

## ETHICS CASE

### Changing Donor Funding and the Challenges of Integrated HIV Treatment

Commentary by Nicoli Nattrass, DPhil, MSc, MA, Rebecca Hodes, DPhil, and Lucie Cluver, DPhil

#### Abstract

Donor financing for HIV prevention and treatment has shifted from supporting disease-specific (“vertical”) programs to health systems strengthening (“horizontal”) programs intended to integrate all aspects of care. We examine the consequences of shifting resources from three perspectives: first, through a broad analysis of the changing policy context of health care financing; second, through an account of changing priorities for HIV treatment in South Africa; and third, through a description of some clinical consequences that the authors observed in a research study examining adherence to antiretroviral therapy (ART) and sexual health among adolescents. We note that AIDS responses are neither completely vertical nor horizontal but rather increasingly diagonal, as disease-specific protocols operate alongside integrated supply chain management, human resource development, and preventive screening. We conclude that health care programs are better conceived of as networks of policies requiring different degrees of integration into communities.

#### Case

You are an infectious disease physician from the United States leading a partnership with a group of local clinics in Southern Africa in providing antiretroviral medications as well as HIV testing and education. Recently, though, there have been discussions among donors about reallocating money to build primary care systems rather than directing resources to respond to specific diseases, such as HIV. Some donors have suggested that building health care infrastructure might be more cost effective and save more lives in the long run and that it is unethical to favor responding to one disease over another. A drawback of the infrastructure-building approach is also acknowledged in these discussions: thousands of people with HIV will lose access to antiretroviral medications within the next few months if resources are shifted. You consider that some increase in mortality might be acceptable if benefits are conferred upon a larger number of patients, but you also worry that some of the patients you’ve been treating will be directly affected by these policy changes. How should you and other physicians working in this context balance ethical obligations to their individual patients and to donors who must

approach health systems macroscopically? How should these tensions be managed effectively?

### **Commentary**

Financing for health care is in perpetual flux. Physicians and nurses working in resource-constrained contexts might develop their own tactics to optimize treatment and care for their patients. But how should health care workers respond when changing priorities of donors and developmental agencies threaten to disrupt supplies of essential medicines for chronic diseases like AIDS? Should they counsel lifelong adherence to [antiretroviral therapy \(ART\)](#) as a prerequisite for survival, even if ART might no longer be available? This is a core question posed by the case. But, in stating that “thousands of people with HIV will lose access to antiretroviral medications within the next few months if resources are shifted,” the hypothetical case constitutes a clear violation of global, national, and bilateral commitments to sustaining HIV treatment for patients for whom treatment is already initiated [1-4].

Our focus here is on the more subtle ways in which changing donor priorities can impact health resource allocation and clinical care provision. We examine some of the consequences of changing resources from three perspectives: first, through an analysis of developments in the political economy of health care financing; second, through an account of changing priorities for HIV treatment in South Africa; and third, through a description of clinical consequences. Our perspective on the ethical dilemmas that health care workers might confront in the aftermath of shifts in donor funding for health care is based on our research on the socioeconomic and experiential aspects of HIV treatment in South Africa; we run the largest known longitudinal, community-based study on medicines-taking and sexual health among HIV-positive adolescents [5-8]. And with an HIV-prevalence rate of 18.9 percent among adults aged 15 to 49 [9] and approximately 5.9 million South Africans who are HIV-positive, South Africa has the world’s largest HIV epidemic [2].

### **The Changing Policy Context of Donor Funding for ART Programs**

Donor financing for [HIV prevention](#) and treatment has shifted from supporting disease-specific (“vertical”) programs to health systems strengthening (“horizontal”) programs intended to integrate disease-specific care. Since the World Health Organization (WHO) Declaration of Alma-Ata of 1978 [10], there has been a strong current in public health in favor of primary health care and on general health systems as the most efficient way of delivering health care to the greatest number of people. The contemporary push towards horizontal health systems support and primary health care as an alternative to vertical AIDS funding is sometimes framed as a revival of Alma Ata. The horizontal restructuring of health care services, however, does not necessarily result in treatment disruptions for HIV-positive patients. Nevertheless, if health care services are not integrated

cautiously—in response to the needs of local patients, clinicians, and services—this could be detrimental at the individual and systems levels [11, 12].

The AIDS epidemic galvanized one of the most effective health activist efforts of the twentieth century. This movement emerged among gay men in the metropolitan centers of the United States and Europe in the mid- to late-1980s and grew into a broader international response among health care activists. Key scientific advancements followed, particularly the development of the first ART in 1987 and then generic formulations in the 1990s [13]. Nevertheless, the exorbitant cost of ART was an impediment to treatment delivery in resource-poor countries, inspiring new forms of social mobilization and policy changes in line with global commitments to providing universal access to ART [14].

The ethical core of the international AIDS response was the demand for ART as a human right [11] rather than as a good available only for citizens in well-resourced countries. In the late 1990s and early 2000s, influential US officials, including a former head of the [United States Agency for International Development \(USAID\)](#), opposed the public provision of ART in the global South, citing patent laws, the high costs of branded medicines, and the perceived inability of patients in resource-poor areas to adhere adequately [15]. Through advocacy and evidence, however, this stance began to change. In 2003, President George W. Bush pledged \$15 billion to AIDS through the [President's Emergency Plan for AIDS Relief \(PEPFAR\)](#) [16]. In 2005, the Group of Eight (G8)—France, Germany, Italy, the UK, Japan, the US, Canada, and Russia—promised Africa \$25 billion to provide universal HIV treatment by 2010 [17]. Humanitarian agencies, such as the [Joint United Nations Programme on HIV/AIDS \(UNAIDS\)](#), and philanthropic agencies, such as the Global Fund to Fight AIDS, Tuberculosis and Malaria, started investing in the global rollout of ART. Partnerships among donor agencies, government health departments, local health care workers, and nongovernmental organizations (NGOs) flourished [18, 19]. Investment in ART was motivated not only by the development of cheap generic formulations of ART, but also by the international focus on HIV as an issue of global security [4, 12].

The unprecedented international response to HIV/AIDS helped fund national ART programs in developing countries. Although funding increased globally for health initiatives from the mid-2000s, donor funding for AIDS rose faster than other categories of health spending [20]. Rather than “crowding out” other health spending, the international AIDS response helped mobilize additional resources for health systems [12]. Because of their explicit commitment to funding ART, national health departments in sub-Saharan Africa, in collaboration with donor agencies such as the [Global Fund](#) and PEPFAR, could use HIV-specific funds to strengthen health care systems more broadly [16, 21–22].

The vigorous AIDS response supported patients and health care workers, strengthened distribution networks for medical services, pumped essential resources into pharmacies and diagnostics, and helped reduce the rate of new HIV infections and AIDS-related mortality and morbidity [12, 21, 23-25]. These initiatives also strengthened health systems more broadly [16, 21-22].

After the financial crisis of 2008, however, there was growing concern among physicians and program leaders that funds dedicated for ART would be reapportioned, leaving patients in the lurch. At the XVIII International AIDS Conference held in Vienna in 2010, Ugandan physician Peter Mugenyi described how past arguments concerning the cost effectiveness of ART had resurfaced:

Once again, we are facing some of those prospects which we faced in the mid-1990s. We are beginning to hear this language once more, that universal access is too expensive and that we can't do it... We need commitment from our governments, from the international community, and from the leadership of rich countries. The emergency has not gone away. We have a financial crunch. AIDS, more than anything else, requires that resources be increased so that we can continue to solve the century's most devastating health problem [26].

Without access to ART and support in adhering to it, patients face the threat of return to a pre-HIV treatment era. Not only would this violate their [human right to health care](#) [27], it also would place momentous strain on health care systems, as wards would again be filled with HIV-positive patients with advanced opportunistic infections and precarious prospects for recovery and survival.

### **Changing AIDS Policy in South Africa**

Political responses to HIV in South Africa over the last decade have been the focus of much public attention [28, 29]. The AIDS denialism of President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang is one of the most contentious issues to have arisen during the post-apartheid era [30]. The protracted battle for public ART access was waged between South Africa's HIV activist movement and political officials during the late 1990s and early 2000s. However, this did not stop health care workers and bilateral partners from piloting programs to treat and manage HIV in keeping with advancing evidence [18]. Donor-funded projects helped support ART programs from the early 2000s, but it was only after 2005 that ART began to become accessible beyond these individual programs [28]. As donors and bilateral agencies such as UNAIDS, the World Health Organization, the Global Fund, and PEPFAR honed their focus on ART provision, the scope of South Africa's HIV treatment program expanded rapidly. By September 2005, 85,000 people had initiated ART in South Africa's public health sector

[31]. By 2015, South Africa had the world's largest ART program, with 2.6 million people on HIV treatment [32].

South Africa's public provision of ART is the result of a vast mobilization of patients, health care workers, government officials, NGOs, bilateral agencies, and international donors, who have worked together to provide and sustain public access to HIV treatment [19]. To help shoulder the weight of AIDS clinical care, cohorts of [community health care workers](#) were employed and clinics began to promote HIV treatment [17]. Mobile HIV testing sites also offered blood sugar testing and contraceptive counseling. Clinic infrastructure was improved, both to host HIV testing and treatment programs and to better capture epidemiological and clinical data [19, 33].

South Africa is one of the states whose national HIV treatment programs helped strengthen health systems and save lives. South Africans on ART can now expect relatively normal life spans [34]. But, as we suggest below, this success is vulnerable to changes in donors' and governments' health care priorities and practices [20, 34].

### **Donor Decisions, Clinical Consequences**

The effects of changing donor commitments and of governmental reapportioning of resources are evident in our research with HIV-positive adolescents in the Eastern Cape, one of South Africa's poorest provinces with among the highest rates of infant mortality. Many of the adolescents in this research (aged 10 to 19) were born during the era of President Mbeki's AIDS denialism, prior to the establishment of a national program to prevent mother-to-child transmission of HIV. Thus, their mothers could not access medicines to reduce perinatal HIV transmission.

Our research, constituting over 1,000 hours of observation at South African public health care facilities over the course of three years, has shown the importance of carefully considering, as the case scenario suggests, the chasm that can develop between neatly defined donor objectives and their real-world implementation.

This chasm can be seen in one of the health care facilities specializing in the treatment of multidrug-resistant tuberculosis (TB) in which we worked and where many patients are co-infected with HIV and TB. Prior to the drive to integrate HIV services with general care, a dedicated HIV clinic and patient "folder depot" served these patients. To solve the problem of relevant clinical information being kept in separate parts of the clinic, which could potentially add hours to a patient's waiting time, the "folder depot" enabled adolescent patients to fetch their folders from a consolidated data source, see a nurse for a medication refill, and complete their clinical visit within three to four hours.

In the second half of 2015, however, the policy imperative to try to integrate services according to the model of a streamlined, "horizontal" service disrupted the clinic's own

model for optimizing the treatment and management of HIV-positive patients. This model had been developed slowly, by a team of nurses, pharmacists, data capturers and—critically—expert patients who received their own ART at the clinic. The result of this change was not necessarily a shorter waiting time for patients in general, but a longer waiting time for patients on ART, who were combined with patients receiving general services. For adolescents participating in our research who needed ART, this meant that they had to arrive early in the morning and be prepared to wait all day. They reported missing days of school (for which they could be punished) and were further at risk for stigmatization if their HIV status became known to teachers. For the patients' caregivers, this could mean the loss of a day's wages or make it more difficult to maintain a regular job, threatening a reduction in family resources and worsening poverty and food insecurity. For the families reliant on this health care facility, horizontal services integration has not reduced HIV stigma or improved equality; instead, it has exacerbated the challenges of living with HIV and AIDS.

### **Conclusion**

Although the provision of ART in developing countries like South Africa was facilitated by donor support, retreat of donors from their commitments to funding ART programs could portend harmful consequences for patients, as is evident in our study of HIV-positive adolescents in South Africa's Eastern Cape. The shift in health care spending from disease-specific interventions to the more general provision of services is being justified with reference to the equity considerations of the Declaration of Alma-Ata [10]. Yet we have seen that AIDS responses are neither completely vertical nor horizontal but, rather, increasingly *diagonal*, as disease-specific protocols operate alongside integrated supply chain management, human resource development, and preventive screening [35]. In the decades after Alma-Ata, research has shown that health care programs are better conceived as networks of policies requiring different degrees of integration into communities [36]. The success of integrated health care, especially in countries with high HIV-prevalence, depends on the sustained provision of HIV treatment [37]. A strictly horizontal approach is blind to the challenges of managing ART programs and to the broader public benefits (fewer new HIV infections, lower morbidity and mortality) of a strong ART program. A weak ART program will harm patients and risk a resurgent AIDS epidemic. In South Africa, political obstructions to ART have subsided in the wake of successive government commitments and ambitious plans for the provision of HIV testing and treatment programs. The difficulties of sustaining ART provision, and of developing patient-led strategies to support adherence to ART, are the next challenges that frontline health care workers will confront.

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