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Structural barriers to ART adherence in Southern Africa: challenges and potential ways forward

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Abstract

Structural barriers to antiretroviral treatment (ART) adherence are economic, institutional, political and cultural factors, that collectively influence the extent to which persons living with HIV follow their medication regimens. We identify three sets of structural barriers to ART adherence that are salient in Southern Africa: poverty-related, institutional, and political and cultural. Examples of poverty-related barriers are competing demands in the context of resource-constrained settings, the lack of transport infrastructure, food insecurity, the role of disability grants and poor social support. Examples of institutional factors are logistical barriers, overburdened health care facilities, limited access to mental health services and difficulties in ensuring adequate counseling. Examples of political and cultural barriers are controversies in the provision of treatment for AIDS, migration, traditional beliefs about HIV and AIDS, poor health literacy and gender inequalities. In forging a way forward, we identify ways in which individuals, communities and health care systems may overcome some of these structural barriers. Finally, we make recommendations for further research on structural barriers to ART adherence. In all likelihood, enhancing adherence to ART requires the efforts of a variety of disciplines, including public health, psychology, anthropology, sociology and medicine.

Keywords

Structural barriers; adherence; antiretroviral treatment

The scope of the AIDS pandemic

In 2007, approximately 33.2 million people were living with HIV (UNAIDS/WHO 2007) and approximately three million people were receiving antiretroviral therapy at the end of that year, nearly 950 000 more than in 2006 (WHO 2008). Sustained virological suppression of HIV requires high adherence to ART to ensure positive treatment outcomes and to prevent the development of drug resistance (Paterson et al. 2000). If patients develop drug resistance many will need to switch to second line treatments, which are much more

expensive than first line drugs (WHO 2007). By all accounts, inadequate adherence contributes to treatment failure as determined by a detectable viral load.

Various studies have estimated adherence levels in resource-constrained settings. Beginning in 2002, initial studies of ART use in Africa reported high rates of adherence (Orrell et al. 2003). However, given limited resources prior to 2004, ART use was initially confined to those who were very sick and highly motivated. Pooled data from samples of patients in several African countries indicate that 77% achieved adequate levels of adherence (Hardon et al. 2007). Yet, much of these data were collected in experimental settings in which patients were required to meet specific criteria before enrolling, such as disclosure of their HIV status to at least one other individual. Patients also received social support, such as psychosocial counseling, the opportunity to join peer support groups, and material support, such as pillboxes, drug identification charts and daily schedules (e.g. Coetzee et al. 2004).

It appears, therefore, that the intensity of adherence support has likely been greater than will be achieved with rapid scale up to the full population of ART users. The move towards expanded routine HIV testing and universal access in many countries has meant that large numbers of patients, particularly those who are socially and economically marginalised, will enter HIV care and treatment programs (Gill et al. 2005). Where national ART roll-outs occur in non-experimental settings, it is to be expected that less emphasis will be placed on careful selection of patients and the provision of individual support to enhance adherence rates. A public health approach toward adherence will necessarily have to evolve to complement the public health approach to ART being developed in many high sero-prevalent countries. In this paper we use the term 'adherence' in a broad sense that encompasses both adherence to treatment (pill-taking) and attendance at clinic appointments or adherence to care.

Individual-level barriers to adherence

Most of the literature on ART adherence thus far has focused on individual level determinants, e.g. perceived social support (Holstad et al. 2006); psychiatric disturbance, most notably depression (Kilbourne et al. 2005); substance abuse (Tucker et al. 2004); and concerns about stigma (Klitzman et al. 2004). In a meta-analysis of patient-reported barriers and facilitators to adherence, it was found that fear of disclosure, substance abuse, forgetfulness, suspicions of treatment, treatment complexity, the number of pills required, decreased quality of life, work and family responsibilities, were among the major barriers to ART adherence (Mills et al. 2006). A recent meta-analysis, examining programs to improve adherence, indicated that most interventions involved various forms of individual, couple and group counseling, education about adherence and electronic reminders (Simoni et al. 2006). There has thus been little emphasis on examining the role of structural barriers to ART adherence.

Structural barriers to adherence

While adherence to care has traditionally been conceptualised as an individual undertaking, adherence behaviour is seldom purely volitional and is often governed by larger structural issues that may be resistant to change. Structural factors are particularly salient in low-income countries such as South Africa, where economic, social and political realities are often more constraining on individual behaviour than in wealthy industrially developed nations. We acknowledge that at a micro-level, individual psychological and behavioural issues play an important role in adherence. However, as a point of departure, we focus on the social, economic, institutional, political and cultural domains that collectively make up the social structures that, to a greater or lesser extent, influence the behaviour of patients (Shriver et al. 2000).

In terms of a conceptual paradigm, Bronfenbrenner's Ecological Systems Theory (1972) and Ewart's Social Action Theory (1991) are useful approaches to conceptualise the way in which structural factors influence individual behaviour. Ecological Systems Theory (Bronfenbrenner 1972) postulates three levels of environmental influence that shape behaviour, namely, the immediate environment such as the family in which a person operates, social institutions such as the health care system, transportation system, and local economy, and the larger cultural and political context in which people live. This theory fits well with Social Action Theory (SAT), which emphasises contextual influences on behaviour by characterising settings and systems in terms of the goals they activate and the personal capabilities, social interactions, motivational appraisals, and action strategies they support (Ewart 1991). We have divided the most salient structural barriers into: (1) poverty-related factors, (2) institution-related factors, and (3) culturally and politically-related factors. We include the issue of gender inequality as an additional structural factor because each of the other barriers could differentially influence men and women.

Poverty-related structural barriers

Poverty—Poverty is likely to affect adherence to care, as financial resources may need to be directed elsewhere, funds for travel to a medical clinic that provides ART may not be available, and child-care may not be readily accessible for parents who attend clinic appointments. The combined stresses associated with poverty, such as inadequate housing, community violence, unemployment and forced migration, may obviate an acknowledgement of the importance of regular clinic visits, and what may be perceived as rigid treatment regimens.

Problems with access to transport—Low and middle income countries are characterised by several deficits in environmental infrastructure, notably inadequate transport. As most patients who attend public health clinics do not have private transport they rely chiefly on public means, which are in many cases expensive and unsafe, and in some areas unavailable (Kagee et al. 2007). The limited incomes characteristic of patients in low income countries may in some cases preclude even using public transport. Thus, if clinics are located far from residential townships, patients often have to walk, which may require considerable effort, particularly if they feel unwell.

Food insecurity—In a qualitative study conducted among ART users in Uganda, Tanzania and Botswana, participants reported that they were unable to afford food needed to satisfy their increased appetites following commencement of treatment, especially in the early stages of treatment when their bodies needed extra nutrition to regain lost weight and strength (Hardon et al. 2007). Food insecurity may affect the regularity of ART doses, as some patients have reported taking their medication only when they have food available (Hardon et al. 2007).

Lost wages and the threat of losing employment—In the context of high unemployment in many low income countries, many patients lacking regular employment make themselves available as day laborers to employers willing to pay them a wage. Often, the need for a day's wages eclipses the potential benefit of a clinic visit (Kagee et al. 2007). The disincentive to seek clinic contact is exacerbated if patients are asymptomatic and have to wait for many hours to interact with a health provider in order to receive a supply of medication. Moreover, frequent absences from work create conditions under which employers may terminate employment if they do not know the reason for such absences. The threat of losing employment for this reason, therefore, often impedes clinic attendance.

Disability grants as a disincentive to adherence—In South Africa, AIDS sickness is coupled with eligibility for disability grants, and patients are entitled to a state-funded monthly income because of their illness-related incapacity to work. However, widespread unemployment has meant that disability grants are an important and at times the only source of income, even if patients are well enough to work. When disability grants are tied to AIDS-related indicators, such as CD4 counts or viral load, non-adherence may become an attractive option for patients who fear losing their grant if their CD4 count were to increase (Nattrass 2006a).

The absence of social support—Positive social and family support have been shown to be associated with good medication adherence (e.g. Holstad et al. 2006). However, difficult living circumstances in low income countries, contributed to by residence in informal settlements, the absence of basic amenities, high rates of migration, overcrowded living conditions, family violence and substance abuse, often create conditions under which the quality of social support to patients is poor. Also, the desire for privacy due to HIV stigma can be a barrier to accessing social support from within a patient's social network.

Institution-related factors

Logistical barriers to accessing treatment—Breen et al. (2007) showed, that among patients receiving treatment for mental disorders, logistical problems included having to line up in darkness outside the clinics as early as 4 a.m., having to wait many hours before they could collect their medication, and being fearful of attack by criminals while waiting in queues. Some patients, in an attempt to reduce the frequency of clinic visits, would decrease their doses so that their supplies would last longer. Thus, the way public health clinics are organised may determine the nature and level of access that patients have.

Inadequate medical care services—Many clinics in Southern African countries have long patient waiting times, inadequate infrastructure and facilities, and insufficient staff (Medicines Sans Frontiers 2007). The fact that the scope of practice of nurses employed in public health clinics in several instances has now been expanded to include HIV counseling may lead to burn-out, work dissatisfaction and even emigration among clinic staff. Severe staff shortages in public health clinics have necessitated only cursory exchanges between patients and their providers. When personnel are available, they may find themselves poorly prepared for the demands of ongoing relationships with patients who may be chronically ill (Swartz and Dick 2002).

Inadequate mental health services—Mental health problems, particularly mood, anxiety, and substance use disorders, have been associated with compromised adherence levels (Antelman et al. 2007). However, inadequate services exist for the diagnosis, treatment and management of mental health problems in many resource-constrained settings. We consider this inadequacy a structural problem requiring resolution.

Inadequate training of lay counseling—In an effort to alleviate the burden placed on professional health care workers, lay counselors have been employed to assist with pre- and post-test HIV counseling. Yet, in the context of competing demands on resources, insufficient emphasis is often placed on adequate training and ongoing supervision, and support for such personnel and counseling is reduced to the dissemination of information, rather than processing of patients' emotions and cognitions, to alleviate distress and alter long-standing behaviour patterns, including non-adherence (Rohleder and Swartz 2005).

Political and cultural barriers

Political controversies surrounding AIDS care—In South Africa, AIDS denialism has been articulated by the former president; nutrition as a superior alternative to ART has been advocated by a former health minister; and nutritional supplements have been peddled by entrepreneurs claiming their effectiveness in treating AIDS. Such campaigns have sown confusion among the public and many persons living with AIDS (Nattrass 2006a), which is detrimental to care-seeking behaviour.

Voluntary and forced migration—Internal migration for economic reasons is common in many low income countries, as people often seek employment in areas far from their places of origin. Ensuring continuity of care for people who migrate in search of work opportunities is often difficult, and such persons are considered ‘lost to follow-up’ or ‘defaulters’ by health authorities. Political instability and civil strife countries, such as the Democratic Republic of Congo, Uganda and Sierra Leone, have also given rise to large numbers of refugees. Refugees infected with HIV may not have access to health services if they are resident in a host country illegally, as it is difficult for undocumented persons to become integrated into local health care systems and many fear repatriation if they were to present themselves for care. In addition, refugees often face linguistic barriers when seeking care that inhibit effective patient-provider interaction and result in poor comprehension of medical instructions. In the absence of adequate translation services, which is true for most public health clinics in the sub-Saharan region (Swartz 1998), miscommunication is likely, leading to further alienation for many patients.

Traditional beliefs as a barrier to AIDS care—Inadequate public health care services, and familiarity with and belief in the cultural framework within which traditional healers work, make these service providers an attractive option for many patients (Walker et al. 2004). Although in many instances the interventions rendered by traditional healers may complement those of biomedicine, in some cases these may preclude full adherence to ART, either by fiat or by unwittingly creating uncertainty among patients about their effectiveness.

Low levels of health literacy—In many resource-constrained countries, health literacy is low (Kalichman and Simbayi 2004) and vigorous efforts are needed to ensure adequate knowledge about the trajectory of HIV and the need for sustained treatment. Many patients consider medication only as a tertiary measure following the onset of symptoms, rather than as a prophylactic intervention. Health literacy is linked to education level, and in many low and middle income countries is inferior among non-elite segments of the population.

Stigma—Persons living with HIV are often subject to stigma and discrimination. If patients are seen by members of their social constellation, such as neighbors, family members or friends, to be taking ART or attending an HIV clinic, it may signal that they are HIV-positive. Often HIV-positive individuals choose to attend clinics far from their local communities to avoid being seen and identified as HIV-infected by others, thereby compounding the problems of transportation and lost time from work.

Gender inequalities—Pervasive gender inequalities make it likely that the effects of the other structural barriers on adherence are different for women and men. Women experience higher levels of poverty and encounter greater barriers to accessing care than men because of multiple work and child-care burdens, restricted mobility, and economic dependence upon men (Gupta 2005). Initial concerns that the number of HIV-positive women receiving ART might be low relative, to their proportion in the population, have been assuaged by recent studies showing that HIV-positive women are not less likely (and may be more so) to be on ART (Braitstein et al. 2008, Nattrass 2006b). For example, in South Africa, men who

present for ART are sicker on average than women, suggesting delays by men in getting tested or care-seeking once tested (Bekker et al. 2006). A study of HIV positive men in the Cape Town area found that additional barriers included the notion that clinics are 'places for women' and HIV/AIDS is 'a women's issue'. Constructions of masculinity fostered denial of illness because this sign of 'weakness' conflicted with expectations that a man is the family breadwinner (Beck 2004). One US study found that women more often than men reported having difficulty taking medications openly at home (Sayles et al. 2006), which may be related to the likelihood that women are at greater risk of suffering adverse consequences if their status becomes known, including the possibility of physical abuse, termination of a relationship, and loss of financial support. By contrast, men's adherence difficulties may be related to beliefs about masculinity.

Potential ways forward

Re-organising the way ART is dispensed

Patients for whom travel to their ART clinic is difficult, due either to prohibitive costs or long distances, may benefit from the provision of transport coupons arranged by local NGOs, volunteer organisations or the clinics themselves. The feasibility of mobile clinics located within neighborhoods also warrants examination, although introducing such facilities brings into focus issues of confidentiality for patients who may not wish to be identified in their residential areas as receiving treatment for AIDS. However, if mobile clinics were to offer a range of such services, including treatment for other diseases, this may serve to reduce the stigma associated with their utilisation. Any solutions to transport problems faced by AIDS patients immediately bring into focus the issue of equity with regard to patients living with other conditions. To this end and in an effort to further destigmatise HIV, it is perhaps reasonable to recommend that patients living with conditions such as diabetes, hypertension and asthma may also have access to such services.

Integrating care for women and their children who are HIV-positive can circumvent the logistical problems of scheduling separate visits for adults and children. There are some examples that suggest that integration of HIV services within general care may serve to enhance adherence. For example, Bardeguez et al. (2008) showed that the odds of perfect adherence were significantly higher for women who had initiated ARVs during pregnancy compared to those who were initiated post-partum. Malta et al. (2005) suggested that improving networking between services, establishing effective referral mechanisms, and increasing the integration of health workers could result in improved adherence. Similarly, Friedland et al. (2007) showed, that in public health settings in Malawi and South Africa, collaboration and integration of clinical services for patients with tuberculosis and HIV could be successful. Also, data from a pilot study in Durban, South Africa, showed that directly observed treatment for tuberculosis could serve as an entry point for the introduction and monitoring of ART (Jack et al. 2004). Thus, it appears that there is some evidence in support of integration of services in many settings.

Minor adjustments to the way in which clinics are organised may include dispensing medications at two or three monthly intervals so that patients do not have to travel as frequently to collect their medication. In Haiti, Mukherjee et al. (2006) have shown that integrating HIV testing into primary care services, rather than waiting for patients to present for VCT, increases HIV case-finding. Once diagnosed with HIV, patients are provided with treatment at no cost, and transport to additional appointments is covered by the health system (Mukherjee et al. 2006). Adapting patients' clinic hours to patients' work schedules and reimbursing transportation costs may also reduce defaulting from care (Pearson et al. 2006). What has not been discussed in the literature, to our knowledge, is the possibility of

24 hour clinics staffed by health workers who would be available to see patients on a walk-in basis.

New technologies

Even in some very poor countries, the spread of new technologies, including cellular telephone technology, has been remarkably rapid (Kaplan 2006), e.g. medication kits with paging systems and other electronic reminder systems to support adherence (White 2005). To help address inadequacies in the HIV prevention and treatment work force, we recommend funding for the development and dissemination of innovative tools that can be used widely by a broad range of healthcare providers. For example, multimedia technology, such as the use of laptops and pre-programmed psycho-educational materials, has been used effectively in other health related interventions in resource poor settings (e.g. Schinke et al. 2004). Such tools have the advantage of using videos and pictures to teach patients, including those with poor literacy, about: HIV care and adherence; improving quality control and consistency of delivery of intervention content; and requiring minimal supervision and training.

Working with employers

Employers may require education and even incentives to allow their workers paid absences from the workplace to attend clinic appointments. Two incentives immediately recognisable to most employers are the lower rate of worker absenteeism due to opportunistic infections associated with AIDS and a lower rate of AIDS-related deaths among the workforce. The former will serve to ensure uninterrupted production while the latter may reduce the need for costly hiring processes and training for replacement workers.

Poverty-relief

In Southern Africa, a Basic Income Grant (BIG) has been considered as a means to provide citizens with an income, to enable the poorest households to meet their basic needs, to stimulate equitable economic development and promote family and community stability. The BIG holds promise to address serious problems such as food insecurity which, even in the absence of the need for ART adherence, remains a social, health and human rights concern. Meanwhile it has fallen on NGOs, charity organisations, and faith-based organisations to make available food packages on which many impoverished persons have been able to sustain themselves. Another direct way to promote access to care is to waive user fees, which has been implemented in some countries such as Haiti and South Africa (Mukherjee et al. 2006).

Disability grants

Nattrass (2006a) has shown that South Africa's disability policy has created the perverse incentive for people to become and/or remain ill, which could in turn be exacerbating the AIDS pandemic to the extent that the ART roll-out may be undermined. Among the various possibilities explored by Nattrass (2006a) is what is termed a 'treatment-support grant', which, while lower in value than the disability grant, would serve to provide some poverty-relief for persons living with AIDS. However, such a strategy may be perceived as unfair by fellow citizens who have never had access to the disability grant in the first place. Moreover, if persons with AIDS were able to access a disability grant when they were ill, and then a 'treatment support grant' once on treatment with their health restored, this could worsen the perverse incentive to become HIV-positive. This is an area that awaits investigation.

Bridging the cultural divide

There has been some acknowledgement of the need to integrate the biomedical and public health models of health care with local indigenous conceptualisations of health and illness. The fact that in many African countries traditional healers enjoy credibility and prestige among the population (Walker et al. 2004) suggests that their services require acknowledgement by the public health service to a greater extent than is the case at present. Simultaneously however, there is a danger that folk conceptualisations of HIV may compete with and undermine public health efforts at controlling the HIV pandemic. Yet, to frame the two paradigms as binary opposites is likely to undermine the potential for their complementarity. It is possible that traditional healers may serve as entry points to the western model and sources of complementary treatments (Kale 1995). While such treatments are unlikely to have an effect on the HIV virus itself, they may enhance patient satisfaction and thus retention in care.

Resolving political controversies

These include AIDS denialism and official questioning of the efficacy of ART in South Africa; the federal ban on needle exchange programmes in the US; the prohibition of methadone to opiate-dependent people in Russia; and American funding via the PEPFAR programme that requires abstinence-only prevention programmes (Remien et al. 2008). Public information campaigns on the effectiveness of ART require full prominence in the public health system and there may be a role for traditional healers in correcting such false understandings associated with AIDS care.

Reducing stigma

Most studies of stigma-reduction interventions have been conducted in industrially developed countries and have been shown to have limited success (Brown et al. 2003). However, political organisation by stigmatised groups that challenge their stigmatised status is a powerful tool for change (Parker and Aggleton 2003), e.g. the Treatment Action Campaign in South Africa. The involvement of HIV positive individuals in such groups may have a helpful effect on medication adherence and retention in care through reduction in their own perceptions of stigma. To date, however, support groups for HIV positive persons in treatment-related settings entail the goal of individual empowerment through gaining knowledge, skills, and the means to financially support oneself, but few have explicitly included a focus on social and political action to challenge the stigmatised status of HIV positive individuals. This is an arena where local NGOs may provide leadership by including a rights-based agenda in the support services they provide. At a political level, a central goal needs to be the enactment and enforcement of laws prohibiting discrimination of any kind against HIV positive people.

Addressing mental health needs

The HIV/AIDS epidemic will significantly increase the burden of mental illness and, consequently, the need for providing and expanding mental health care services (Patel et al. 2006). The inadequate mental health services in many countries (WHO 2001) necessitates training for health care personnel in primary care settings, especially regarding how to adequately recognise and manage mental health problems. Such efforts will increase adherence, improve quality of life and potentially limit disease progression (Pence et al. 2007). Solutions to the mental health burden in the HIV/AIDS epidemic may include a greater integration and collaboration of HIV and mental health services (Collins et al. 2006) which, while being organisationally challenging, could contribute in some part to improved access to the former services.

Recommendations for further research

We consider it imperative to have a multi-pronged research agenda that takes into account the range of factors likely to impact on ART adherence, from the most personal to the broadly political. It is of fundamental importance to gain an understanding of patients' experiences with the health care systems, the associated structural barriers to care in the countries in which they live, and their ideas about how to overcome these barriers. The triangulation of patients' perspectives with those of health care providers and administrators, regarding the structural barriers to care and ways to overcome them, is a logical step in this line of investigation. At the same time, policy level analyses are also necessary so that the broader societal factors which could facilitate or inhibit ART adherence can be better understood. If we are to seriously address the structural barriers we have mentioned earlier, it follows that interventions focusing only on behavioural issues, though necessary, are unlikely to be sufficient. It is necessary to carefully examine the range of country-specific issues that may affect ART adherence in resource-poor settings. Only after this preliminary groundwork has been done will we be able to sketch a clearer agenda for future intervention research. Such a trajectory of research would yield the components of a series of logistical, administrative, policy and behavioural interventions, aimed at assisting patients to overcome specific structural barriers to optimal ART adherence. Ultimately, there will be a need for strong collaborative partnerships among researchers and clinicians, policy makers and funders, as well as community groups, to develop and implement the necessary interventions so that effective programmes are not only achievable but sustainable in a wide range of settings.

Stigma

Research is needed to develop valid measures of structural and institutional HIV-related stigma. Enabling a more comprehensive assessment of stigma over time, such measures would help identify and evaluate potential factors to reduce discrimination at the structural/institutional level. Also, in the context of scale-up of HIV testing, research is needed on how stigma affects, and is affected by, widespread ART use.

Contextual factors

Research is required to examine patients' actual pathways to care and their experiences of care at public health clinics. In tandem with patient-focused research, studies examining the ways in which indigenous healers experience and interact with the health care system are required. Action to facilitate interaction between indigenous healers and HIV clinics, as well as to evaluate the effectiveness of these interactions, is also necessary, so that problems that arise in the context of such interactions may be tracked and potentially resolved.

Economic factors

Given the salience of economic deprivation in many resource-constrained settings, research on enlisting local structures, such as street committees and micro-credit organisations in efforts to enhance adherence to care, require exploration.

Research on adherence groups

It has often been assumed that adherence is a matter of individual volition. Yet, the unit of analysis in many resource-constrained settings may extend to families, groups and even whole communities, and patients may access care via their support systems rather than as individuals. The cultural and contextual factors associated with accessing care through groups require examination. Moreover, persons in positions of authority, such as parents, tribal chiefs, and even religious leaders, may play a significant role in influencing decision-

making regarding health care, including adherence to care. Research regarding the role of community leaders in influencing adherence is thus indicated.

Organization of Services

In addition to using formal intervention research to test the efficacy of new approaches to the delivery of services, it is important to include a strong programme evaluation component whenever any health or related services are modified. Programme evaluation is valuable when a local health district or NGO makes a small innovation in care without prior research (such as altering clinic hours or providing free transportation), as well as when such a change is based on a research-demonstrated efficacious programme (such as the integration of HIV and primary or reproductive health services). In the latter case, much can be learned about how to successfully institute the new programme in a particular setting. In both situations, monitoring changes through relatively simple service logs and obtaining feedback from staff and clients can help identify whether the new programme is reaching the people it is intended to target, for which groups of clients the new programme is most acceptable, whether clients are satisfied with the services, and how to overcome any implementation challenges that are faced.

Conclusion

Despite considerable research on adherence to antiretroviral therapy, the matter remains unresolved, as many patients enrolled in treatment programmes around the world continue to default on treatment. Pursuing adherence research may yield benefits at the level of improving health outcomes, extending the life span of HIV-infected persons, reducing the number of child-headed households and children orphaned by HIV, decreasing the burden on health care systems, and reducing worker absenteeism and death. These benefits will, therefore, accrue at the level of the individual, the family, the community, and the broader society in resource-constrained countries.

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