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HIV/AIDS, ART Management and Adherence: A major public health concern

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Abstract: *HIV/AIDS, the epidemic has become a major public health concern as it has devastated the huge population around the globe. Since the beginning of the disease globally around 34 million people infected with HIV, 60 million have contracted HIV and nearly 30 million have died of HIV related causes. Antiretroviral treatment therapy though helped in controlling the virus among PLHIVs and prolongs their life to a great extent but non-adherence has occurred as vital barrier in the management of HIV. The present study aiming at understanding the factors causing non-adherence in antiretroviral treatment is a summary of eight focus group discussions held with PLHIVs (People living with HIV) in selected hospitals of Delhi through stratified random sampling as part of the methodology. Findings: PLHIVs don not accept the treatment as life savior due to prominent stigma and discrimination against the epidemic in the society.HIV infected women, being widow face many inhuman situations(such as sin on society, infected and kill husband, bad character excel from the house , no treatment access, no care and support , dependency, gender disparity etc.) in society . Moreover the various social support systems such as DNP+ (Delhi Positive Network), WNP+ (Women Positive Network) are unable to support and even access them effectively. Counseling of family members, community awareness on treatment is not considered accurately. Result and Conclusion: the ground reality of non-adherence found in society which suggests that only institutional helps through treatment, counseling are not sufficient for the success of treatment and adherence , social systems and institutions are equally required to promote for the betterment of PLHIVs. The social work profession also found of immense support to PLHIVs as far as their human rights and social justice is concerned.*

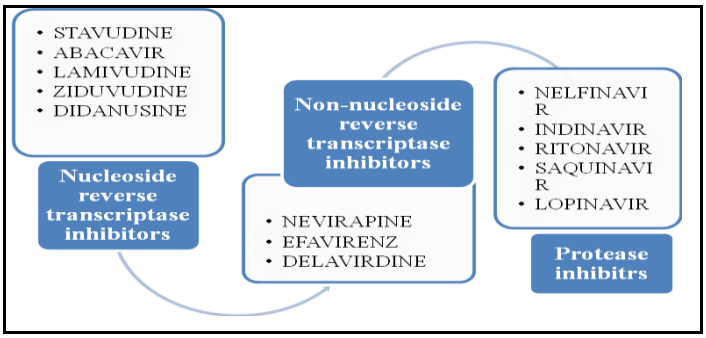
Keywords: *HIV/AIDS- Human Immune Deficiency Syndrome, Acquired immune deficiency syndrome, ART-Anti-retroviral treatment/therapy, PLHIVs-People living with HIV.*

I. HIV/AIDS At A Glance

HIV/AIDS, the epidemic has become a major public health concern as it has devastated the huge population around the globe. Since the beginning of the disease, globally around 34 million people infected with HIV, 60 million have contracted HIV and nearly 30 million have died of HIV related causes [1]. In the 30 years since HIV/AIDS was first discovered in 1981, the disease has become a devastating pandemic, taking the lives of 30 million people around the world; more than 60 million people worldwide have been infected with HIV. In 2010 alone, HIV/AIDS killed 1.8 million people, 1.2 million of whom were living in sub-Saharan Africa more than 390,000 infants and children were newly infected with HIV in 2010, and 2.7 million total new HIV infections occurred in the same year a rate that has held relatively constant since 2006 Because individuals in their most productive years (15-49 years old) are most commonly infected with HIV/AIDS [2]. India has been badly affected with the epidemic, since the first case of HIV reported in 1986. Presently, India has the estimated 20.89 lakh population with HIV infection. Though the HIV prevalence at national level declined from estimated level of 0.41 percent in 2001 to 0.27 percent in 2011due to the inception of antiretroviral treatment (ART Therapy), still the country estimated to have the third highest number of people living with HIV/AIDS, after South Africa and Nigeria [3].

II. Antiretroviral Treatment And Adherence

The antiretroviral therapy is a key element of the overall management.The Antiretroviral therapy has moved from mono-therapy to triple therapy. Standard antiretroviral therapy consists of the use of at least three antiretroviral (ARV) drugs to maximally suppress the HIV disease also known as highly active antiretroviral therapy (HAART) [4].



Source:[5]

Figure 2.2. The Classification of Antiretroviral drugs

The inception of antiretroviral treatment (ART therapy) has not only significantly enhanced the life of PLHIVs but it has improved their quality of life also. Though it is not a cure but suppress the HIV virus from spreading. The disease HIV has transformed into a chronic manageable disease instead of a fatal disease. The treatment adherence which is also known as compliance, concordance defined as the extent to which patients take medications as prescribed by their healthcare providers [6]. It is the essential component of antiretroviral treatment success. Minimum 95 percent adherence is essential for effective treatment and estimated 30-50 percent of prescribed medication is not taken as recommended [7]. People on ART should not miss taking pill more than three times a month in a twice daily regimen. Non-adherence occurs if a person on ART does not take his/her medication as prescribed by the doctors. It has become a big constrain in the success of ART treatment. Non-adherence or poor adherence in treatment causes treatment failure and drug resistance. Subsequently the need for second line ART treatment occurs which is rarely available and accessible to all. The issue has enormously gained the attention of medical and social scientists for effective intervention. Globally around 33 to 38 per cent of HIV infected adults do not adhere to treatment regimen of ART and the rates of non-adherence to ART regimen [8]. The non-adherence in HIV/AIDS in India is an issue of concern as the country is among the top few countries that share the burden of HIV infection.

III. Studies

Empirical research suggests that non-adherence in any treatment is not a new issue. It continues to emerge from the ancient time. Many centuries ago Hippocrates (the ancient medical professionals) got aware of this fact that patients in illness pretended to have taken their medication. Non-adherence issue has gained recognition at the end of 1950s when physiologists studied outpatient therapy with a tuberculosis agent and drew attention to the compliance phenomenon. David Sakett had first explored adherence or compliance in hypertension after having observed unpredictable and disappointing responses to treatment [9]. In India adherence among patients in treatment varies quite considerably from 14 per cent to 80 percent. There are 35 per cent of the patients missed picking up their monthly drugs at least once and 4 per cent were lost to follow up in a period of 2 years at Indian ART program [10]. In a cross-sectional hospital based study at the ART clinic of the Lok Nayak Jai Prakesh Hospital (LNJP) at New Delhi, it was attempted to ascertain the reasons for non-adherence to ART, The study findings shows that the patients tend to miss their medication due to being away from the home and simply forgot the medication [11].The higher chance of survival was observed among patients adherent to ART than who were non-adherent [12]. Non-adherent patients had a mortality of 65 deaths per 100 patients years compared 15 deaths per 100 patients' year among adherent patients. Therefore adherence to ART is associated with higher chances of survival of HIV infected patients.

Non-adherence among PLHIVs further leads to mortality due to the disastrous causes of AIDS. The patient continues to face problems due to the infection, causing low development of the country and low work efficiency etc. Several studies have tried to study this problem from a different perspective. Some suggested the factors which are responsible for non-adherence among the PLHIVs. Some studies have emphasized the strategies and techniques to minimize the frequencies of patient's non-adherence tendency in ART therapy. Some people are unable to avail the treatment due to non- accessibility, availability of the drugs and psycho-social aspects [13]. They naturally become non-adherent though they wish to get the treatment. Gender issues were also explored in non-adherence to treatment in HIV/AIDS [14]. Whatever may be the reason the ultimate bearer of all this repercussion is the patient itself for whom the treatment is given.

Social Dimensions And Social Support

The social environment means the quality and characteristics of one's life, situation, including inter personnel relationships, resources for meeting one's needs and one's position, roles and participation in the society. Social systems or social institutions denote the economy, politics, the family, education, health care,

transportation and religion functioning in social roles. The reference author in [15] has called it person in environment perspectives including feelings, attitudes, values, beliefs, behavior, mental and physical health status.

Social well being implies harmony and integration with in the individual, between each individual and other member of the society and between individuals and the world in which they live. The social dimensions of health include the level of social skills one possesses, social functioning and the ability to see one self as a member of a larger society. In general social health takes into account that every individual is part of a family and of wider community and focus on social and economic conditions and well being of the "whole person "in the context of his social network. Social health is rooted in "Positive material environment" which is concerned with the social network of the individual**.**

The ecological model of human behavior views individuals, families, and small groups as having transitional problems and needs as they move from one life stage to another. This approach integrates both treatment and reform by conceptualizing and emphasizing the dysfunctional transactions between people and their physical and social environments. It tries to explore both internal and external factors and views people as dynamic and reciprocal integrators to their environment [16]. The present study with regards to this approach tends to find out social factors which may cause non-adherence in ART treatment. Since a person with HIV has not only to deal with the disease but to survive within the society. He /she is characterized by social rejection and emotional isolation. A social worker must identify those aspects while applying the ecological approach. Stigma and discrimination towards people with HIV/AIDS is very prominent in the society in lieu of which a person with the disease lost his/her hopes to survive, go for treatment. If person starts ART treatment he/she fears of being discriminated and stigmatized in the community , society and hospital due to which he/ she does not continue his/her treatment or take as per the prescriptions. These has been analyzed in literatures also that social factors do influence adherence negatively.

It is also important to note that these social aspects of person's life not only affect mental health but also health in general, which illustrates the important role played by social system in as far as an individual's health and mental health is concerned. These cultural, environmental and familial dimensions influences on the expression and the experience of illness [17]. The researcher found during her tenure that the following social / environmental matters could lead to non-compliance (Table 1).

Table.1. Social & Environmental matters of Non-adherence

1.	Acceptance of the disease and belief in therapy
2.	Literacy/ Knowledge/ Education
3.	Socio-economic status
4.	Accommodation: Housing rural/urban, prisoners, renting
5.	Ethnics, cultural traditions and religious beliefs
6.	Social support systems, Family support, marital status, sexual matters, disclosure of status
7.	Social stability, Social security and Social occasions.
8.	Transportation
9.	Nutrition

Source: [18]

Social support distinguishes between four types of support Emotional support is associated with sharing life experiences. It involves the provision of empathy, love, trust and caring. Instrumental support involves the provision of tangible aid and services that directly assist a person in need. It is provided by close friends, colleagues and neighbours. Informational support involves the provision of advice, suggestions, and information that a person can use to address problems. Appraisal support involves the provision of information that is useful for self-evaluation purposes: constructive feedback, affirmation and social comparison [19].

In a global sense, social support can be defined as information that people receive within social interactions, including actual assistance and feelings of embedded ness in a social network that is believed to provide love and care. Durkheim was one of the first to observe a higher risk of committing suicide among socially isolated individuals than among those with regular social bonds. In line with this, there exists a research tradition of looking for the objective quantitative roots of social support. Because relationships may be unhelpful as well as supportive, the focus of research has shifted from network size to an understanding of individual perception of social support as well as the context in which it is given.

Social support can be provided by formal or informal sources. An informal and very important support source is the family (e.g., parents, spouses, other relatives). Other informal sources of support might include friends, partners, coworkers, peer groups, and neighbors. Formal social support may come from services such as self-help groups, drop-in centers for information, and formal community services. For example, schools, which often seem to be a source of stress for pupils, can also be a source of social support for children who experience problems with their parents. Hence, these formal support sources can be focused on specific populations of individuals who may be at risk, such as children and older people living in isolation, or they may be open to all

people in general. Empirical studies indicate that both formal and informal support sources are positively related to health and well-being, although people seem to rely more on informal support sources for emotional help and seem to prefer formal sources for receiving instrumental support. In addition to human help, household pets can provide support. Analyses of pet support measures show that pets fulfill many of the same support functions as do humans (e.g., emotional support, social integration, closeness) and that pet support, like human support, is associated with less stress and better adjustment. However, studies that have analyzed sources of support are limited. Thus, further research should collect information about sources of social support in special groups differentiating special kinds of support.

IV. Methodology

The rationale of this study lies in the fact that adherence is a key to the success of ART therapy; irregularities in treatment will cause drug resistance, treatment failure, increasing number of AIDS cases huge requirement for second line drugs which are merely available and accessible by all**.** The present work is output of group discussions. Total eight, (N-8) Focus group discussions were conducted with PLHIVs (People living with HIV) from four selected hospitals of Delhi. Each group consists of 8-10 both male and female clients.

Table. 1. Details of Participants in Focus Group Discussion.

S No	M	F	Total	Age		ART Center
				Male	Female	
Group 1	5	3	8	(38-45)	(27-45)	Ram Mnohar Lohia Hospital
Group 2	4	4	8	(39-50)	(27-45)	Ram Mnohar Lohia Hospital
Group 3	3	4	7	(24-50)	(21-40)	Guru Teg Bahadoor Hospital
Group 4	5	2	7	(28-40)	(24-28)	GuruTeg Bahadoor Hospital
Group 5	3	5	8	(26-32)	(30-60)	B.R.Ambedkar
Group 6	6	4	10	(25-50)	(27-35)	B.R.Ambedkar
Group 7	4	4	9	(24-47)	(28-40)	Deen Dayal Upadhaya Hospital
Group 8	2	4	6	(30-37)	(32-45)	Deen Dayal Upadhaya Hospital

A. Findings

The research findings indicated that most of the respondents were illiterate and having low level of educational level which further shows that low education has association with non-adherence as respondents with low literacy were having different problems with medication such as reading the tablets name, acceptance towards the treatment etc., while those having some education could better able to understand the seriousness of the treatment and future harmful causes.. This could be an indication that literacy does play a role in seeking medical treatment. The researcher also found that many respondents were married. Hence this findings show that despite having married, respondents were reluctant to adhere to ART therapy. The assumption can be made that people who are married somehow not able to obtain support of their partner to be adherent in treatment. The majority of the respondents were migrated from different parts of the country. Very few numbers of people are born and brought up in Delhi. This shows that migration is rapid in Delhi. This was also found as major reason of non-adherence in ART treatment as people have to visit their native place frequently and thereby they miss to collect their Antiretroviral drugs (ARVs) in time . Regarding accommodation, the findings showed that most respondents were residing in rural areas of Delhi and particularly in slum, unhygienic condition. Most of the respondents were found working in private field for financial earnings. Very few numbers of the respondents were found either having their own business or small trade; a considerable number of the respondents were found no job because of HIV infection and its severity, they had to quiet their job.

The further analysis of FGDs showed that HIV is still considered as a fatal virus by the people living with HIV due to prevalent stigma and discrimination in the society. People on ART do not talk in their community on HIV/AIDS, antiretroviral treatment(ART) and other related issues openly, while treatment they face stigma and discrimination at every place and it varied by people' attitude and behavior and even educated people do discriminate with them at hospital The findings also revealed that Respondents were dissatisfied with inaccurate care and support given by the institution The investigator found here that owing to the sensitive issues related to HIV/AIDS and antiretroviral treatment , the respondents were not found motivated to be part of support group such as DNP+ (Delhi Network of HIV Positive People and WNP+ (Women Network of positive people) such support groups were not indicated as being of any significant influence as far as non-adherence is concerned. Other social factors found responsible for non-adherence were lack of family support, peer and friends support, social status.

Moreover while asking about family support one respondent claimed that stigma and discrimination does exists within your family and begins from there, all in family do not show but keeps that mindset. Especially women (widow) with HIV and being on antiretroviral treatment were found more in pathetic situations. They were forced to live house, given no financial support and care by the family once her husband died due to HIV. As stated

earlier that both formal and informal social support sources are positively related to health and well-being, although people seem to rely more on informal support sources for emotional help and seem to prefer formal sources for receiving instrumental support.

V. Conclusion

The researcher‘s finding indicated that support groups are important to minimize non-adherence in ART treatment but lack of social support system has remained a major cause for the same. They were not found to be associated with any support system or groups. These are not perceived as strengths and their accountability is questioned. There is several support groups located around the city with similar aims at supporting people affected by HIV/ADS and all of them need to be coordinated. Therefore closer networking with NGOs and better utilization of their services may enhance the quality of services given to PLHIVs and this could lead to reinforcement in minimizing non-adherence by means of home visits in supporting PLHIVs as well as family members. Social work should carry out more research into improving their professional involvement in the field of research as there is dearth of research on adherence issues in ART treatment and the profession should be in the forefront in this field.

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