

Expanding access to antiretroviral therapy through the public sector — the challenge of retaining patients in long-term primary care

The growing movement to make antiretroviral therapy (ART) widely available in South Africa has spurred discussion on different aspects of delivering HIV treatment services,^{1,2} deliberations that have taken on new importance in light of the national government's recent announcement of a plan to make ART widely available in the public sector. Yet one critical aspect of delivering ART effectively within HIV care services has received surprisingly little attention, namely the challenge of retaining patients in long-term programmes of primary care. Here we discuss the importance of distinguishing adherence to medications from retention in care, as well as the possible interventions that may be employed to improve long-term patient retention.

Adherence with antiretroviral medications is critical in achieving favourable clinical outcomes and preventing HIV resistance.³ While the basic notion that patients must be retained in care in order to adhere to their treatment regimens may seem obvious, it has been overlooked in many studies of ART adherence to date. For instance, one recent publication of medication adherence patterns among clinical trial patients in Cape Town found that 16% of participants dropped out of treatment within 2 years. But rather than being considered non-adherent after they dropped out (because they could no longer access ART), these patients were either excluded from adherence analysis, or analysed according to the results of their

last pill count before leaving the study. This approach, which has been used by other authors as well, is likely to overestimate the actual adherence of patients initiating treatment, suggesting that the relationship between adherence to treatment and retention in care requires clarification.

Adherence to treatment typically focuses on patients' pill-taking behaviours, and usually on the proximal factors (such as knowledge of treatment and its side-effects, barriers and attitudinal issues) which can be addressed through counselling interventions.⁵ In contrast, retention in care is a broader concept that emphasises attending regularly scheduled clinical appointments and making modifications in lifestyle needed for effective chronic disease management.⁶ A patient's retention in HIV care is a necessary precursor to his or her adherence to HIV therapy, but adherence with clinic visits and care does not necessarily imply adherence with medications. Moreover, adherence to care for HIV-infected individuals not yet eligible for ART may be associated with substantial benefits, for instance receipt of psychosocial support or prophylaxis against opportunistic infections.

Retention in care of patients with chronic diseases, particularly when asymptomatic, is a longstanding challenge to health care systems. Most local experiences of retaining patients in HIV treatment programmes come from well-



resourced, small-scale service or research projects,⁷⁻⁹ and it is unclear how these experiences will relate to large-scale and resource-constrained public sector treatment programmes. Useful insights may be drawn from the experience of other public sector primary care services. For instance, during 2002 the completion rate for tuberculosis treatment among new smear-positive cases ranged across provinces from 52% to 74%.¹⁰ In hypertension management programmes, available estimates of the proportion of patients retained and managed successfully over the short term are approximately two-thirds,^{11,12} somewhat better than the widely recognised 'rule of halves' in which only half of individuals with documented hypertension are treated effectively.¹³ If these figures can be extrapolated to future large-scale public sector HIV treatment programmes, then perhaps we may optimistically anticipate levels of retention in ART services at 60 - 80% per year. By definition, patients who are not retained in care cannot adhere to therapy, placing probable levels of medication adherence somewhere below this level — and substantially lower than the estimates predicted by research studies.

Pilot programmes across South Africa and elsewhere have developed various strategies to help ensure patient retention in care over the long term. Many programmes utilise social and/or behavioural eligibility criteria in an attempt to restrict access to treatment to those patients thought most likely to be retained in care. This may involve limiting enrolment to patients who have demonstrated the ability to attend regular clinical appointments during a preparatory phase, those who have disclosed their HIV status, and/or those who have easy access to the health care facility.⁷ However, there is evidence that providers have limited success in predicting adherence prospectively,¹⁴ and such selection processes may be problematic in public sector programmes that seek to make ART widely available. In the long run, identifying and addressing the major barriers to retention in care may be more fruitful than attempting to exclude patients facing such barriers. Another common measure to ensure patient retention in HIV treatment programmes involves tracing patients who have missed an appointment to their homes. Yet given the large number of patients and limited resources facing public sector services, it will be more efficient to prevent missed appointments than to spend staff resources tracking those who have already missed visits.

HIV treatment programmes may also be designed using specific structural elements that help facilitate patient retention. Comprehensive services that emphasise clinical care across the spectrum of HIV disease, rather than simply providing ART to relatively ill patients, will help to orient patients to the habit of attending regularly scheduled appointments before they initiate ART. Programmes that integrate the delivery of clinical care with non-clinical support services, such as psychosocial support, nutritional interventions, and/or income generation, can help to address the social and contextual barriers to long-term care that many patients will face. Importantly, HIV treatment programmes that are family-oriented, and that are able to provide care to families and households rather than discrete individuals, will help to take advantage of patients' social contexts to ensure long-term retention in care. Over the

past decade, HIV treatment programmes in the developed world have struggled to find interventions that can create a strong social network to support patients in long-term care.¹⁵ Services that provide integrated care to women, men and their children (recognising the complexities of defining 'families' in many instances) can begin to take advantage of existing social support networks. Such family-oriented treatment programmes may help to increase the likelihood that patients continue to attend appointments and receive services, in turn improving drug adherence and clinical outcomes.

This is by no means a comprehensive list of all the steps that may be taken to help patients remain in HIV primary care over the long term, and there are likely to be other, locally adapted and creative approaches to ensuring high rates of retention in care.^{6,16} Recognising the separate but related challenges of first retaining patients in care programmes, and then having patients adhere to their drug regimens, may make a critical contribution to the long-term impact of HIV treatment services in the public sector.

Landon Myer

School of Public Health and Family Medicine
University of Cape Town

Wafaa El-Sadr

MTCT-Plus Initiative and
Center for Infectious Diseases Epidemiologic Research
Mailman School of Public Health
Columbia University
New York
USA

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