The Leading Edge

Leveraging the lessons learned from HIV/AIDS for coordinated chronic care delivery in resource-poor settings

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1. Introduction

Though far from complete, the global fight against the HIV/AIDS epidemic has made significant strides. Since 2001, global incidence of new HIV infections has declined by 38% annually, including a 58% decline in new infections in children.1 Fifteen million people are now receiving antiretroviral therapy, compared to less than one million ten years ago.2 Much of this progress has been accomplished in sub-Saharan Africa, which bears the burden of the epidemic with 71% of the global number of people living with HIV/AIDS. In this region, 87% of patients who know their status and are eligible for antiretroviral therapy (ART) are now receiving treatment, and 76% of those patients have achieved viral suppression.1 AIDS-related deaths have decreased by 35% since their peak in 2005, and 4.8 million deaths are reported to have been averted by the development and delivery of safe, effective antiretroviral therapy in sub-Saharan Africa alone.1 Many have taken to declaring the “end of an epidemic” and looking forward to an “AIDS-free generation”.3 However, despite the relative gains made in the health system response by sub-Saharan African countries for the chronic management of patients with HIV/AIDS, a diverse group of other chronic conditions comprise a major driver for the burden of disease in these countries.4,5 Non-communicable diseases (NCDs) comprise a large proportion of such chronic diseases, including, but not limited to, rheumatic and congenital heart diseases, post-infectious renal failure, malignancies, sickle-cell anemia, type 1 diabetes, asthma, depression, epilepsy, and the chronic sequelae of trauma in its various manifestations. This group of diseases accounts for 36% of deaths, 33% of years of life lost, and 44% of DALYs in low-income countries amongst the population younger than 40 years of age.6,7

2. Catalyzing health system development to address chronic disease

In addition to the human and population impact of the response to the HIV/AIDS epidemic, perhaps its most lasting impact has been on health delivery systems in sub-Saharan Africa.8-10 Supported only to deliver a handful of targeted interventions for acute conditions in addition to basic preventive measures, health systems in sub-Saharan Africa were not properly equipped to address the chronic implications of the massive HIV/AIDS epidemic.11,12 Some experience with provision of services for chronic care had existed in the form of directly observed treatment for tuberculosis, which since the early 1990s had been implemented in some regions, though without clear benefit.13,14 Isolated experiences with chronic care organization also existed
for several non-communicable conditions, such as provision of hypertension and diabetes services in primary health facilities, although not on a large scale.\textsuperscript{15} Parallels with other conditions were limited, and HIV/AIDS existed on a separate magnitude of prevalence for an imminently lethal chronic disease than had ever been experienced before.\textsuperscript{16}

A crucial frame shift in the response to HIV/AIDS was the coordination of health care services to focus beyond individual patient encounters and emphasize longitudinal care for individual patients.\textsuperscript{17} Through the HIV/AIDS response, health systems were required to extend and reorganize health services to provide primary and secondary preventive measures, deliver acute management, and provide follow-up care to patients for future visits in the same health care setting with the same health care provider. Policy makers and implementers were forced to rapidly assess infrastructure and capacity needs, scale up staffing and human resources, update diagnostics and laboratories, adapt charts and registers, strengthen procurement strategies and supply chains, and create large-scale monitoring and evaluation systems to address a disease that could not be cured, but had to be treated over the course of years and potentially decades. The strengthening of health systems to provide chronic care was one laden with many challenges; however, the resultant decrease in premature morbidity and mortality from a coordinated HIV/AIDS response now demonstrate the potential impact of effective chronic care delivery within otherwise under-resourced health systems.

3. Key elements of chronic care delivery from the ART experience

Fortunately, the framework for health delivery systems in resource-poor countries to address the burden of chronic disease, including endemic NCDs, mental disorders, and the chronic consequences of injury and disability, has already been constructed, evaluated, and improved over the past 15 years in response to the HIV/AIDS epidemic. Key elements of the HIV/AIDS response (summarized in Table 1), once thought to be novel and innovative, have become the backbone for ART delivery systems throughout sub-Saharan Africa and beyond.\textsuperscript{18}

3.1. Task shifting

One of the major barriers to delivery of care in the HIV/AIDS epidemic was the lack of well-trained health care workers capable of providing the perceived complexities of chronic care for HIV/AIDS.\textsuperscript{19} In 2006, 36 African countries reported a critical shortage of health care professionals (less than 2.3 doctors, nurses, and midwives per 1000 population), thereby rendering the provision of essential services highly unlikely.\textsuperscript{20} However, with the development of evidence-based clinical algorithms and guidelines, clinical decision support tools, and training curricula and methodology, clinical decisions and tasks previously thought to be in the realm of only highly trained specialist physicians were transferred to general care providers, including nurses and lay health care workers.\textsuperscript{11} Recent studies have shown no decrement in patient outcomes even when lower rates of patient loss from care when ART delivery is shifted from physicians to nurses.\textsuperscript{22,23} In addition to didactic trainings, ongoing quality assurance, continuous quality improvement, and mentorship support for health care workers are now recommended to maintain high-quality ART services.\textsuperscript{24} Task shifting/sharing not only creates a larger workforce able to meet the demands of HIV care and treatment, but also allows more specialized clinicians to focus on more complex or advanced pathology.

3.2. Decentralization

The HIV epidemic was challenged with the prospect of providing care not only to highly populated referral centers, but increasing geographic access to services for rural communities and hard-to-reach populations. In order to provide appropriate access to services, new facilities were needed, and staff, medications, tools, and other commodities were required to deliver services closer to patients’ communities and homes. The drive to decentralize services stimulated innovations in diagnostic and treatment modalities, as well as task shifting of clinical services. There was a renewed interest and emphasis on the use of community health workers for case detection, contact tracing, linkage to services, and adherence support. Mobile technology, primarily in the form of mobile text reminders, has shown promise in linking patients to facilities, tracking lost patients, and supporting patient adherence to therapy.\textsuperscript{25,26} Several recent studies have demonstrated a decrease in patient attrition after decentralization of ART services to peripheral health facilities and community-based delivery programs.\textsuperscript{27,29}

3.3. Medical commodities

The need for effective antiretroviral drugs, as well as other essential medications, became an urgent call for simplification and stabilization of supply chains for the HIV/AIDS response. There was the need for “disruptive technologies” and “game changers”, which did not depend on incremental and iterative improvements of previously existing innovations, but rather a dramatic change in the paradigm of how care was delivered.\textsuperscript{18} Upon development and

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<td>Task-shifting</td>
<td>Supporting adequate staffing, developing novel curricula and training methodology with simplified context-specific algorithms; providing mentorship for continuous quality improvement</td>
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<td>Decentralization</td>
<td>Prioritizing rural access to care and infrastructure development with training, equipment, and accreditation of rural facilities; piloting mobile, point-of-care, and community-based solutions</td>
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<td>Medical commodities</td>
<td>Innovating and subsidizing of drugs and technologies, improving and stabilizing supply chains, expanding public sector formulations and integrating with existing health insurance schemes</td>
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<td>Retention and adherence strategies</td>
<td>Providing community support, developing mobile technologies, and mitigating socioeconomic barriers to care, including transport, nutrition, and referral costs for most vulnerable</td>
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<td>Patient groups and peer support</td>
<td>Creating community-based or facility-based patient care and peer support groups</td>
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<td>Health information systems</td>
<td>Developing electronic medical record capacity and automated reporting; establishing aggregated data collection and reporting on key indicators for epidemiologic, programmatic, and policy decision making</td>
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marketing of such options, such as combination ART pills, rapid HIV test kits, and dried blood spots for early infant diagnosis, national programs were supported with adoption and approval of such technologies. With the help of public–private partnerships, forecasting and distribution were strengthened to improve supply chains to maintain antiretroviral therapy and laboratory services, and new commodities were either subsidized or integrated into existing health insurance schemes.

3.4. Retention and adherence strategies

Strategies to maximize adherence to ART have been diverse, and outcomes have been mixed, with the use of treatment supporters, directly observed therapy, mobile phone text messages, diary cards, and food rations having demonstrated significant positive effect on treatment adherence in particular settings. The use of community health workers and treatment partners to support treatment have demonstrated successes in maximizing retention in care, treatment adherence, and ultimately, patient outcomes. Removing well-known socioeconomic barriers to care, such as fees for service, transport costs, and long wait times also improve patient retention and satisfaction.

3.5. Patient groups and peer support

Both facility and community-based models focused on group visits have shown promise in providing individual patients with a peer support network to maximize adherence, improve patient retention, provide patient education, monitor side effects, and achieve therapeutic gains. Such models may also potentially contribute to decongesting health facilities, decreasing wait and travel times, and maximizing health system efficiency, though such gains have not yet been clearly demonstrated. Peer support groups have also been used in a diversity of settings through the HIV/AIDS response, and numerous experiences have demonstrated positive effects on mortality and morbidity, retention in care, and quality of life measures.

3.6. Health records and information systems

The need for patient-focused chronic care delivery by health systems during the HIV/AIDS response in sub-Saharan Africa highlighted the need for patient-level data collection and reporting. The advance of patient level electronic medical record systems have allowed for standardized clinical decision making, though effects on quality of care and patient outcomes has not been well established. National HIV control programs required central databases to register and track aggregated data to inform the response to the epidemic and identify ongoing gaps in the uptake and quality of services. Clear metrics, linked to clinical and epidemiologic targets, were generated in order to assess the response, and quantify its shortcomings.

3.7. Health system reorganization and integration of vertical programming

The integration of HIV prevention and treatment programs into existing health care systems, although still in progress, has been key to the institutionalization, scale-up, and sustainability of the HIV response. This process has required detailed integration at all levels of the health care system, from central-level policy and management to facility-level reorganization of the physical location and delivery of chronic care services. Tools, trainings, and information systems have been adapted to focus on the core principles of chronic care delivery (e.g., screening for adherence or arranging appropriate follow-up), but simultaneously have required an appropriate level of disease-specific clinical decision support. Through the HIV/AIDS response, there is growing evidence that the common themes of chronic disease management and health systems strengthening must take precedence over vertical approaches for specific disease management for sustainable health systems change to occur.

3.8. International advocacy agenda and targets

Much of the success of the response to the HIV/AIDS epidemic has been attributed to international collaboration in establishing common targets for programmatic success. For example, the Millennium Development Goals represented a momentous shift towards consensus building with agreed upon international targets in decreasing HIV incidence and achieving universal treatment coverage, similar to more recent calls for "90-90-90," or 90% of individuals knowing their status, 90% on ART among those infected, and 90% with viral load suppression among those on ART. A common language for HIV/AIDS clinicians, policy makers, and program implementers was established, and a roadmap for success was laid. Such efforts undoubtedly facilitated the generation of an unprecedented level of funding for the HIV epidemic. Whereas HIV/AIDS accounted for 3.7% of the global burden of disease in 2010, 45.9% of global development assistance for health by donors was targeted for HIV/AIDS. In contrast, funding lags behind significantly for other chronic diseases. In 2014, while $US 611 million in development assistance for health was allocated to NCDs in low- and middle-income countries, over $US 10 billion was allocated for HIV/AIDS in the same year.

4. Looking forward – the need for coordinated chronic care

Despite numerous calls to leverage HIV care delivery systems, progress in development and scale-up of other chronic care services has been slow. Experiences with screening and delivery of care for NCDs within existing ART platforms has been attempted and described in several resource-limited contexts. In Cambodia, for example, hypertension and diabetes services were introduced into ART clinics at two referral hospitals, demonstrating good outcomes in both retention in care and clinical outcomes, as well as positive effects on adherence and stigma. Descriptions of such experiences, however, remain limited in the literature and generally confined to higher volume or urban referral centers. Alternatively, HIV screening and treatment has been attempted within vertical programming for NCDs, though the size and scope of this approach remains isolated. In a pilot intervention in Kenya, for example, where NCD screening and treatment was provided for clients attending an HIV clinic, clients reported satisfaction with integration of services and providers were appreciative of the overlap between HIV and NCD services. However, systems challenges, such as adequate infrastructure and commodities, as well as coordination of referrals and specialists, remained challenging. More numerous efforts in task-shifting of care for NCDs in sub-Saharan Africa have been described, though most reports are typically focused on a single disease type. More comprehensive efforts to deliver NCD services in rural primary health centers in Cameroon and South Africa have demonstrated feasibility and even successful clinical outcomes, though adherence to treatment and loss-to-follow-up remains challenging. These interventions, although promising for the ability to task-shift and decentralize NCD services, do not yet include or integrate with HIV services. These efforts fail short of the development of large-scale delivery programs capitalizing on the key lessons learned in the HIV/AIDS epidemic. As a result, effective coverage of treatment services for most chronic diseases lags far behind that of HIV, both
in sub-Saharan Africa, as well as throughout low- and middle-income countries worldwide.55,56

If these lessons learned from the HIV epidemic have been well established and previously codified, what then is limiting an integrated delivery response to chronic disease? The answer may lie in the inability to coordinate the decentralization and integration of different chronic care services at all levels of the health system.77 As chronic care services are planned and developed, decentralization of services should be thoughtful and prospective, with greater degrees of specialization at higher levels of the health care system and greater integration at the primary and community levels, depending on disease prevalence and available human resources (Fig. 1). Coordination of such services would not only provide the advantage of greater satisfaction for the patient experience, but it would build greater efficiency in the delivery of chronic care services from a health systems perspective. Vertical funding and advocacy measures by disease-focused groups should be leveraged for the collective advance for integrated chronic care services, which could be catalyzed by greater coordination within governments (i.e., chronic care clusters and integrated technical working groups) and among disease-specific groups within international funding agencies, foundations, and bilateral donors.

In order to make true progress in transforming health delivery systems to be able to address the diversity and magnitude of chronic disease care delivery, larger efforts are necessary.15 Coordinated chronic care delivery is one solution, with care for HIV/AIDS, NCDs, mental health, palliative care, injuries with chronic disabilities, and other chronic conditions to be progressively decentralized with the optimal level of integration or specialization depending on the level of the health system. Experience on this scale is still limited, and such large-scale reform would require strong political commitment, as well as close collaboration, by national governments and implementation partners. Whereas this is an ambitious goal and daunting task, the potential benefits of this approach are clear. Patients with debilitating and life-threatening disease could live longer, healthier, and productive lives as a result of accessible and appropriate health services, as do so many people currently living with HIV. Health care systems could avoid the balkanization of health services, dependent on separate and unreliable vertical funding streams, and provide more efficient and effective integrated systems for chronic care.58,59 This vision for care and treatment of chronic disease is within our reach if the lessons from HIV/AIDS can be properly realized and leveraged.

References
