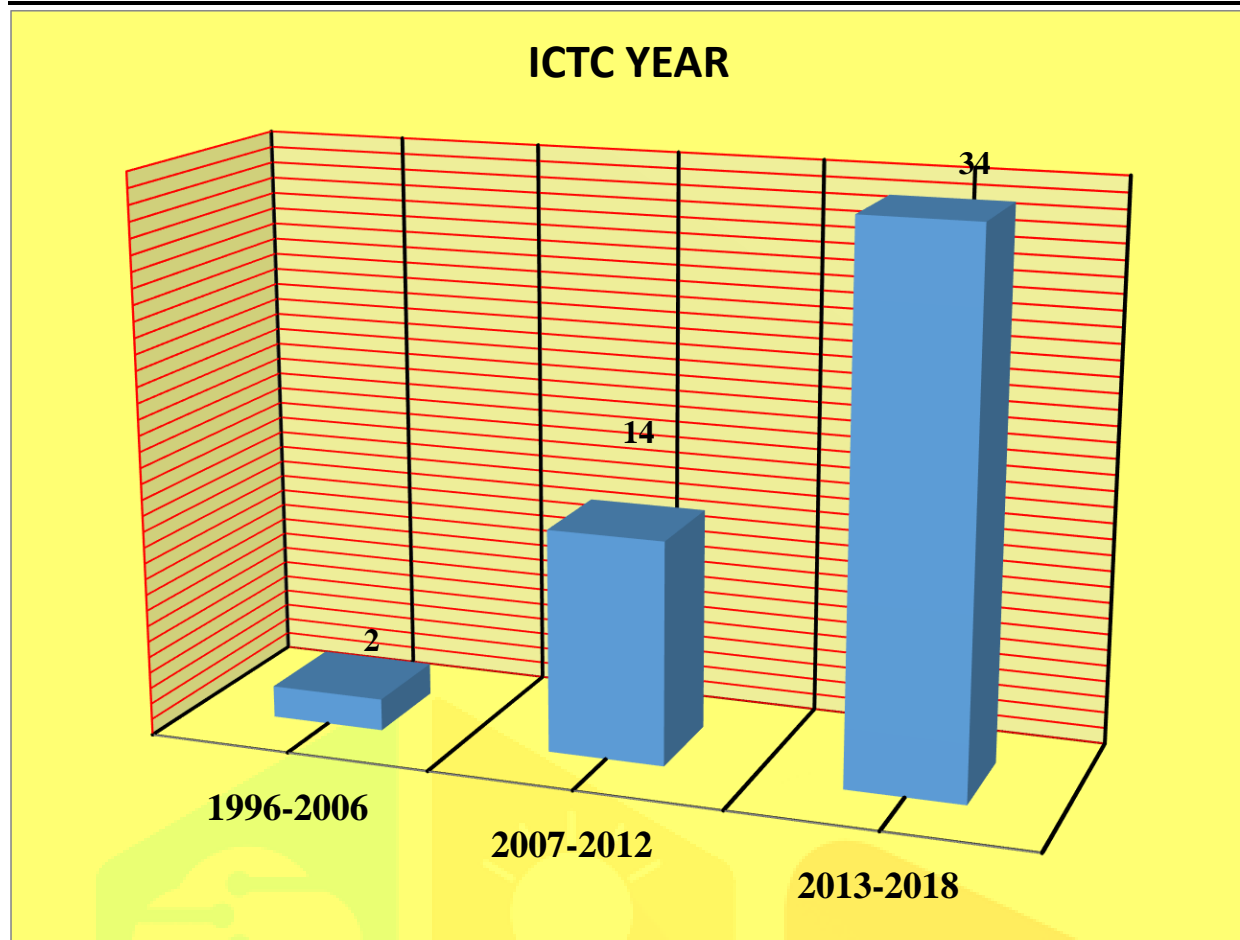
**Figure 14** 3 D line diagram representing the place of first screening

**Figure 14** represents the place of first screening. 70% of the subjects undergone screening in a private sector and 30% undergone HIV testing in a government centre



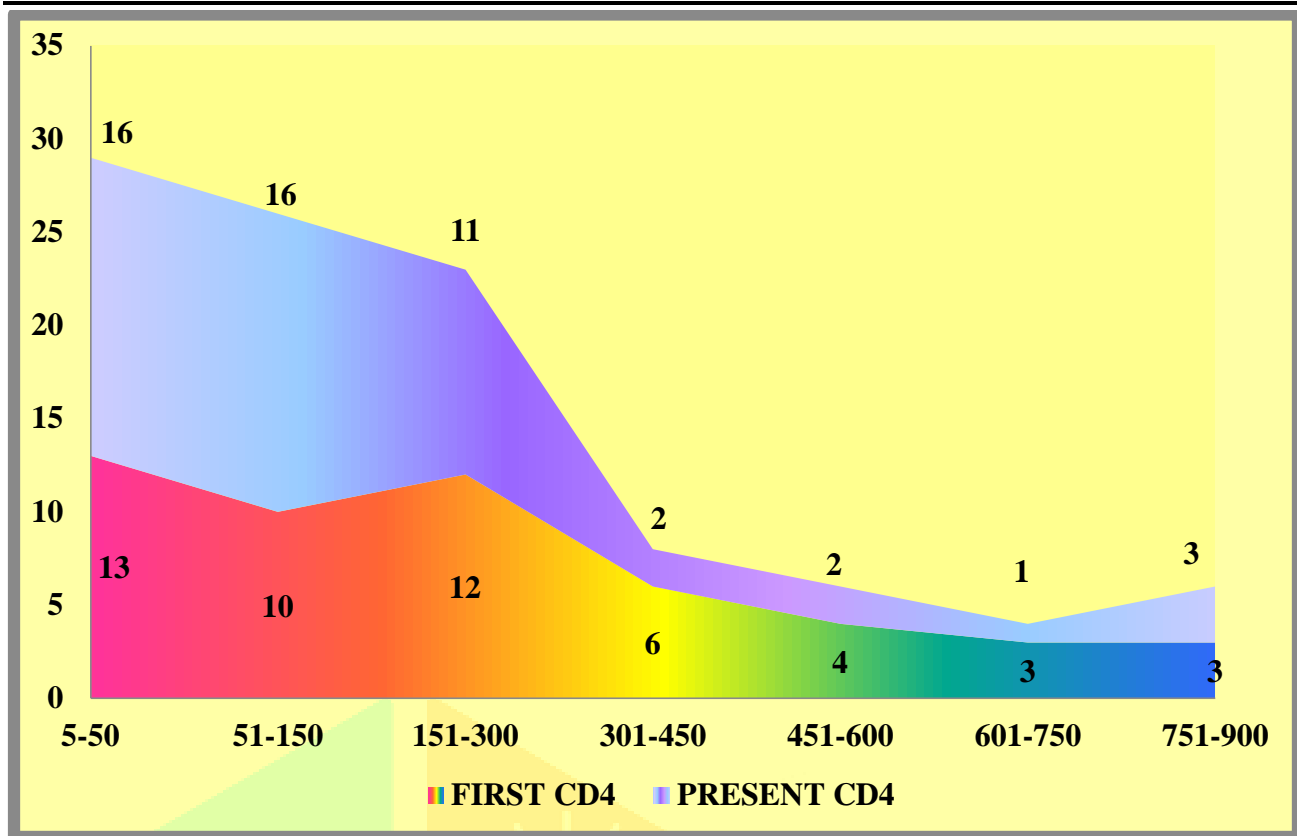
**Figure 15 100% pyramid diagram representing the year of first screening.**

Figure 15 depicts the first HIV test year. Majority 22 (44%) of the subjects has undergone their first HIV testing in the year 2007 -2012. 12 subjects (24%) has undergone the testing in the year 1996-2006. 32% 16 of the subjects has undergone screening in the year 2013-2018.



**Figure 16 column diagram representing the year ICTC.**

Figure 16 depicts the year of ICTC. Majority 34 (68%) of the subjects has undergone their first HIV testing in the year 2013 -2018. 14 subjects (28%) has undergone the testing in the year 2007-2012. 4% (2)of the subjects has undergone screening in the year 1996-2006.



**Figure 17** Area chart depicting Frequency and percentage distribution of subjects according to first and present CD4 count.

**Figure 17** represents the present and first CD4 count of the sample analysis shows that there is a difference in patient's first CD4 count and the present. The mean first CD4 count was 246.36 and the mean of present CD4 count is 181.02



Table: 6 Frequency and percentage distribution of subjects according HIV status disclosure

HIV STATUS DISCLOSURE			
PARAMETERS		FREQUENCY	Percentage
Spouse	Yes	31	62%
	No	19	38%
Mother/Father	Yes	16	32%
	No	34	68%
In-Laws	Yes	16	32%
	No	34	68%
Siblings	Yes	13	26%
	No	37	74%
Children	Yes	17	34%
	No	33	66%
Relatives	Yes	12	24%
	No	38	76%
Friends	Yes	12	24%
	No	38	76%

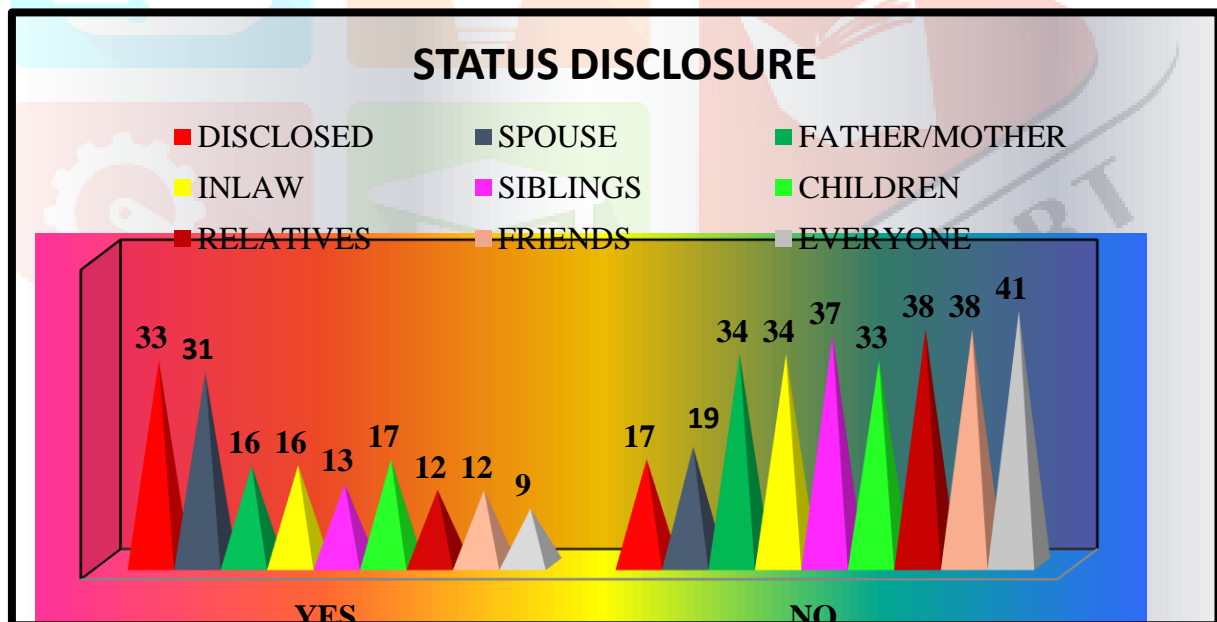


Table 18 represents the HIV disclosure of the client. Majority of the subjects 33 (66%) subjects disclosed there HIV status while 17 (34%) has not disclosed there HIV status. Among those disclosed there HIV status most of the sample disclosed there HIV status to their spouse (38%). 9 subjects has disclosed there HIV status to all

**Table No: 7 Frequency and percentage distribution of subjects according to substance use**

VARIABLE		FREQUENCY	PERCENTAGE
<b>ALCOHOLISM</b>	Yes	31	62%
	No	17	34%
	Previously	5	10%
<b>SMOKING</b>	Yes	33	66%
	No	17	34%
	Previously	6	12%
<b>TOBACCO</b>	Yes	34	68%
	No	16	32%
	Previously	5	10%

**Table no 7** depicts that 17 (34%) subjects currently and 2 (4%) subjects smoked previously. 17 (34%) subjects drink alcohol currently and 2 (4%) subjects smoked previously. 34 subjects take tobacco currently and 5 (10%) subjects used tobacco previously.

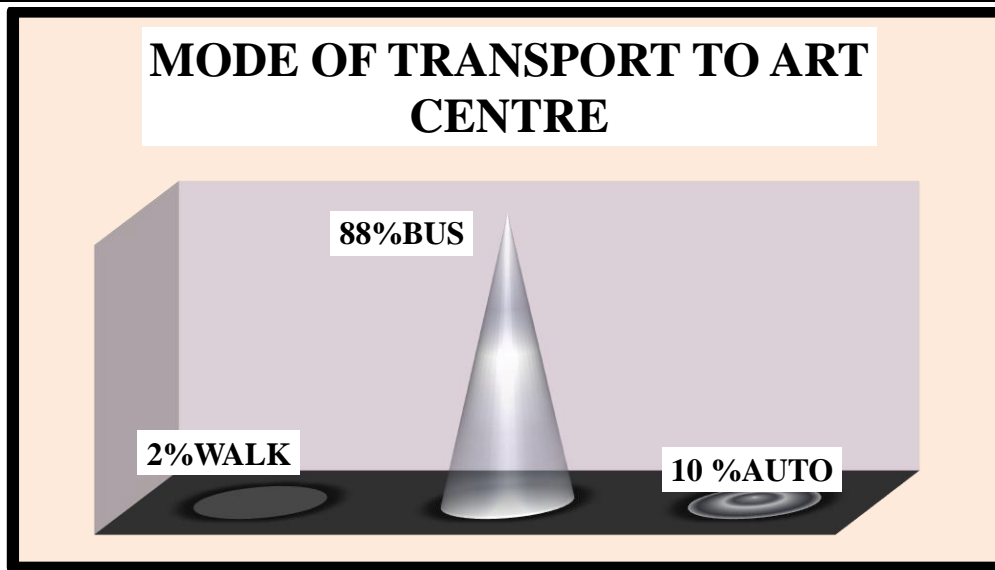


Figure no 19 pyramidal diagram Frequency and percentage distribution of subjects according mode of transport.

Figure 19 diagram represent mode of transport 88% of subjects use bus as mode of transport while 10% depend on a auto for travelling while 2% need walk to ART centre.

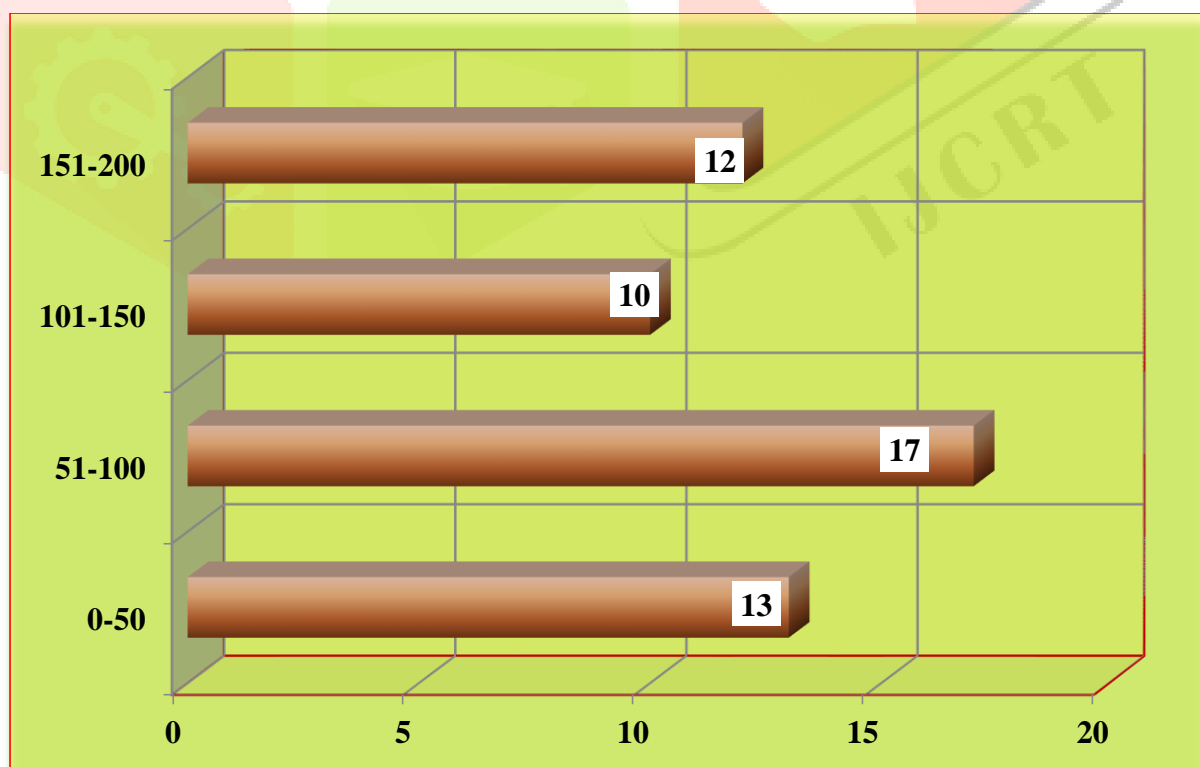
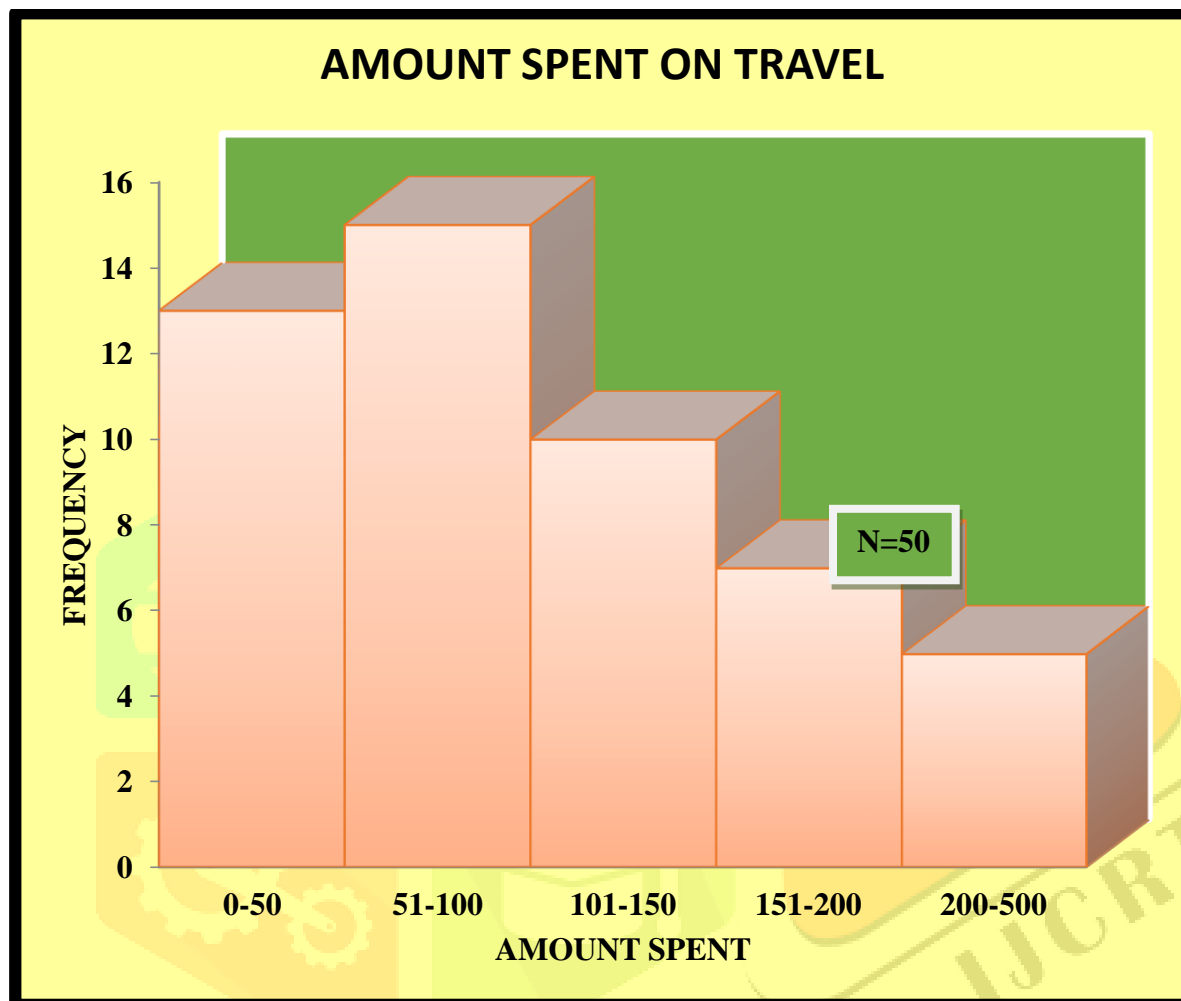


Figure : 20 Column diagram depicting Frequency and percentage distribution of subjects according to distance travelled to reach ART centre

**Figure 20** Majority of the sample had travel a mean distance of 51.3%. 58% of the subjects travelled around 0-50 km to reach their facility. 34% travelled by bus 8% had to travel more than 100 km to reach their destined ART centre.



**Figure 21** Colum diagram Frequency and percentage distribution of subjects according to amount spend to reach ART centre.

**Figure 21** represents the amounts spent by the subject to reach the ART centre. Majority of the subjects spend around a mean of 113.79 Rs to reach their ART centre. 11 (22%) subjects spend about 0-50 Rs, 15 (30%) subjects spends around 100 Rs. 2 (4%) subjects spends around 100-150 Rs, 6% spends about 200-250 Rs and about 2% of the subjects pay around 500 Rs to reach their centres

Table no: 8 Frequency and percentage distribution of subjects according enrolled to Alternative  
medicine

ALTERNATIVE MEDICINE				
Category	Frequency	Cum Frequency	Percent	Cum Frequency
NO ALTERNATIVE	35	35	70	70
AURVEDIC	10	45	20	90
YOGA	0	45	0	90
UNANI	0	45	0	90
SIDDHA	4	49	8	98
HOMEOPATHY	1	50	2	100

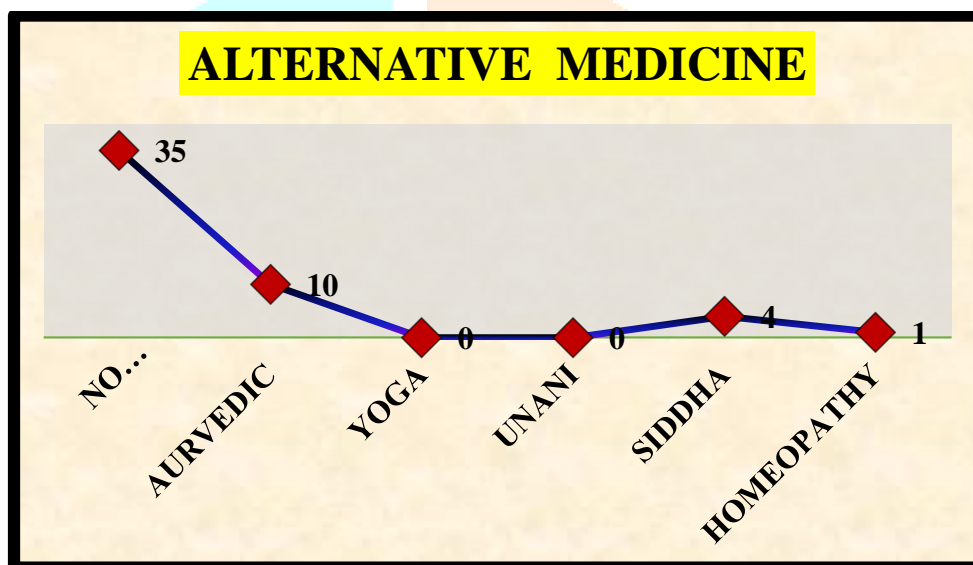


Figure 22 Line diagram depicting alternative medication

Figure 22 around 30% of the subjects depend on alternative medication.

Table no 9 frequency distribution of on barriers to ART enrolment.

VARIABLE		FREQUENCY	PERCENTAGE
ART Centre	Yes	20	40%
	No	30	60%
ART Registration	Yes	20	40%
	No	30	60%
ART-Medication	Yes	20	40%
	No	30	60%
ART-Initiation	Yes	20	40%
	No	30	60%
ART- Free Of Cost	Yes	20	40%
	No	30	60%
ART- Life Long	Yes	20	40%
	No	30	60%
Fear Family Members Will Betray	Yes	8	84%
	No	42	16%
Fear to start ART	YES	39	78%
	NO	11	22%
Others Might Find Out	YES	44	88%
	NO	6	12%
Done-Wrong	YES	22	44%
	NO	28	56%

Table no 9 depicts the barriers to ART. 60% of the subject's doesn't have knowledge regarding ART. 78% of the subjects have fear to start ART.88% of the subjects revealed that they might be found out if they go to an ART centre.

## SECTION II: ANALYSIS AND COMPARISON OF DATA

### SECTION A

**Table 10** Analysis of data to find relationship of total stigma and and demographic variables.

Parameter	Mean	S d	Se	Min	Max	Rang e	F(V)	Pr(>F)	Signific ance	
Age	40 Years Or Less	3.24	0.51	0.11	2.3	4.04	1.74	1.01	0.32	Not Significant
	40 Years To 70 Years	3.44	0.52	0.1	2.2	4.09	1.87			
Gender	Male	3.42	0.51	0.1	2.22	4.09	1.87	1.01	0.32	Not Significant
	Female	3.27	0.53	0.11	2.23	4.09	1.87			
Employment	Employed	3.38	0.5	0.07	2.22	4.09	1.87	3.81	0.06	Not Significant
	Not Employed	2.67	0.52	0.37	2.3	3.04	0.74			
Education	Fourth STD or Less	3.25	0.54	0.16	2.3	3.91	1.61	2.45	0.10	Not Significant
	Fifth through Tenth	3.69	0.49	0.16	2.61	2.22	4.09			
	High School or More	3.69	0.49	0.16	2.61	4.09	1.48			

**Table.10 depicts that** there is no significant association between stigma and selected

Demographic variables.

**Table 11 Analysis of data to find relationship of total stigma and HIV disclosure**

ANOVA OF HIV DISCLOSURE AND STIGMA									
Parameters		Mean	S D	Se	Sum Sq	Mean Sq	F Value	Pr(>F)	Significance
HIV Disclosure	yes	3.26	0.56	0.1	0.842	0.8418	3.28	0.08	Not significant
	no	3.53	0.37	0.09					

**Table 11** represents HIV disclosure and stigma has no significance.

## SECTION 2: ANALYSIS OF DATA TO FIND RELATIONSHIP BARRIERS OF ACCESSING CARE AND DEMOGRAPHIC VARIABLES.

**Table 12 ANOVA of Total Barriers of accessing care with Demographic Variables**

PARAMETER		Mean	sd	Se	Min	max	F(v)	Pr(>F)	SIGNIFICANCE
GENDER	MALE	1.73	0.43	0.08	1.03	2.63	0.21	0.65	Not Significant
	FEMALE	1.68	0.41	0.08	1.03	2.43			
Education	4=<4	1.5	0.37	0.11	1.03	2.07	5.31	< 0.01 **	Significant
	5-10	1.68	0.4	0.07	1.03	2.05			
	>11	2.05	0.33	0.11	1.03	2.63			
Occupation	Unemployed	1.35	0.17	0.12	1.23	1.47	3.12	0.02 *	Significant
	Daily Wager	1.65	0.44	0.15	1.03	2.2			
	Farmer	1.57	0.37	0.1	1.03	2.43			
	Businessman	1.45	0.32	0.16	1.1	1.87			
	Others	2.06	0.37	0.11	1.53	2.63			



	Drivers	1.75	0.34	0.11	1.27	2.3			
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Table 12 reveals that there a significant association between occupation and education, while there is no significant association with the other demographic variables.

**Table 13 Analysis of data to find relationship Total Barriers of accessing care with HIV disclosure.**

ANOVA OF HIV DISCLOSURE AND BARRIERS FOR ACESSING CARE								
Parameters		Mean	Sd	Sum Sq	Mean Sq	F Value	Pr(>F)	Significance
Hiv Disclosure	Yes	1.66	0.41	0.565	0.5649	3.48	0.07	Not significant
	No	1.79	0.41					

Table 13 represents that there is no significant association between HIV status on accessing care.

**Table no : 14 Analysis of data to find relationship Total Barriers of accessing care with Substance Use.**

ANOVA OF SUBSTANCE USE AND BARRIERS FOR ACESSING CARE						
Parameters		Sum Sq	Mean Sq	F Value	Pr(>F)	Significance
Substance Use	Alcoholism	0.197	0.1970	1.16	0.29	Not significant
	Tobacco use	0.138	0.1380	0.81	0.37	Not significant
	Smoking	0.098	0.098	0.57	0.45	Not significant

Table 14 depicts that there is no significant association between substance use in accessing care

1. **Table 15. Analysis of data to find relationship Total Barriers of accessing care with Taking Alternative Medication.**

ANOVA OF TAKING ALTERNATIVE AND BACE SCALE					
Parameters	Sum Sq	Mean Sq	F Value	Pr(>F)	Significance
Alternative Use	0.025	0.025	0.144	0.71	Not significant

Table 15 depicts that there is no significant association between alternative medications in accessing care

### SUMMARY

This chapter dealt with the analysis and interpretation of the study. The study findings are represented in tables and graphs and it answers the research question that people have faced barriers. Research findings suggest Barriers to using HIV care included occupation, education, fear of stigma and HIV disclosure, substance use and high transport costs. Subjects had inadequate knowledge regarding ART which is also one of the major barriers for not non enrolment to ART. Denial of HIV status, belief in spiritual healing, and absence of AIDS symptoms were also barriers.

# CHAPTER V

## SUMMARY AND RECOMMENDATIONS

**“Educating is learning what you didn’t even know and you didn’t know.”**

The present chapter deals with summary, discussion, conclusion and recommendations as per the findings of the present study. The research never ends unless the findings of the study is summarized and communicated.

### OBJECTIVES

- 1 Identify the barriers leading to non enrolment of PLHA for ART initiation.
- 2 Explore the contextual factors regarding the identified barriers of non – enrolment of PLHA for ART initiation.

### RESEARCH QUESTION

What are the barriers faced by the PLHA leading to delayed enrolment to ART?

### ASSUMPTION

1. There may be a number of factors that prevent PLHA from enrolling to ART
2. The various barriers which may lead to non-enrolment are preventable and measures can be taken for enrolling PLHA for ART.
3. PLHA will be sincere in giving responses to questions asked and will share their data.

**MAJOR FINDINGS OF THE STUDY**

1. With regards to age majority of the subject were males 27 (54%) and females were 23(46%).
2. With respect to education category 11 (22%) subjects had their basic education, 30 (60%) were from fifth to tenth STD. Nine (18%) subjects were from high school or above.
3. Of 50 subjects, majority 30 (60%) of subjects were married, 18 (36%) were without partner, 2% subjects were divorced and 2% subjects were separated.
4. Among the subjects whose spouse were living most of the spouse had a basic education and above and most of the partners were in the age group 20 to 70 year and with a mean age of 40.37 years. Majority of the samples had their basic education. 36% of the partners were employed of these 11 (22%) were Farmer. 9% (3 subjects) were Drivers. Majority of the partners had a very good income ranging from 0 to 40000 Rs with a mean of 8200 Rs.
5. Among the subjects 30% of the subjects were farmers. 18% were daily wagers, 18% were drivers, 8% were businessman, 22% of the subjects were occupied in other category, and 4% were unemployed. Majority of the subjects were economically stable with a good earning ranging from 0 to Rs. 45508 per month with a mean of 14402.160. Socio economic patients were well settled of the sample was good most of the people owned own land (50%), and 98% of the subjects owned their own assests. Net income of the samples ranged from 0 to about 7 lakh per year and a mean of 180001.9 Rs.
6. Majority of the subjects who were married had children with a mean age of 10.56 and most of the children and most of them were educated and were employed had income with a mean of 2257.63 Rs.
7. Of the sample who was living in a joint family, most of the family members were educated and had occupation the mean earnings was 1436.00 with a maximum of 50000 Rs.
8. 62% of the sample had HIV testing done before 2010 and 70% of the subjects have done their investigation from a private sector.
9. 46% (23) of the subjects underwent ELISA TEST. 21 (42 %) had Tridot test and 6 (12%) subjects was screened using a western blot test.
10. 66% of the sample disclosed there HIV status while 34% has not disclosed there HIV status. Among those disclosed there HIV status most of the sample disclosed there HIV status to their spouse (62%)

11. Most of the people revealed that fear and stigma as the major reason for non disclosure of status and this had lead to non enrolment to ART. While 1 subject feels that he will lose his social status if he reveals his status to anyone 2% feels that stigma as a barrier to disclose status.
12. Majority of the subject's family members were screened for HIV and among the living 30 spouse who were screened 16 spouses were HIV positive and 14 subjects were screened negative.
13. On analysing the CD4 level of the subject the study findings suggested that there is a decline in the first CD4 count and the present CD4 count the mean first CD4 count was 246.36 and the mean present CD4 count is 181.02.
14. Currently 34% of the subjects smoke, 38% of the subjects drink alcohol and 68% of the subjects chew tobacco.
15. 62% of the sample knew that they have to undergo treatment. Majority of the subjects (98%) were healthy and had thought that there is no need for further treatment and samples reported that fear as a major barrier for not enrolling to ART 30% revealed that they are on alternative medication.
16. 30% of the subject depends on an alternative medication for their treatment. Among these 20% take Aurvedic medicine, 1% rely on a Homeopathic treatment and 6% rely on Siddha medicine.
17. A dichotomous review on the knowledge on ART revealed that 60% of the subjects knew that they have to initiate ART, they have to do pre ART enrolment had basic knowledge about ART. 82% of the subjects revealed that they have fear that their family members will betray them .78% of the subjects fear that ART can cause side effects for them and 88% has fear that others will find out their status if they go to an ART centre. 56% of the subjects feel that they had done something wrong

## **FINDINGS OF DEMOGRAPHIC VARIABLES AND ZELAYA SCALE**

There is no significance found between the demographic variables and stigma.

## **FINDINGS OF DEMOGRAPHIC VARIABLES AND BACE SCALE**

Findings of the study suggested that there is a significant association of occupation and education.

## DISCUSSION OF THE STUDY

In this study, concerns related to barriers for enrolment to ART among PLHA are reported. The findings revealed that almost same number of subjects belonged to the education level of primary (18%) and high school (62%) and higher than high school (18%) Most 48 (96%) of the subjects were self-employed.

Some of the barriers identified in this study are consistent with the literature from both developed and developing countries a similar study has revealed that Among patients not eligible for ART, those having >12 years of education were more likely to have timely uptake of subsequent CD4 count. Among ART eligible patients, being an unskilled labourer predicted lower uptake.<sup>106.107</sup>

### NURSING IMPLICATIONS

The findings of the study have several implications in the field of nursing practice, nursing administration, nursing education and nursing research.

#### Nursing practice and Service

- In nursing practice and service, nurses play a very important role in patient care. Since the beginning of the HIV epidemic, nurses have played a critical role in caring for persons with HIV, both as members of care teams and as primary HIV care providers.
- Nurses has shifted their task from a nurse to an advanced nurse practioner in HIV care extending its hand as an independent practioner in a community setting and in global HIV care, nurses are not looking to prescribe medications without having ongoing referral options, interdisciplinary communication, and support by collaborating physicians.
- A better term for this mode of practice is "task-sharing," where nurses can and do prescribe antiretroviral medications, but they do so in collaboration with, and with the support of, their physician colleagues.
- Nurses play an important role in health promotion.

- The current study focus on promoting life of people living with HIV, illness prevention and care for individual's as well as families in a diverse setting. And in this study nurses play an important role in risk reduction intervention of health of the vulnerable group minority and the marginalised ones.
- In this study nurses play an important role educating patient on the compliances and adherence to treatment.
- The increasing demand for HIV primary care and specialty care is occurring at a time when physicians who began providing care early in the epidemic are expected to retire or transition out of clinical practice.
- To avoid human resource shortages in HIV healthcare settings, there is widespread professional support for the greater involvement of nurses in HIV care.

### **Nursing Administration**

- Nurse administrator should plan and execute practices for early initiation of ART as the nurse administrator has an important role in planning and administration.
- Nurse administrators must advocate staff nurses regarding the prime role they have in protecting the rights of this population to remain healthy both physically and mentally.
- They should organize in-service education and continuing education with a focus on capacity building of nurses in terms of issues faced by people with HIV and their by nurses enhances the counselling skills for the initiating ART for the PLHIV.
- In this study one of the major role of nurse administrator is linking patient as well referring patient for further management, i.e., all the patients who were positively screened for HIV should be linked for ART.
- Nurse administrator also plays an important role in patient advocacy.

### **Nursing Education**

- With changing health care trend, nursing education must emphasize on comprehensive community care and primary health care approach which should focus on prevention rather than only providing symptomatic care.

- The nurses must be trained on the importance of national programs as well as modification that are made to health programs and on the guidelines as they are an important part in planning for the health of the patient.

### Research in health systems and outcome of care

- Nursing research has a major role in health system and outcome of care.
  - The nurse play an important role in identifying the success of presently existing health care delivery system and on the identification of measures for developing affordable quality of health care to individual family and to community.
  - Nurses have an important role in evaluating the effectiveness of existing policies and programmes for the health care of the people.
  - This study also focus on the "90-90-90" as well "treat all" initiative launched by the National Aids Control Organization (NACO) for early diagnosis as well as treatment of the PLHA.
  - The study also helps in developing a care model for the treatment for those people who defer from the treatment.<sup>106</sup>
- Nursing Research**
- Nursing education helps in building evidence based practice.
  - Considering the HIV-TB burden in India, it is important to focus on research in various setting like hospital and community so as to improve the physical and social wellbeing of affected people.
  - More researches should be undertaken to develop possible interventions to provide a high care model to the patient.

### RECOMMENDATIONS

1. The study can be replicated on a large sample with different setting to make generalizations.
2. Qualitative studies can be undertaken to evaluate the actual barrier perceived by the PLHA .
3. Qualitative studies can be undertaken to analyse the impact of barriers on the family as well as on the society.
4. A quantitative study can be conducted on developing a care model for PLHA.



5. A similar study must be conducted on the importance of counselling for initiating ART among the PLHA.
6. A study can be done on ART adherence in people living with HIV who initiated their treatment from a private sector.
7. A similar study can be conducted on the barriers for ART initiation, adherence and retention in a long run.

## CONCLUSION

- The study concluded that there are a large number of factors that lead to non enrolment of PLHA for ART even after being tested positive .
- The study could explore the significant factor such as stigma related to non disclosure of status, substance use, education, occupation as the barrier to ART enrolment among PLHAs. Other factors supporting were large distance to ART centre and rely on traditional medicine.
- These hidden barriers needed to be worked upon for people to have a health seeking behaviour and improve their health status.

## PERSONAL EXPERIENCE:

The entire study was an enriching experience to the investigator. It helped the investigator to develop her skill in critical thinking and analysis and realize the importance of effective communication with the respondents. The study also helped the investigator to better understand the concept the research as a whole. At every stage the investigator received guidance and support from the college authorities, this boosted the confidence to go ahead and carry out the planned activities. The co-operation from every respondent was remarkable. The entire research went on smoothly and gave a sense of satisfaction and accomplishment to the investigator. To conclude, it was a good learning experience.

## SUMMARY

The overall experience of conducting this study was satisfying and adventurous. This study has given a broad area of social, personal and professional experience for student researcher in applying steps of research process and in overcoming difficulties and problems faced by the subjects during the study. There was good co-operation from the staffs of the selected hospital. The respondents were satisfied and happy with the information they received. This chapter dealt with major findings of the study, nursing implication of the study, recommendation that are given by the study.

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