

A Professional Advocacy of Social work in A Health Setting

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Abstract: “Human Immunodeficiency Virus” (HIV), the virus that causes, “Acquired Immunodeficiency Syndrome” (AIDS), has become one of the World’s most serious health and development hazards. The first case as reported in 1981 and today, 30 years later, there are approximately 35.3 million people living with HIV, close to 26 million are eligible for antiretroviral therapy, under WHO 2013 consolidated ARV guidelines. At the end of 2012, 9.7 million people had access to antiretroviral therapy and nearly 30 million people have died of AIDS-related causes since the beginning of the epidemic. (World Health Organization, 2013). Since 1995 alone, antiretroviral therapy has saved more than 14 million infected with the disease. Moreover, antiretroviral therapy, amongst other preventative and treatment services for pregnant woman, has been detrimental to the decrease of new HIV infections: causing a 43 percent reduction of new infections within children from year 2003 to 2011. (UNAIDS).

While cases have been reported in all regions of the World, almost all those living with HIV (97%) reside in low- and middle-income countries. Most people living with HIV or at risk of HIV do not have access to prevention, care, and treatment, and there is still no cure. HIV primarily affects those in their most productive years; about half of new infections are among those under age 25 years. HIV not only affects the health of individuals, it affect households, communities, and the development and economic growth of nations. Many of the countries hardest hit by HIV also suffer from other infectious diseases, food insecurity, and other serious problems.

Despite these challenges, new global efforts have been mounted to address the epidemic, particularly in the last decade, and there are signs that the epidemic may be in changing course. The number of people newly infected with HIV and the number of AIDS-related deaths have declined, contributing to the stabilization of the epidemic. In addition, the number of people with HIV receiving treatment in resource poor countries have increased more than 20-fold since 2001, reaching 6.6 million in 2010. (The Global HIV/AIDS Epidemic, Fact Sheet Oct’ 2013).

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I. Introduction

Women and children are increasingly becoming vulnerable to HIV/AIDS. The new findings conclude that 38 percent of the infected persons in India are women. This indicates the increasing **feminization** of HIV/AIDS in India. This alarming trend is being observed closely as more HIV positive mothers will unknowingly pass the virus on to their children.

According to UNICEF (2007), there are 220,000 children infected by HIV/AIDS in India. It is approximated that every year 55,000 to 60,000 children are born to mothers who are HIV positive. About 30 percent of these children are likely to be infected themselves. (Child line India Foundation) 2008.

Overview of HIV Epidemic in India¹

¹ National AIDS Control Organisation & National Institute Of Medical Statistics, ICMR. India HIV Estimations – Technical Report 2015. Ministry Of Health & Family Welfare, Government Of India. Accessed On 15 Dec. 2015 At [Http://Naco.Gov.In/Upload/2015%20MSLNS/HSS/India%20HIV%20Estimations%202015.Pdf](http://Naco.Gov.In/Upload/2015%20MSLNS/HSS/India%20HIV%20Estimations%202015.Pdf). See Also, India Has 3rd-Highest Number Of HIV-Infected People: UN. The Hindu. July 17, 2014. Accessed On 5 Dec. 2015, At [Http://Www.Thehindu.Com/Sci-Tech/Health/India-Has-3rdhighest-Number-Of-Hivinfected-People-Un/Article6220483.Ece?Css=Prin](http://Www.Thehindu.Com/Sci-Tech/Health/India-Has-3rdhighest-Number-Of-Hivinfected-People-Un/Article6220483.Ece?Css=Prin); National Aids Control Organization (NACO). Annual Report 2014-15. Part B. Accessed On 5 Dec. 2015, At [Http://Www.Mohfw.Nic.In/Writereaddata/L892s/5632145698745632.Pdf](http://Www.Mohfw.Nic.In/Writereaddata/L892s/5632145698745632.Pdf); World Bank. HIV/AIDS In India. July 10, 2012. Accessed On 5 Dec. 2015, At [Http://Www.Worldbank.Org/En/News/Feature/2012/07/10/Hiv-Aids-India](http://Www.Worldbank.Org/En/News/Feature/2012/07/10/Hiv-Aids-India); NACO. Sentinel Surveillance 2012-2013. Technical Brief. Accessed On 5 Dec. 2015, At [Http://Naco.Gov.In/Upload/NACP%20-%20IV/HSS%20TECHNICAL%20BRIEF/HIV%20Sentinel%20Surveillance%20Technical%20Brief.Pdf](http://Naco.Gov.In/Upload/NACP%20-%20IV/HSS%20TECHNICAL%20BRIEF/HIV%20Sentinel%20Surveillance%20Technical%20Brief.Pdf); National Institute Of Medical Statistics & NACO. Technical Report – India – HIV Estimates 2012. 30th Nov. 2012. Accessed On 5 Dec. 2015, At [Http://Www.Unaids.Org/Sites/Default/Files/En/Media/Unaid/Contentassets/Documents/Data-And-Analysis/Tools/Spectrum/India2012report.pdf](http://Www.Unaids.Org/Sites/Default/Files/En/Media/Unaid/Contentassets/Documents/Data-And-Analysis/Tools/Spectrum/India2012report.pdf)

As per India HIV Estimations – Technical Report 2015, **National Adult (15–49 years) HIV prevalence** is estimated at 0.26% in 2015 – with 0.30% among males and 0.22% among females. Among the states/UTs, in 2015, Manipur has shown the highest estimated adult HIV prevalence of 1.15%, followed by Mizoram (0.80%), Nagaland (0.78%), Andhra Pradesh & Telangana (0.66%), Karnataka (0.45%), Gujarat (0.42%) and Goa (0.40%). Besides these States, Maharashtra, Chandigarh, Tripura and Tamil Nadu have shown estimated adult HIV prevalence greater than the national prevalence (0.26%), while Odisha, Bihar, Sikkim, Delhi, Rajasthan and West Bengal have shown an estimated adult HIV prevalence in the range of 0.21–0.25%. All other States/UTs have levels of adult HIV prevalence below 0.20%. The adult HIV prevalence at national level has continued its steady decline from an estimated peak of 0.38% in 2001-03 through 0.34% in 2007 and 0.28% in 2012 to 0.26% in 2015.

The total number of **People Living With HIV (PLHIVs)** in India is estimated at 2.1 million in 2015 compared with 2.2 million in 2007. Children (<15 years) account for 6.54%, while two fifth (40.5%) of total HIV infections are among females. Undivided Andhra Pradesh and Telangana have the highest estimated number of PLHIVs (0.4 million) followed by Maharashtra (0.3 million), Karnataka (0.2 million), Gujarat (0.17 million), Bihar and Uttar Pradesh (0.15 million). These seven States together account for two thirds (64.4%) of total estimated PLHIV. Rajasthan (0.1million), Tamil Nadu (0.14 million) and West Bengal (0.13 million) are other States with estimated PLHIV numbers of 0.1 million or more. The estimated number of PLHIV in India has been more or less stable during 2013-15.

India is estimated to have around 86 (56–129) thousand **New HIV Infections** in 2015, showing 66% decline in new infections from 2000 and 32% decline from 2007, the year set as baseline in the NACP-IV. Children (<15 years) accounted for 12% (10.4 thousand) of total new infections while the remaining (75.9 thousand) new infections were among adults (15+years). Andhra Pradesh & Telangana, Bihar, Gujarat and Uttar Pradesh currently account for 47% of total new infections among adults with each of these States contributing 7.5 thousand or more new infections in 2015. West Bengal and Rajasthan have more than 5 thousand but less than 7.5 thousand new infections, while Maharashtra, Odisha and Tamil Nadu have new infections in the range of 3-4 thousand. Chhattisgarh, Delhi, Haryana, Jharkhand, Karnataka, Madhya Pradesh and Punjab have 1-2.4 thousand new infections among adults and the rest of the States/UTs have less than 1 thousand new adult HIV infections in 2015.

A clear decline in new infections, as noticed at national level, has been also observed in most of the States/UTs. New infections among adults have declined by 50% or more in the States of Andhra Pradesh & Telangana, Karnataka, Maharashtra, Manipur and Odisha during 2007-15. Bihar, Jharkhand, Kerala, Mizoram, Nagaland, Rajasthan and Uttarakhand are the other States where annual adult new infections declined by 32-47% during the same period. However, a rising trend in new infections among adults during 2007-15 has been detected in Assam, Chandigarh, Chhattisgarh, Gujarat, Sikkim, Tripura and Uttar Pradesh.

The proportions of people who do not have Access to Antiretroviral Therapy Treatment (ART) are 64 per cent in India, in spite of major scale up of access to HIV treatment. At the end of 2013, more than 700,000 people were on antiretroviral therapy, the second largest number of people on treatment in any single country. Since 2007, when the number of AIDS Related Deaths (ARD) started to show a declining trend, the annual number of AIDS related deaths has declined by 54%. In 2015 an estimated 67.6 thousand people died of AIDS-related causes nationally. This decline is consistent with the rapid expansion of access to ART in the country. It is estimated that the scale-up of free ART since 2004 has saved cumulatively around 0.45 million lives in India until 2014. The annual number of AIDS-deaths has declined by 70-81% during 2007-15 in Karnataka, Maharashtra and Tamil Nadu. Annual AIDS-related deaths declined by 60-70% from the baseline values of 2007 in Andhra Pradesh & Telangana, Goa, Himachal Pradesh and Nagaland while a decline of 40-47% was estimated in Chhattisgarh, Gujarat and Punjab.

Stigma and Discrimination against PLHIVs remains an enormous barrier in fighting the HIV and AIDS. Stigma and discrimination among the general public, to a considerable degree even among the educated, was mostly due to lack of awareness/inaccurate information about the transmission of HIV and fear thereby of contracting the illness.

In sum, the 2015 HIV Estimates affirms positively the country's efforts in halting and reversing the HIV epidemic responding to HIV/AIDS epidemic. Between 2000 and 2015, new HIV infections dropped from 0.25 million to 86 thousand, a reduction of 66% against a global average of 35% - thereby reaching one of the targets of MDG6. **However**, there remain a number of challenges to reach the targets of NACP- IV for 2012-17

(reducing new infections, universal access to treatment and care, preventing mother to child transmission (PMTCT), reducing stigma and discrimination, etc.)

Goals of Antiretroviral Therapy

From the point of view of patients, the primary goal of therapy is improvement of quality of life consequent to the reduction in morbidity, a result of treatment induced immune recovery. The goals of therapy can therefore be summarized as follows: improvement of the patient's quality of life, reduction of HIV related morbidity and mortality, restoration and or preservation of immunologic function and maximal and durable suppression of the viral replication (Republic of Kenya, MoH, 2005).

Specific Adherence Issues in Children

Barriers faced by adult caregivers that can contribute to non-adherence in children include forgetting doses, changes in routine, being too busy, and child refusal of medications. Some caregivers may place too much responsibility for managing medications on older children before the children are developmentally able to take on such tasks. Many other barriers to adherence exist for children with HIV infection. For example, caregivers' unwillingness to disclose the child's HIV infection status to others may create specific problems, including reluctance of caregivers to fill prescriptions locally, hiding or relabeling of medications to maintain secrecy within the household, avoidance of social support, and a tendency for doses to be missed if the parent is unavailable.

Provision of ART in India

The Provision of free antiretroviral treatment (ART) by the Government of India in 2004 was an important milestone in India's response to the HIV epidemic.

A simple anti-retroviral drug administered to the mother during labour and a spoonful of syrup to the baby soon after birth can prevent transmission of the AIDS virus to the newborn.

In India, the transmission of the virus from the mother-to-child during pregnancy, labour and delivery or breastfeeding is called parent-to-child-transmission to emphasize the role of the father in both the transmission of the virus and management of the infected mother and child.

II. Objective

The very objective of the present paper is to identify the significant attributes/factors that influence child and caregivers on ART for ART adherence.

III. Review Of Literature

Though there is volumes of facts and findings on HIV/AIDS status at various stages, literature directly relevant to subject under study, i.e., on adherence is very scarce. Almost the present study is a maiden attempt in India, on assessment of ART Adherence, that to from children below 18 years.

There is an earlier study in Ethiopia (D.Nagese, Nov' 2012) related to understanding the factors associated with disclosure of HIV/AIDS status to HIV Infected Children on Anti Retroviral Therapy (ART). According to the study, extensively accepted that the rate of disclosure of HIV positive status to children living with HIV/AIDS is low. Caregivers of young children were independently and significantly associated with disclosure of HIV status. HIV clinical Resources, Clinicians and other members of the multidisciplinary team should collaborate with caregivers of HIV-infected children to disclose the diagnosis of HIV to the child in a developmentally appropriate manner. The same research findings are found in present study also.

The attention on this topic has also seen the associated terminology change from compliance to adherence. The idea of compliance is patients doing what they have been told by the doctor. In essence it is an act conforming, implying lack of patient participation (Trostle 1988). **Conversely, adherence involves a mutual decision making process between the patient and the health care provider. In adherence, therefore, the patient plays an active role in the decision and commitment to follow the prescribed regimen (Population Council et al 2004).**

This change in terminology thus represented an effort to boost adherence by moving away from the authoritative directions to a more collaborative process between the patient and the health care provider. Recent research has shown that involvement of the patients leads to significant improvement in interaction and adherence outcomes (Marelich et al 2002). The patient-Centered perspective is the hallmark of adherence. This perspective views patients as active participants in their treatment (Donovan and Blake 1992). Medication related factors such as palatability, formulation, and difficult regime were among the common reasons for non-

adherence. These findings are consistent with earlier studies. (Boni, et al, 2000; Giacomet et al., 2003; Gibb et al., 2003; Goode et al, 2003; Martin et al., 2007; Pontali et al., 2001; Temple et al, 2001).

While improving access to child-friendly formulations is vital, the use of simplified regimen, fixed dose combinations and less frequent dosing requirements, coupled with educating caregivers on the benefits and side effects of ART may also improve adherence (WHO, 2006; Working Group on Antiretroviral Therapy and the Medical Management of HIV-Infected Children, 2006).

IV. Methodology

A brief description of methodology adopted for the study is given below.

Year of the Study

The actual data (information) for the present study is elicited during the year of 2011 – 2014.

Study Area and Sampling Procedure

The prevalence of HIV/AIDS among children is very high as per records in the four districts of Andhra Pradesh, namely, 1. East Godavari 2. West Godavari 3. Krishna and 4. Guntur Districts. The area of study is confined to four NGOs, namely, St. Joseph Hospital, Damian Leprosy Center, Assisi Hospital and St. Xavier’s Hospital who are providing Care and Support to the Children living with HIV/AIDS in the four districts of Andhra Pradesh only. Hence, the four NGOs of this four districts namely (St. Joseph Hospital, Damian Leprosy Center, Assisi Hospital and St. Xavier’s Hospital) from East Godavari, West Godavari, Krishna and Guntur Districts, considered for the present study respectively. **Therefore, Purposive Random Sampling Technique is adopted for the selection of the sample. All children who are registered and continuing for the treatment (ART) for HIV/AIDS infection in this four NGOs of four districts are the actual sampling units of the present study.**

Location Maps of Study Area:

World Map



Photo.1

India Map



Photo.2

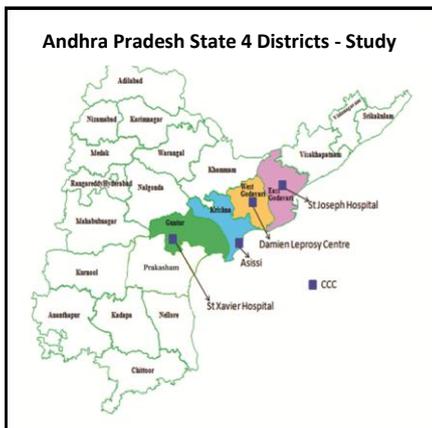
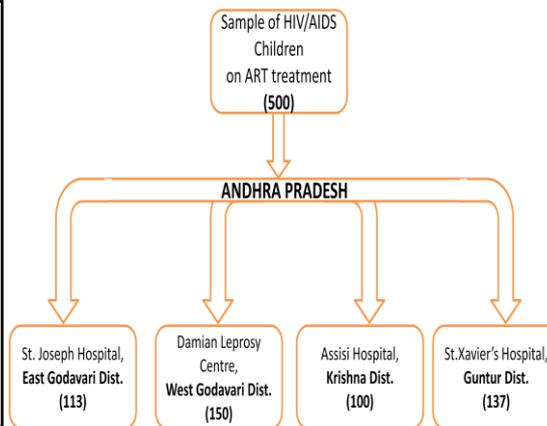


Photo .3



Sampling Process (Diagram 1)

The HIV epidemic remains a major public health challenge in Andhra Pradesh, with an estimated 4.9 lakhs people living with HIV/AIDS. With highest burden of PLHAs, Andhra Pradesh accounts for 20 percent of all HIV infections in country. High positivity among pregnant women was recorded in the districts of East Godavari (0.53%), West Godavari (0.50%), Krishna (0.49%), Rangareddy (0.43%) and Guntur (0.41%).

Nature of Data

Data is in two forms as Primary and Secondary data. The primary data is collected by the researcher himself with the help of an **Interview Schedule** from the sampling unit with help of **recall** method. The Secondary data is gathered from the **NGOs records**, and also information is elicited from **medical and paramedical professionals** of the subject under study.

Tool for data collection

A well structured **Interview Schedule** is developed; tested through Pilot study is being utilized for the collection of primary data. Secondly, a tool '**Adherence Tool**' which is developed by Karnataka Health Promotion Trust, Bangalore, India is also utilized for assessment of Adherence.

Sampling Unit

An Infected Child (7 to below 18 years) who is on ART at least from last 4 months – and his or her caregiver.

Sample Size

The total sample size of the study is 500 pairs – Infected child and his or her care giver.

Results and Discussions:

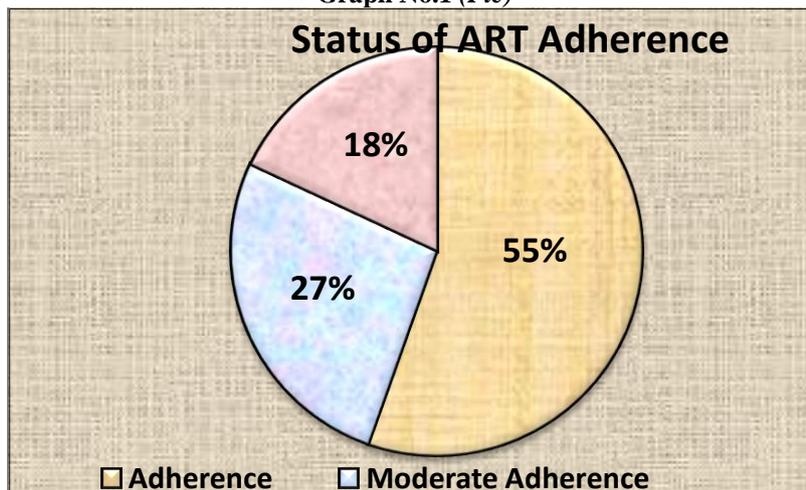
After collection and editing of data, data is analyzed with the help of Statistical Package for Social Sciences (SPSS) for tabulation and statistical understanding.

The general characteristics of the sample under study (infected children) and about their caregivers are studied by their religion, sex, age, educational status. And these characteristics are analysed in relation with the children's (sample) adherence status. The purpose of this analysis is to look into the association or relation between these characteristics in general, with their adherence status.

Table No.1: Number and Percentage distribution of Children according to their Status of ART Adherence

| Status of Adherence | Frequency | Percent |
|---------------------|------------|--------------|
| Adherence | 277 | 55.4 |
| Moderate Adherence | 133 | 26.6 |
| Non-Adherence | 90 | 18.0 |
| Total | 500 | 100.0 |

Graph No.1 (Pie)



Status of ART Adherence

The sample under study, i.e., infected children under ART treatment, are categorised into three groups as '**Adherence, Moderate Adherence and Non-Adherence**'. This categorisation is based on the application of **adherence tool** which is developed by Karnataka Health Promotion Trust, Bangalore, 2008. As the Table - 1 shows, the categorization of 500 sample of infected children under study; 277 (55.4%) are categorised as **Adherence** towards their ART treatment, 133 (26.6%) are categorised as **Moderate Adherence** towards their

ART treatment, and 90 (18.0%) infected children are categorised as **Non-Adherence** towards their ART treatment. From these findings, it could be concluded as adherence status towards ART treatment is high (55.4%) among the HIV infected children under study. The various attributes / factors related to the child, caregiver, structural, social and drugs supply at care centre are analyzed in the study. Out of this, attributes which have significant contribution to the child’s adherence status are discussed in the present paper.

Age of the child

Table – 2: Age of the Child Vs Knowledge on ART

| Chi-square value | p-value | ART Adherence | | | Total |
|------------------------------------|----------|---------------|--------------------|---------------|--------|
| | | Adherence | Moderate Adherence | Non Adherence | |
| 9.458* | 0.041 | | | | |
| Level of knowledge of child on ART | Low | 116 | 66 | 41 | 223 |
| | | 52.0% | 29.6% | 18.4% | 100.0% |
| | Moderate | 89 | 26 | 19 | 134 |
| | | 66.4% | 19.4% | 14.2% | 100.0% |
| | High | 72 | 41 | 30 | 143 |
| | | 50.3% | 28.7% | 21.0% | 100.0% |
| Total | | 277 | 133 | 90 | 500 |
| | | 55.4% | 26.6% | 18.0% | 100.0% |

**Significant at 5% level*

The Table - 2 shows as the adherence status is associated with the level of knowledge of child on ART treatment they are undergoing. This association is significant at 5 percent level, statistically proved with the help of chi-square test.

Table – 3: Number and Percentage distribution of Children According to Adherence Status Vs. Age

| Chi-square value | P-value | Age | | | Total |
|------------------|--------------------|----------------|----------------|----------------|-----------------|
| | | 7 to 10Yrs | 10 to 14 Yrs | 14 to 18 Yrs | |
| *11.463 | 0.022 | | | | |
| Adherence Status | Adherence | 109 (64.5%) | 91 (50.8%) | 77 (50.7%) | 277 (55.4%) |
| | Moderate Adherence | 39 (23.1%) | 55 (30.7%) | 39 (25.7%) | 133 (26.6%) |
| | Non-Adherence | 21 (12.4%) | 33 (18.4%) | 36 (23.7%) | 90 (18.0%) |
| | Total | 169 (33.8%) | 179 (35.8%) | 152 (30.4%) | 500 (100.0%) |

**Significant at 5% level,*

Adherence status of children under study in relation with their age is analysed and presented in Table 3. The table shows as, there is much age differentials among children infected under study. About 65 percent of the infected children are in the age group 7 to 10Yrs, followed by 51 percent each in the age group 10 to 14 yrs and in the age group 14 to 18yrs respectively in the category of adherence, in the present study. But, moderate adherence and non-adherence is increasing trend as the age of child increases. Here in the study, high adherence is observed among infected children in the age group 7 to 10 years (64.5%), compared to that of other categories. The association or influence of the age towards ART adherence is significant as shown in the Table 3.

Table – 4: Level of knowledge of child on ART Vs Age

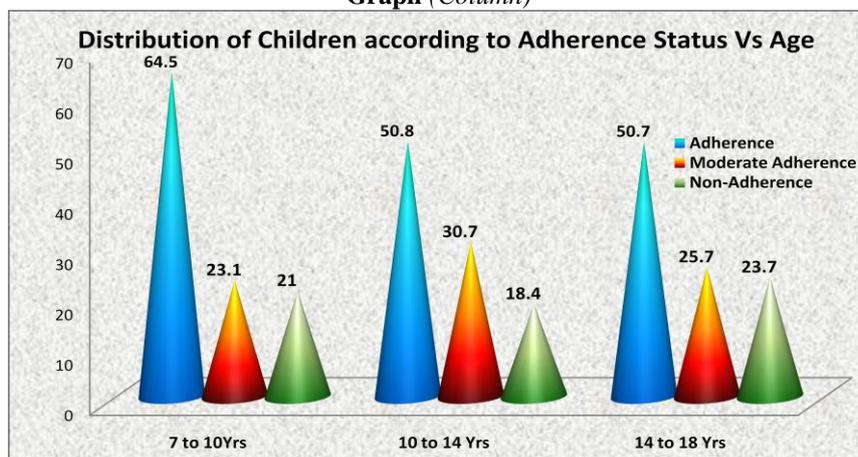
| Chi-square value | p-value | Level of knowledge of child on ART | | | Total |
|------------------|--------------|------------------------------------|----------|-------|--------|
| | | Low | Moderate | High | |
| 35.553** | 0.000 | | | | |
| Age | 7 to 10Yrs | 55 | 51 | 63 | 169 |
| | | 32.5% | 30.2% | 37.3% | 100.0% |
| | 10 to 14 Yrs | 71 | 54 | 54 | 179 |
| | | 39.7% | 30.2% | 30.2% | 100.0% |
| | 14 to 18 Yrs | 97 | 29 | 26 | 152 |
| | | 63.8% | 19.1% | 17.1% | 100.0% |

| | | | | |
|-------|-------|-------|-------|--------|
| Total | 223 | 134 | 143 | 500 |
| | 44.6% | 26.8% | 28.6% | 100.0% |

**Significant at 1% level.

The Table 4 discloses that, the association between the age of the child under study and their knowledge regarding the ART treatment they are undergoing is highly associated. The association is statistically significant at 1 percent level which is proved with the help of chi-square test.

Graph (Column)



Education of the Child

Table -5: Education Vs. Adherence Status

| Adherence Status | Child Educational Status | | | | Total |
|---------------------------|------------------------------|------------------------------|------------------------------|----------------------------|-------------------------------|
| | Not going to School | Elementary | High school | Intermediate | |
| Adherence | 67 (55.4%) | 121 (57.1%) | 73 (52.9%) | 16 (55.2%) | 277 (55.4%) |
| Moderate Adherence | 31 (25.6%) | 59 (27.8%) | 35 (25.4%) | 8 (27.6%) | 133 (26.6%) |
| Non-Adherence | 23 (19.0%) | 32 (15.1%) | 30 (21.7%) | 5 (17.2%) | 90 (18.0%) |
| Total | 121 (24.2%) | 212 (42.4%) | 138 (27.6%) | 29 (5.8%) | 500 (100.0%) |

The adherence status of infected children is observed as high among elementary educated (57.1%). Normally, by getting older, children’s tendency to deviate from restricted schedule of treatment increases as their exposure expands. But, it is to be noted that the risk of disease burden will also increase as they already categorised as non-adherent’ towards ART treatment. Non-adherence towards ART treatment is observed as high among children not going to school (19.0%) and among high school children (21.7%).

Table – 6: Knowledge of child on ART Vs Child Educational Status

| Chi-square value | p-value | Level of knowledge of child on ART | | | Total |
|------------------|------------------|------------------------------------|----------|-------|--------|
| | | Low | Moderate | High | |
| 37.381** | 0.000 | | | | |
| Class of study | Not Going School | 62 | 30 | 29 | 121 |
| | | 51.2% | 24.8% | 24.0% | 100.0% |
| | Elementary | 67 | 63 | 82 | 212 |
| | | 31.6% | 29.7% | 38.7% | 100.0% |
| | High school | 75 | 40 | 23 | 138 |
| | | 54.3% | 29.0% | 16.7% | 100.0% |
| | Intermediate | 19 | 1 | 9 | 29 |
| | | 65.5% | 3.4% | 31.0% | 100.0% |
| Total | | 223 | 134 | 143 | 500 |
| | | 44.6% | 26.8% | 28.6% | 100.0% |

** Significant at 1 % level

Table – 7: Child's Knowledge on ART by class of study

| Class of study | N | Mean | Std. Deviation | F-value | p-value |
|------------------|-----|----------|----------------|----------|---------|
| Not Going School | 121 | 7.5124 a | 1.31095 | 14.063** | 0.000 |
| Elementary | 212 | 8.1792 b | 1.41955 | | |
| High school | 138 | 7.3406 a | 1.33726 | | |
| Intermediate | 29 | 7.1379 a | 1.45710 | | |
| Total | 500 | 7.7260 | 1.42653 | | |

Majority of the children in the present study are only in elementary education (42.4%) upto Elementary standard, followed by with high school standard (27.6%). Almost one fourth of the children under study (24.2%) are not going to school at all.

From Table 6&7, it is observed that, it is to say that the educational level of the child under study and their knowledge on ART treatment they are undergoing is highly associated. This association is statistically highly significant at one percent level, which is proved with the help of chi-quire test and ANOVA (14.063**)

Table – 8 : Number and Percentage distribution of Children according to Adherence Status Vs. ART effects on schooling.

| Chi-square value | P-value | ART effects to irregular in schooling issue | | Total |
|------------------|--------------------|---|------------------------|-------------------------|
| | | Yes | No | |
| **15.447 | 0.000 | | | |
| Adherence Status | Adherence | 41 (78.8%) | 236 (52.7%) | 277 (55.4%) |
| | Moderate Adherence | 3 (5.8%) | 130 (29.0%) | 133 (26.6%) |
| | Non-Adherence | 8 (15.4%) | 82 (18.3%) | 90 (18.0%) |
| Total | | 52 (10.4%) | 448 (89.6%) | 500 (100.0%) |

** Significant at 1 % level

Further, infected children were asked to express that whether their schooling is effected or not due to ART treatment. The above (Table -8) discloses as about 90 percent of the sample under study have expressed that their schooling is not effected at all in the present study. It is a very positive/desirable response from the children who are under ART treatment. Quite interestingly, among the children who have expressed as their schooling is effecting due to ART treatment, high proportion of them belong to adherent category (78.84%). This may be due to conscious and careful practice of ART treatment by the children under adherence category. The association or influence of the ART effects on schooling of infected children towards ART adherence is highly significant as shown in the Table 8.

The caregivers occupation/nature of work for their livelihood is analyzed in relation with child adherence status in this study.

Table – 9: Number and Percentage distribution of Children According to Adherence Status Vs. Occupation of the Caregiver

| Adherence Status | Occupation of the Caregiver | | | | | | Total |
|--------------------|-----------------------------|------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| | Not working | Daily Wage | Business | Employee | Agricultur e | Self Employment | |
| Adherence | 41 (56.9%) | 63 (46.7%) | 46 (57.5%) | 38 (62.3%) | 40 (51.3%) | 49 (66.2%) | 277 (55.4%) |
| Moderate Adherence | 22 (30.6%) | 43 (31.9%) | 23 (28.8%) | 11 (18.0%) | 20 (25.6%) | 14 (18.9%) | 133 (26.6%) |
| Non-Adherence | 9 (12.5%) | 29 (21.5%) | 11 (13.8%) | 12 (19.7%) | 18 (23.1%) | 11 (14.9%) | 90 (18.0%) |
| Total | 72 (14.4%) | 135 (27.0%) | 80 (16.0%) | 61 (12.2%) | 78 (15.6%) | 74 (14.8%) | 500 (100.0%) |

As a social variable, occupation of the caregivers in this study area is elicited and analysed in relation with the adherence status of infected children under ART. Majority of the caregivers are daily wage workers only (27%).

Caregivers Occupation (Nature of Work) Vs. Child’s Adherence Status.

Here in the present study a caregiver is a father, a mother, both mother and father, grandparents, relatives, health care organizations in taking care of an infected child of HIV/AIDS under ART treatment. Majority of the caregivers are daily wage workers only (27%), followed by small business (16%), agricultural labours (15.6%), self-employed (beedi makers, embroidery etc.,) (14.8%), and employees (12.2%). There are about 14.4% caregivers who are not working at all. With regarding to adherence status of the infected children, high proportion of adherence children are observed among the caregivers of self-employed (66.2%), followed by employees (62.3%), Business (57.5%), and not working (56.9%), Table 9.

Care givers problems

Table – 10: Care Givers Occupation Vs. Problems faced by caregivers

| Chi-square value | p-value | Problems faced by caregivers | | | Total | |
|------------------|--------------|------------------------------|--------------|--------------|--------------|---------------|
| | | Low | Moderate | High | | |
| 37.992** | 0.000 | | | | | |
| Type of work | Not working | 45 | 11 | 16 | 72 | |
| | | 62.5% | 15.3% | 22.2% | 100.0% | |
| | Daily Wage | 34 | 42 | 59 | 135 | |
| | | 25.2% | 31.1% | 43.7% | 100.0% | |
| | Business | 31 | 25 | 24 | 80 | |
| | | 38.8% | 31.3% | 30.0% | 100.0% | |
| | Employee | 23 | 16 | 22 | 61 | |
| | | 37.7% | 26.2% | 36.1% | 100.0% | |
| | Agriculture | 43 | 14 | 21 | 78 | |
| | | 55.1% | 17.9% | 26.9% | 100.0% | |
| | Others | 32 | 23 | 19 | 74 | |
| | | 43.2% | 31.1% | 25.7% | 100.0% | |
| | Total | | 208 | 131 | 161 | 500 |
| | | | 41.6% | 26.2% | 32.2% | 100.0% |

**Significant at 1% level

The caregivers nature of work (occupation) is highly associated with various problems they are expressing while taking care of the infected children during ART treatment which is proved significantly statistically at 1 percent level with the help of chi-quire test as is shown in the Table.10.

Table – 11: Number and Percentage distribution of Children according to Status of Adherence Vs. Awareness of ART therapy regimen while giving to child by the caregivers

| Chi-square value | P-value | Awareness of ART therapy regimen while giving to child by the caregivers | | Total |
|------------------|--------------------|--|----------------------------|-------------------------------|
| | | Yes | No | |
| *8.545 | 0.014 | | | |
| Adherence Status | Adherence | 273 (56.6%) | 4 (22.2%) | 277 (55.4%) |
| | Moderate Adherence | 124 (25.7%) | 9 (50.0%) | 133 (26.6%) |
| | Non-Adherence | 85 (17.6%) | 5 (27.8%) | 90 (18.0%) |
| Total | | 482 (97.4%) | 18 (2.6%) | 500 (100.0%) |

*Significant at 5% level

Here in the present study, more than 97 percent caregivers under study have expressed that they are able to follow ART therapy regimen while providing care to the infected children and this awareness is high among caregivers of adherent children (55.6%) compared to that of moderate adherents (26.7%) and non-adherents (17.7%) among the sample under study. The association or the influence of the follow-up of ART therapy regimen by the caregiver and the ART adherence status is significant as shown in the Table 11.

Duration of transport/distance to reach ART Center

The researcher is intended to study the relation between the Adherence status and the time takes to reach the ART Centers from the clients residence.

Table – 12: Number and Percentage distribution of Children according to Status of Adherence Vs. Duration of transport/distance to reach ART Center

| Chi-square value | P-value | Duration of transport/distance to reach ART Center | | | | Total |
|------------------|--------------------|--|------------------------|-----------------------|----------------------|-------------------------|
| | | Up to 1Hr | 2 to 3Hrs | 3 to 4Hrs | More than 4Hrs | |
| *12.703 | 0.048 | | | | | |
| Adherence Status | Adherence | 105 (65.6%) | 112 (48.7%) | 46 (58.2%) | 14 (45.2%) | 277 (55.4%) |
| | Moderate Adherence | 34 (21.2%) | 69 (30.0%) | 20 (25.3%) | 10 (32.3%) | 133 (26.6%) |
| | Non-Adherence | 21 (13.1%) | 49 (21.3%) | 13 (16.5%) | 7 (22.6%) | 90 (18.0%) |
| Total | | 160 (32.0%) | 230 (46.0%) | 79 (15.8%) | 31 (6.2%) | 500 (100.0%) |

*Significant at 5% level

Further, the duration of travel time to the ART Center is tried to elicit from the caregivers in the study area. The highest proportion (46%) of caregivers are travelling 2-3 hours with infected children from their residence to ART Centers for treatment, followed by 32 percent of the caregivers who are travelling less than one hour, for treatment in the study area, Table.12.

The association or the influence of duration of transport / distance to reach ART Center and adherence status is significant as shown in the table.

Shortage of drugs in Supply

The researcher is intended to study the relation between the Adherence status and child faced any shortage of drugs/medicines in supplies at ART Center.

Table-13 :Number and Percentage distribution of Children according to Status of Adherence Vs. Shortage of drugs in supply

| Chi-square value | P-value | Do you face any shortage of drugs in supply | | Total |
|------------------|--------------------|---|-------------------------|-------------------------|
| | | Yes | No | |
| *6.063 | 0.048 | | | |
| Adherence Status | Adherence | 18 (69.2%) | 259 (54.6%) | 277 (55.4%) |
| | Moderate Adherence | 8 (30.8%) | 125 (26.4%) | 133 (26.6%) |
| | Non-Adherence | 0 (0.0%) | 90 (19.0%) | 90 (18.0%) |
| Total | | 26 (5.2%) | 474 (94.80%) | 500 (100.0%) |

*Significant at 5% level

Again, about 95 percent of the caregivers have reported as they were supplied with drugs related to ART treatment without any shortage of supply, (Table.13) and this opinion is observed by high proportion of caregivers of children of adherence category. The association or the influence of adherence status and drugs supply has influence towards ART treatment is significant as shown in the Table 13.

V. Conclusion And Advocacy

Infected and affected may be enlightened on the following subjects in the form of awareness campaign / counseling programs:

Patients' education to ensure long term adherence to treatment associated with treatment success should cover

- (i) Lifelong continuous treatment is necessary and the expected benefits of treatment
- (ii) Adherence and its relation to treatment outcome
- (iii) Drug resistance
- (iv) Necessity for regular follow up
- (v) Need to avoid non prescribed drugs including herbal medication whose interaction with ARV drugs.

Health providers should be able to:

- Assess and prepare patients to ensure long-term adherence to treatment;
- Use drugs rationally allowing for future treatment options;
- Ensure regular and adequate monitoring of patients;

- Manage complications of treatment and be able to change or discontinue treatment

Here at this juncture, the studies on adherence enhancing/influencing are of great important, essential in order to yield maximum fruits of the Govt. Programmes.

Suggestions/Social Utility/Potential Utility

The following suggestions may be thought over by the policy makers at Global, National and Regional level for the protection of mankind from the spread of communicable diseases, HIV/AIDS. These are mentioned by the researcher because of his working exposure in the area of HIV/AIDS for a period more than ten years besides this present research findings.

1. Child-Centered (Child focused) Counselling Centers may be established
2. The Counsellors may be trained as Child-Centered Counselors by the subject experts in the related area.
3. As is well known, adolescence period of a life is a sensitive, moulding, a dynamic and a transitional period. The care centers of the infected adolescent children may be separated from children in general, in order to control the spread of HIV/AIDS.
4. Further, instead of sending the infected adolescents to schools along with other infected children they may be provided with different types of vocational trainings along with earnings by the same training for their livelihoods. This is a way of controlling the spread of HIV/AIDS in a healthy and economic (Cost Effective Approach) way. This approach may be thought over as mandatory by the policy makers.
5. In the regular MCH programme, during ANC process, screening of HIV positive should be thought over as a mandatory at all health care centers by the policy makers.
6. The marriages of positives of men and women performing by the Positive Networks at District level may be encouraged for controlling the spread of infections among the un-infected. This approach is also a humanistic, psychological concern and facilitation of the infected community.
7. Further, due to this marriages, the un-infected off-springs may be expected by administering “Nevirapine” treatment to the mother and the baby during the labour period.
8. By encouraging “kinship-care” (familial relations and care) the adherence status may be enhanced among the infected children.
9. Like this, by ensuring the social security measures to the infected children, the stigma and discrimination against those infected may be reduced considerably.

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