Game Changers: Why Did the Scale-Up of HIV Treatment Work Despite Weak Health Systems?

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Abstract: Game changers are radical innovations that result in fundamental and durable changes. The global HIV program scale-up witnessed over the past decade has included some innovations that are not well appreciated. The willingness to rapidly adopt and implement innovations, the flexibility and speed of program implementation, and the readiness to re-examine professional roles are just a few of such game changers. However, moving ahead, further work is needed to enhance the quality of programs, to energetically tackle HIV prevention, to build on this success, and to address other health threats that these same communities face.

Key Words: AIDS, health systems, HIV, innovations, scale-up

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ESSENTIALS OF THE EARLY RESPONSE

“Game changers” are radical innovations that fundamentally change how something is done, thought about, or approached. Technological examples include cell phones, the Internet, and social media, which have profoundly altered global communications and have had such widespread impact. Considerable resources are being invested in the search for game-changing technologies for health, including point-of-care diagnostics, better drugs, and new vaccines. Game changers can also be social, political, or economic events that change the status quo. HIV prevention and treatment scale-up during the first decade of the 21st century qualifies as a game changer that has irreversibly changed perceptions of and approaches to global health.

The leading policy debates around HIV approximately a decade ago concerned what to do about antiretroviral therapy (ART) for the millions of persons in need in low-income and middle-income countries. Early technical discussions were primarily about the feasibility of delivering ART safely and effectively and assuring adherence to treatment. Once political and financial commitments to HIV treatment scale-up had been made through the establishment of PEPFAR and the Global Fund to Fight AIDS, Tuberculosis (TB) and Malaria, a further controversy concerned how best to identify individuals with HIV who would benefit from such programs in settings where many were unaware of their HIV status.1 Despite all these concerns, more than 5 million HIV-infected people in low-income and middle-income countries were receiving ART by the end of 2009, the majority in African countries where health systems were sometimes desperately weak.2 Many of the most affected countries suffered from weak governance, limited planning capability, crumbling infrastructure, a demoralized workforce, limited laboratory capacity, and fragile procurement systems.3 How was such success achieved despite the obstacles faced, can it be sustained, and what are some of the looming challenges? These questions have relevance beyond HIV and are fundamental to how the world deals with health as a whole across disparate low-income and middle-income countries and, indeed, to the very notion of what constitutes global health.

Advocacy, urgency, a sense of optimism that it “could” be done, and political commitment matched by adequate resources provided the foundation for HIV scale-up. With HIV in the industrialized world initially concentrated in disenfranchised groups that were beginning to find their political voice, there were obvious reasons why HIV led to social and professional coalitions that promoted service delivery, HIV prevention, and protection against discrimination.4 The “Lazarus effect” of ART, which visibly and rapidly brought many dying patients back to health, contributed to perceptions of urgency and to the arguments of social justice and international solidarity. The dire situation in low-income countries, especially in sub-Saharan Africa, where tens of millions of persons living with HIV lacked access to treatment, became widely publicized, leading to activism and advocacy that focused on the HIV crisis in countries of the global South. This political and financial commitment to HIV pulled other infectious disease priorities such as TB and malaria into its slipstream. Despite the many clear reasons why HIV garnered this international momentum, there are aspects to the disease’s ability to forge coalitions and generate commitment and support that are difficult to explain fully and that have never been matched by any other health priority.

To achieve scale-up, technical approaches had to be tailored to the reality of health care in resource-poor settings; essential adaptations included emphasis on standardization, simplification, the use of algorithms, minimal reliance on laboratory monitoring, and the use of generic medications.5 Extraordinary international collaboration allowed host country facilities, public health authorities, community and faith-based
organizations, civil society, and professional groups to collaborate with counterparts from the global North to utilize the generous resources provided by PEPFAR and the Global Fund. A coalition of this breadth, established to focus on implementation of a specific health program in diverse countries, had never been achieved before.

GAME CHANGERS

Attention to the unprecedented levels of funding for HIV scale-up has at times obscured some of the truly innovative approaches developed by HIV implementers. New approaches and technologies have been piloted and scaled up at remarkable speed; the rapid introduction of rapid HIV diagnostic tests and early infant diagnosis systems are two such examples. Programs have been flexible and willing to adopt new innovations and change when new evidence arises, such as the move from single-dose nevirapine to combination therapy for the prevention of mother-to-child transmission of HIV (PMTCT). Although the vast majority of PMTCT programs used single-dose nevirapine only two years ago, many of these large and decentralized programs rapidly changed their approach as new evidence emerged to support combination antiretroviral drugs for PMTCT. Such flexibility and speed are also evident in the move away from stavudine-containing ART regimens; this move required not only changes in policy but also changes in procurement, training, guidelines, and job aids. Yet countries such as Zambia, Kenya, and South Africa moved rapidly to adjust their national programs to encompass new regimens, despite recognized challenges.

HIV scale-up has led to questions about long-standing customs and beliefs regarding professional scopes of work and to significant momentum toward change. In some countries, nurses now prescribe ART, nonlaboratorians perform HIV testing, lay persons provide patient education, and “expert patients” give adherence counseling and support. New cadres, from data clerks to peer educators, have been created and included in national health systems, expanding the reach and impact of health initiatives.

Other remarkable characteristics of HIV programs include their ability to incorporate new activities into long-established programs, partnering with decades-old systems to introduce routine HIV testing into TB clinics, labor and delivery wards, and inpatient services, and PMTCT interventions into antenatal care. These additions and expansions required drive and commitment and more quotidian adjustments to TB and antenatal care registers and program monitoring. HIV scale-up has also led to renewed support for decentralization, and to close attention to the technical and management skills of the individuals and institutions backstopping district-level services. In countries such as Ethiopia and Kenya, regional health bureaus and district health teams receive funding and technical assistance directly, in addition to the support channeled through national ministries of health.

HIV and the global response have catalyzed unorthodox partnerships between governments and community-based and faith-based organizations, between civil society and professional societies, between activists and universities, and many others. In many countries, civil society representation and community voices are being heard at local and national levels, including through the country coordinating mechanisms established by the Global Fund.

FUTURE NEEDS AND PRIORITIES

Public health is dynamic, however, and the world in 2011 looks very different than in 2003, when President George W. Bush announced his vision for PEPFAR. After continuous increased funding for global health in recent years, spending is now leveling off, and the fiscal outlook in coming years is likely to remain restrictive. The remarkable success of HIV scale-up has inevitably spawned new debates about sustainability, the need for health systems strengthening, and whether funding for HIV has been disproportionate to funding for other health needs. Success itself highlights areas of health where progress has been slower, especially relating to the other health-related Millennium Development Goals (MDG), including child health, maternal mortality, and provision of safe water and adequate sanitation. It should be noted, however, that there also remain challenges in the global HIV response. These include the approach to monitoring and evaluation of programs, the follow-up of patients in care before ART eligibility and uptake of ART, and the PMTCT of HIV.

In retrospect, an opportunity was missed at the beginning of scale-up to institute a globally harmonized patient monitoring system that would give complete information and allow comparisons across programs. Although the situation with TB is admittedly simpler, because treatment lasts only 6 months rather than being lifelong as for HIV disease, it is nonetheless ironic that the much less well-funded information systems for this old disease have certain strengths lacking in many of our systems for monitoring HIV treatment. Specific attributes desired of an HIV patient monitoring system include standardized approaches to follow-up and documentation of standardized outcomes, including death, loss to follow-up, retention in care, adherence, and response to therapy. Advances in laboratory infrastructure and in diagnostics are beginning to make laboratory monitoring more feasible, and what constitutes optimal laboratory follow-up for patients on ART in low-income and middle-income countries is an important question for operational research. Although great technical challenges exist in implementing a unified system for patient monitoring, including questions regarding data management, it would be useful for global public health authorities to reconsider what is required from an optimal system and how greater harmonization could be achieved. In reporting on global scale-up, emphasis has been placed on numbers of patients receiving ART. The majority of patients accessing ART worldwide initiate treatment at advanced stages of HIV disease with evidence of severe immunosuppression. However, for the many patients who are diagnosed with HIV infection before they are eligible for ART, the follow-up in HIV care is often not effective, and programs have had limited success in tracking such patients and documenting their outcomes. In addition, even for patients who have been found eligible for ART, initiation of therapy is often delayed while they undergo various assessments, staging, and counseling. Such delays have been associated with very high mortality rates. Delay in initiation of ART provides opportunities for HIV-infected persons to be lost to follow-up or to die. The latter
patients are largely invisible to health information systems. Operational research is required to quantify the magnitude of this problem and design interventions to address it.

A final limitation concerns our modest success in HIV prevention. Although recent data indicate a decrease in HIV prevalence in many countries in sub-Saharan Africa, too many individuals are still acquiring HIV infection. New effective prevention interventions have been recently identified, leading to intense discussion globally about what constitutes effective “combination prevention.” With increased numbers of persons requiring services but with the constraints in financial resources, it is more important than ever that programs be based on the best available evidence. In generalized HIV epidemics, combination prevention programs should include HIV testing and counseling, male circumcision for uninfected men, HIV treatment for those who are eligible, “prevention for positives,” and services to prevent mother-to-child transmission, and for most-at-risk populations such as sex workers, injecting drug users, and men who have sex with men. Scale-up of prevention will have to accommodate the rapidly changing evidence base concerning use of antiretroviral drugs for HIV prevention, including through topical and systemic preexposure prophylaxis and HIV treatment.

Scaling-up programs for PMTCT in low-income settings has been more difficult than many anticipated—to some extent because its implementation has been divorced from HIV care and treatment programs, but also because they must be provided through an often weak maternal health infrastructure that also has struggled to meet MDG 5. Reducing maternal mortality will necessitate an integrated approach as it does not depend on a single intervention but on the availability, access, and acceptability of a number of complex services, which include timely transport for a woman to a safe place to deliver, adequately equipped facilities, appropriately trained health care workers, and provision of safe delivery and emergency obstetric services around the clock. A true game changer in PMTCT of HIV will require attention to strengthening maternal and child health services as a whole, synergizing with efforts to avert maternal and neonatal mortality.

There are encouraging examples of efforts to achieve this type of synergy between HIV programming and other health programming. For example, in Ethiopia, funding from the Global Fund to Fight AIDS, TB, and Malaria and PEPFAR has been successfully utilized for enhancing health systems. This has included innovative approaches for expanding the workforce through task shifting, establishing a strong health information system and a streamlined procurement and supply chain system.

CONCLUSIONS

Game changers are irreversible; there is no going back to the situation before the scale-up of HIV programs. Nonetheless, new challenges and priorities continuously emerge. Fiscal constraints; maintaining progress in containing HIV, malaria, and tuberculosis; addressing the unfinished agenda for the MDGs and the communicable disease agenda; and turning toward the increasing burden of noncommunicable diseases and injuries all loom ahead as we enter the second decade of the 21st century, offering challenges and opportunities. Policy makers and implementers would do well to study the history of HIV scale-up for guidance and encouragement in the face of the broader global health agenda that we need to address. Commitment, resources, technical expertise, partnerships—the list of ingredients for success is long, but prominent are principled pragmatism, optimism, and reliance on science and evidence to guide the way.

REFERENCES