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Exploring Factors And Issues Associated To Adherence In Anti-Retroviral Therapy

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Abstract

HIV/AIDS is a disease that cannot be cured permanently and ART is the only available treatment to enhance patient's longevity. After entering into patient's body, HIV/AIDS virus attacks the immune system and due to which patient can easily get infected with other diseases. As the entry of virus reduces CD4 cells in blood, doctors always advise HIV/AIDS patients to start ART when CD4 count is less than 500 cells per cubic millimetre of blood. With less CD4 cells, a HIV/AIDS patient gets infected with other opportunistic infections along with HIV/AIDS more easily. Adherence in ART can increase CD4 cells and make immune system stronger to fight these opportunistic/ co-infections. The focus of the present paper is to analyse various factors and issues that are associated with the adherence to ART by the HIV/AIDS in the city of Patiala.

Keywords: Adherence, ART, HIV/AIDS, Immune system, CD4 cells

Introduction

Number of HIV/AIDS patients is increasing continuously all over the world. It is becoming a threat for all the nations as it is impossible to build a strong nation without a healthy population. One most complicated thing in dealing with this disease is that no permanent treatment is available for HIV/AIDS till now. Anti-retroviral therapy (ART) is the only available treatment for HIV/AIDS, which can help the patients to live longer just like an uninfected person by the use of ART treatment. As HIV/AIDS affects the immune system by reducing CD4 cells in blood, there is a possibility of other co-infections to these patients along with HIV/AIDS. The doctors prescribe ART to the patients whose CD4 cell count is less than 500 cells per cubic millimetre of blood. ART drugs increase CD4 cells count and keep these cells maintained during the adherence to ART treatment. If patient leaves the treatment, then CD4 cells count goes down again and this is not easy for a HIV/AIDS to gain sufficient number of CD4 cells again and again. So it is necessary to make the patient fully aware about the ART treatment as to how ART can help him/her maintain longevity while how non-adherence in ART can be risky.

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HIV/AIDS patients have to go through many emotional, social, psychological, financial turmoil after being diagnosed positive for HIV. As HIV/AIDS patients are not easily accepted in our society. HIV/AIDS patients face stigma and discrimination due to their illness because people relate this illness only with sexual misconduct like multiple sexual relations, visiting commercial sex workers, men having sex with men or some other wrong sexual practices.

The common man is not aware of the fact that sexual route is the main mode of HIV/AIDS transmission but there are also few other modes of transmission like infected blood transfusion, use of un-sanitized tools over any open wound, use of infected syringe or needle, pregnant mother to child etc. People usually ignore other modes of transmission of HIV/AIDS virus and relate this illness only to wrong sexual activities. Lack of awareness and complete knowledge about modes is one of the reasons behind the stigma attached to this condition. The negative attitude of the people makes the life of HIV/AIDS patient miserable and they do not choose to disclose their HIV/AIDS status to others to avoid discrimination. They prefer to keep their HIV positivity confidential due to many reasons such as fear of loss of job, loss of social and family honour, fear of getting abandoned even by family, friends and spouse. Due to all these factors, disclosure of HIV/AIDS status is a major issue which adversely impact adherence to ART treatment. Disclosure to family or partner may /may not help in adherence and so is true of non disclosure. Not just disclosure/non disclosure there are many other reasons as well which are responsible for non adherence of AR. Some of them can be pill burden, distance to ART centre, adverse effects of drugs, travelling cost, unavailability of drugs etc. In this light, the present paper analyses various factors and issues that may be facilitating or impeding factors in the adherence to ART treatment

The research paper has attempted to explore the related literature to compile issues of adherence during ART treatment. Many studies have also been randomly chosen to consider the issue, of non adherence to ART. The main analysis aims to support and confirm some issues with help of reviewed literature which are similar and common in almost every setting and are predominately faced by patients, health care providers and families during ART treatment.

Based on the review, a few of the factors have been discussed in the subsequent sections.

Treatment Longevity and Pill Burden

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Since ART is the only available treatment to deal with HIV/AIDS worldwide, it may continue till the death of the patient. The life long duration of the treatment and the pill burden most often cause non-adherence to ART among the HIV/AIDS patients. **Joshi et al. (2014)** in their study entitled, 'level of suboptimal adherence to first line antiretroviral treatment & its determinants among HIV positive people in India' underlines that the determinants of suboptimal adherence are illiteracy, gender, presence of anxiety, non-disclosure of HIV status to family, lack of motivation for treatment, neglect from friends, frequent change of residence and travel expenses. Optimization of adherence to ART is a shared responsibility of the programme, patient, health care providers, family and community. The major reasons for missing pills, as perceived by the participants were due to personal reasons, forgetting to take pills, irregularity in collecting drugs due to financial problems and difficulty to travel due to illness, inconvenience to carry medicines to work place and drug related factors (pill burden, size of tablets).This study generated an overall estimate of 76 per cent optimal adherence among PLHIV in India who were on free first line ART. Programme evaluation studies in countries including India have revealed missing the scheduled monthly appointments as an important barrier for optimal adherence. In above study data revealed that, about a quarter of patients visited the centre and did not meet the counsellors but just collected the drugs from pharmacy and left. This calls for urgent attention. Meeting between health worker and patient emerged as important factor that improved adherence among patients. Frequent change of residence and cost of travelling to the ART centre was a major barrier for optimal adherence. Strategies are needed to improve quality of adherence support services coupled with attentive monitoring of adherence measurement to achieve optimal adherence to ART treatment.

Adverse Effects of the Drugs

Adverse effects like nausea, vomiting, weight lose; bad appetite, poor digestion, skin irritation etc. are very common among HIV/AIDS patients while having ART treatment. Combination of ART drugs is too strong and HIV/AIDS patients cannot cope with it easily due to weak health condition. Health workers always suggest patients to have good healthy diet along with it and also, to notify them immediately about having any side effects. So, that they can change the combination or also can guide patients, that how to cope with these adverse effects of drugs. But in many cases it has been seen that patients left the treatment due to these initial side effects without notifying and discuss about it with health workers.

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Abdissa, A. E. (2013) highlighted in his study, "Determinant Factors Affecting Adherence to Antiretroviral Therapy among HIV Infected Patients in Addis Ababa" that change of ARV medications and high level of social stigma concern by itself was found to be a significant independent predictor of medication non-adherence. The current study showed that knowledge about HIV disease and antiretroviral therapy was significantly associated with adherence to ART. Participants who had adequate knowledge about different aspects including taking HIV medications, possible side effects of HIV medications, benefits of antiretroviral therapy, and importance of adherence reported better adherence than those who did not have adequate knowledge. In view of the common finding, patients should be well informed about their disease and the importance of taking HIV medications properly as prescribed. Besides, it would be very important to provide appropriate information about the benefits of ART and the importance of adherence in a simplified way so that patients can easily understand the concepts. This is necessary to tackle any possible misconceptions that may arise about HIV disease and antiretroviral treatment. The health care providers should give emphasis to the provision of structured and relevant information to patients about their disease before the initiation of ART and throughout the course of their treatment on a regular basis to maintain better adherence.

Travelling cost and Distance

In many studies it has been found that majority of HIV/AIDS patients belong to low socio economic background. In that case, they cannot afford travelling cost to visit ART centre for collection of medicines or follow-up. Travelling cost and distance to ART centre leads to non adherence among HIV/AIDS patients with low economic background. **Chindedza et al. (2013)** highlighted in their study "Perceived Barriers to Accessing and Achieving Adherence in Antiretroviral Therapy among HIV Patients at a Rural Mission Hospital in Zimbabwe" that distance and economic constraints particularly related to transport costs were documented to be the major challenges to access and adhering to ART schedules and regimes. Institutional issues such as long waiting times and inadequate levels of staffing were reported but were not perceived by respondents as contributing much to adherence to ART resupply schedules. Also social issues such as religion, culture and stigma were reported to contribute to a marginal extent as barriers to ART access and adherence.

Non-disclosure of HIV/AIDS Status

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HIV/AIDS patients usually do not disclose about having HIV/AIDS to their family members, partner /spouse and also on workplace due to fear of stigma and discrimination. So, non disclosure to family and employees can lead to non adherence, as it is difficult to take leave from work place without notifying them about having any illness. It is also difficult to visit ART centre every other month or may be earlier, without disclosing to the family members. **Erah & Arute (2008)** reported in their study, 'Adherence of HIV/AIDS patients to antiretroviral therapy in a tertiary health facility in Benin City' that dispensing of antiretroviral drugs to them in a common room was seen as inappropriate and exposing them to discrimination since patients entering the room were identifiable as HIV positive. Furthermore, some patients (11.4 percent) reported they were often unwilling to obtain permission from their working places to attend clinic regularly because they could not disclose their HIV status to their superiors. Medication adverse effects and stock-out of medicines were the two reasons accounting for the gap in treatment. None of the non-adherent patients wanted to be visited at home to be given their medications because of fear of being identified as a person living with HIV in their communities.

Availability and Easy Access to Drugs

Unavailability of drugs is also responsible for non adherence as patients do not feel comfortable to visit again and again to collect medicines due to weak health, lose of earning and travelling cost as well. So, proper maintenance of stock and availability of drugs can increase adherence among patients. **Wasti et al. (2012)** in their study 'factors influencing adherence to antiretroviral treatment in Asian developing countries: a systematic review' highlighted responsible factors for non-adherence as lack of financial support, better accessible points for medicine refills, consulting doctors for help with side effects, social support and trusting relationships with care providers. In this study authors clearly concluded that adherence to ART varies over time and between individuals. According to study in Asian developing communities, the factors impeding ART adherence are financial difficulties, stigma and discrimination, simply forgetting, being too busy, concurrent substance abuse and side effects. On the other hand, self-efficacy, family support and financial assistance facilitated adherence. Study also suggested that health care providers should give clear instructions and proper counselling to patients about how to manage ART if side effects occur.

Staff Behaviour and Confidentiality

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Vol-22-Issue-4-October-December-2019

HIV/AIDS patients are not only physically distressed but they feel psychologically distressed too due to stigma and discrimination related to it. So, to avoid discrimination they prefer not to disclose their status to others. They also expect from the concerned health workers to keep their identity and information confidential and to treat them respectfully. Reliable and supportive behaviour of staff can enhance adherence in HIV/AIDS patients**. Mbirimtengerenji et al. (2013)** in their study 'Factors That Influence Anti-Retroviral Therapy Adherence among Women in Lilongwe Urban Health Centres, Malawi' revealed that ART adherence among women is influenced by knowledge levels on perceived importance and consequences for not adhering to ART, short waiting time, good relationships with the next of kin and service providers, trust and effective coping mechanisms to stressful events. Moreover, short waiting time of the women at the hospital during the ARV refill period is highly associated with ART adherence level. On the other hand, factors that contribute to non-adherence are reduced knowledge level, side effects of ART, and bad relationships with service providers and relationship with the next of kin as well as occupation of the patient.

Depression and Substance Use

Depression and some other psychiatric disorders are common among HIV/AIDS patients due to life threats, stigma and discrimination related to the disease. Along with it, substance use is also predictable among patients to ease their stress which is an important factor that cause non-adherence during treatment. **Sarna et al. (2008)** highlighted in their study, "Adherence to antiretroviral therapy & its determinants amongst HIV patients in India" that several factors are associated with adherence like depression and psychiatric illness, active alcohol or drug use, and lack of social support are associated with lower adherence. In general, socio demographic factors do not seem to predict adherence behaviour, although some studies have found that older age, higher income and higher education and literacy correlate with better adherence. A patient's ability to identify medications and his/her understanding of the relationship between adherence and medication resistance also predict better adherence. Health literacy and HIV related knowledge are found to be associated with better adherence. Patient health care provider relationship and trust of patient in his health care provider is believed to be a motivating factor for adherence. A high pill burden and inability to integrate the treatment regime into patient's daily routine have been reported as barriers to adherence. Severe depression was found to be strongly associated with lower

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adherence in the study. Depression is shown to be an independent predictor of poor adherence in other studies. Depression is also common among HIV infected persons. Healthcare providers must be knowing the presence of depression among their patients. Early identification and management of severe depression and interventions to provide adherence support would be required to maintain high levels of adherence.

Age Factor

There are many factors which are directly and indirectly related to the adherence during treatment and age is one of them. It has been seen that HIV/AIDS is most common among young population or in reproductive age group due to their increased involvement in sexual activities. But in young age, a life threatening disease like HIV/AIDS can get negativity in them which lead to non adherence during treatment. **Adefolalu et al. (2013)** in their study "The Complex Nature of Adherence in the Management of HIV/AIDS as a Chronic Medical Condition" illustrate that adherence rates are higher among patients who are taking medications for acute medical conditions compared to those with chronic medical conditions. Study revealed that adherence level among adolescents is usually lower than adults and elderly patients on ART. A survey done among HIV patients in India also revealed poor adherence among people who were aged below 40 years. The explanatory factors responsible for this difference may be due to the fact that older individuals are more likely to have experience taking medication for age-related diseases and may have already become used to. Another reason may be related to the fact that lifestyle adjustments necessary for successful adherence are often less burdensome for adults compared to young patients.

Low Socio-Economic Condition

It has been concluded in many studies that people with low socio-economic background are more vulnerable to HIV/AIDS due to lack of adequate knowledge about disease and prevention measures. **Joglekar et al. (2011)** explored in their study 'Barriers to ART adherence & follow ups among patients attending ART centres in Maharashtra, India' that multiple barriers to ART adherence are financial barriers factors including unemployment, economic dependency, and debt, social norm of attending family rituals, and fulfilling social obligations emerged as socio-cultural barriers, patients' belief, attitude and behaviour towards medication and self-perceived stigma were the reasons for suboptimal adherence, and long waiting period, travel, migration, doctor-patient relationship and less time devoted in counselling at the centre contributed to missed visits.

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Vol-22-Issue-4-October-December-2019

Suggestions to improve adherence during ART

- Reliable and respectful relationship between patient and health worker can lead to regularity in ART treatment. If patient can talk freely with the health worker without any hesitation about problems and treatment experiences, it can help to maintain better adherence. Respectful behaviour, reliability, confidentiality, privacy during consultation can also improve adherence.
- Family support is also an important factor responsible for adherence. Unsupportive behaviour of family and spouse can disappoint the patient which tends to non adherence. So health workers and counsellors have to motivate the family members of the patients to support them during ART.
- Easy access to drugs on shortest distances and regular stock up of medicines can help to improve adherence level among HIV/AIDS patients whereas long distance to health centre and unavailability of drugs can cause non adherence.
- Facility of free travelling pass to HIV/AIDS patients can increase adherence among patients with low socio economic back ground, who left the treatment due to non availability of travelling cost and long distances to visit ART centre.
- Awareness among general population about HIV/AIDS to diminishing stigma and discrimination towards HIV/AIDS patients can also help to maintain good adherence level among HIV/AIDS patients. As many patients do not visit ART centre due to fear of being discriminated after recognised by someone while visiting ART centre.
- Maintenance of privacy during consultation and dispensing of medicines also helps to improve adherence as in many cases patients left treatment due to fear of disclosure of identity during their visit to ART centre or collection of medicines in open.
- Proper counselling and guidance to cope with adverse effects of the drugs, throughout the treatment helps the patient to deal with it. Adverse effects in ART treatment are very common which can lead to non adherence if not resolved or motivated to deal with it.

Conclusion

So there are number of factors are associated with adherence in ART including social, institutional, psychological and personal factors. Non- adherence in Patient's possible due to several personal issues like pill burden, pill size, adverse effects, unavailability of drugs,

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unwilling to treatment, unable to travel due to illness, lack of family support, financial dependency and many more. Social factors like stigma and discrimination with HIV/AIDS patients is also responsible for non-adherence in ART. Depression is very common among HIV/AIDS patients which intends to non-adherence during treatment but counsellors and health care providers can deal with it by providing appropriate counselling and motivation to patients about benefits and importance of treatment at right time. Institutional factors like unavailability of medicines, lack of counselling and privacy, staff behaviour, level of comfort with health care providers also plays an important role in adherence. Trustful and comfortable relationship with health care providers can lead to better adherence whereas lack of consent and confidentiality can cause non-adherence among HIV/AIDS patients. So, health care providers and counsellors have to build a trustful relationship with patients so that patients can explain and discuss every issue related to their illness and treatment with them without any hesitation. In this way health care providers can help and motivate them for better adherence by resolving their issues with their skills.

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