Antiretroviral Adherence

Patient experiences and strategies for ART adherence in KwaZulu-Natal

The population of South Africa has been severely affected in recent years by HIV infection and AIDS, and the country has been promoting antiretroviral medications on a larger scale since 2004. With an estimated adult HIV prevalence of 22% in 2005, the province of KwaZulu-Natal has one of the highest prevalence rates in the country. By 2007 more than 100,000 patients were taking antiretroviral medications in KZN.

STUDY OVERVIEW

MEASURE Evaluation, in partnership with Health Systems Trust, and in collaboration with the Department of Health of KwaZulu-Natal (KZN), and conducted a study of patient experiences on antiretroviral therapy (ART) in KZN to learn about patients' concerns in taking antiretrovirals (ARVs). Researchers sought to identify adherence strategies that succeeded or failed in helping patients take ARVs on time and remain in the program. The findings were used to develop a tool to assess the circumstances of ART patients with the goal of increasing adherence and retention. For the study, 172 current and former patients enrolled in ART programs in five facilities across the province were interviewed, including 52 patients who had dropped out of a program. Health care providers working in these programs were also interviewed.

FINDINGS

The conversations with patients indicated that achieving high adherence depends less on a particular strategy for remembering when to take ARVs than on how that strategy is maintained over time within a household. The data suggest that ART programmes should examine the living situation of patients (household composition, income sources, employment) to assess patients' need for assistance, and that, since these circumstances change over time, counsellors need to monitor patients' household circumstances carefully. The study found that the following elements affect patient adherence and programme retention; the more attention paid to each element, the better the adherence:

- Role played by a treatment supporter
- Ability to disclose HIV test results and being on ARVs to others
- Management of side effects
- Judicious use of a government grant
- Ability to find nutritious food regularly
- Ability to find funds to pay for transportation cost for monthly pickup of pills.

RECOMMENDATIONS

Identification of treatment supporters — The system of identifying individuals to serve as treatment supporters to ART patients should be strengthened to reduce the number of patients who begin ART without such a supporter and to monitor their interactions with patients over time. Health care providers all considered the role of treatment supporter as critical for high adherence. Although many patients said someone would remind them when to take their pills, that person was not necessarily someone who had attended classes and played the role of treatment supporter. Potential ART patients should understand the importance of having a treatment supporter and how to select someone to play that role as well as bring to the initiation classes.

Disclosure to others — Prospective ART patients should be helped to understand the importance of disclosing their HIV status to family members and friends, not only to increase the potential for social support and care, but also as a way to accept their situation. They will also need to discuss strategies about how to disclose, especially if they fear negative reactions. The directors of ART initiation classes should verify that

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their curriculum addresses the importance of disclosure in a safe and effective manner. In addition, the issue of disclosure should be addressed regularly by counselors who see patients when they return to fill their monthly prescriptions.

Managing side effects — ART patients need more assistance in monitoring and treating side effects as they arise, for the negative effects brought on by ARVs may lead to skipping doses or stopping the medication altogether. Improving the management of side effects has several aspects: discussions during the ART classes so patients know what to expect; forceful discussion of side effects and health status by counsellors and HCPs when patients return for their medication; a rapid and effective way to treat any signs of illness as they arise to minimize the discomfort they produce. The impact of side effects can only be dealt with effectively when all three elements are addressed at the same time.

Provision of support grants — Clarifying and streamlining the rules and qualification criteria for receiving a disability grant from the South African government would be useful for ART health care providers and for patients. Doctors fill out the grant application for ART patients with a CD4 count of less than 200 and advise patients to then send the application to the government grants office for processing. Some patients interviewed said their household became dependent on the grant for basic necessities, and their situation became difficult when their health improved and their CD4 count surpassed 200, and consequently, the grant stopped. Several said they stopped taking ARVs because they no longer received the grant, thus making the grant itself a disincentive to optimal adherence.

Food security — The majority of patients interviewed were not employed. The proportion of unemployed patients was significantly higher among dropouts than among those who remained in the programme. Most of those who were unemployed were dependent on other family members or government grants for funds for food and transportation to a health facility as well as for other basic needs. The DoH and other support organizations could assist facilities in developing a programme of food assistance through the provision of food parcels or another approach to avoid situations in which patients miss doses or stop taking ARVs because they lack adequate food. ART managers currently lack the staff and the funds necessary to provide such food assistance.

Funds for transportation — Finding funds for a monthly visit to pick up medications can be problematic for some patients for brief periods. Counselors who know about their patients' household situation, and monitor it monthly, can assist them in developing a plan to finance their transportation when they lack funds.

The use of tracer teams — Using patient tracers appears to be an effective strategy for reducing attrition rates. Two of the five research sites had active tracer teams to visit ART patients who missed appointments. The process of tracing patients who have stopped taking ARVs seems to be working very well for these sites, so it should be possible to achieve the same result elsewhere with additional resources. As the numbers of patients grow, so does the importance of tracking patients who appear to default.

Collect and use more information about patients' socioeconomic situation — Many of these suggested improvements depend on consistently obtaining accurate information from patients, as their needs and resources change from month to month. A treatment supporter may move away, a patient may refuse to disclose to anyone at all, a person may need help in dealing with a side effect, a source of income may disappear, or a patient may become ill. This information is not systematically tracked and utilized to support patients effectively. Monitoring the social and economic situation of patients as their circumstances change over time can improve adherence if identified needs are addressed.

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__We recommend__ that counsellors make time for discussions with patients as they return for their prescriptions each month. This study has developed a tool for periodic data collection about the needs and resources related to taking ARVs that counselors can use in interviewing patients. The tool designed from the findings facilitates that process. More work is needed to test the acceptability of the tool by providers and ultimately to understand whether correct and consistent use of the tool improves adherence.