Echoing the Lessons of HIV

How to Serve the Millions with Cardiovascular Disease

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Millions of people around the world die from complications of diabetes, a disease that has been treatable for a century. But poor countries with weak health systems are ill-equipped to deal with the growing problem. The questions are daunting: How can people learn about diabetes and when to seek care? How can countries provide access to low-cost diagnostic testing, affordable medications and effective counseling to help people manage high blood sugar? How can health workers reach and treat far-flung people with limited means? Because diabetes is a chronic disease, there is another critical challenge: How can health systems provide care over a lifetime? In 2010, when health professionals gathered in South Africa to discuss diabetes, their frustration was palpable.

One aspect of the situation was eerily familiar to the HIV experts in the room. Their colleagues who were trying to tackle the diabetes problem were focusing their energies on underfunded and fragmented attempts to treat individual patients, while making little headway on the big picture—the systems and strategies needed to diagnose and treat millions with the disease. “History is repeating itself,” murmured these HIV specialists amongst themselves—and not just with diabetes. Across the world, the same pattern is also playing out for other chronic conditions, including heart disease, lung diseases and others.

Heart disease is the world’s leading cause of death, killing 17 million people in 2008. The World Health Organization (WHO) notes that heart disease deaths are increasing “astonishingly fast” in low- and middle-income countries, where the disease strikes young adults as well as the elderly. Forty-two percent of those who die from heart disease in poor countries do so before age 60, compared with only 4 percent in wealthy countries. These deaths ripple out across society, shattering families and communities, reducing productivity and slowing economic growth.

At first glance, this “slow-motion emergency” of chronic illness seems to have little in common with the explosive devastation of the HIV/AIDS epidemic. In fact, there are many similarities. In both cases, millions of people are in need of diagnosis and lifelong treatment in countries lacking health workers, medications, infrastructure and the systems and policies needed to address a complex and large-scale health crisis. And chronic care, over years and decades instead of hours or days, is dramatically different from shorter-term health interventions, such as immunizations, care for pregnant women or treatment of acute infections, such as pneumonia or diarrhea.

Whether facing an infectious chronic disease like HIV or noninfectious chronic diseases like diabetes and heart disease, health systems need to deliver the same essential services. Patients need information, easily accessible testing and long-term, high quality care from well-trained, available health workers. And health systems must be guided by effective, humane and equitable policies based on the best available evidence.
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### THE PATIENT’S PERSPECTIVE

*Individuals with chronic conditions need to:*

- Interact with the health system on a regular basis, often for life.
- Follow up with medical appointments and laboratory testing.
- Sustain healthy behaviors, such as treatment adherence, healthy nutrition, and smoking cessation.
- Access psychosocial support services to assist with the emotional, financial and social impact of chronic illness.

### THE SYSTEM’S PERSPECTIVE

*Health systems providing chronic care services need to:

- Diagnose patients and enroll them in care and treatment programs by: identifying risk factors; developing simplified and standardized diagnostic protocols; decentralizing diagnostic technologies; using swift diagnostic tests that do not require specialized laboratories; and educating communities about risk and treatment.
- Enhance retention in care and adherence to treatment by: developing appointment systems; identifying people who miss appointments and reaching out to re-engage them in care; training patients to provide education and support to their peers; securing medication supply chains; and enhancing support for pharmacies and their staff.
- Help patients to complete referrals to clinics, laboratories, pharmacies and other appointments by: providing reminders, transportation and/or someone to accompany them to appointments.
- Improve medical records and program data by: developing medical charts and simple tools (such as flowsheets) to help providers manage patients over time; and identifying a few standardized and robust indicators to evaluate program performance.
- Make care more acceptable, effective and efficient by: identifying opportunities for task shifting and task sharing; attending to the needs of families as well as individuals; and ensuring access to both clinical and psychosocial care.

### SOURCE: Rabkin M., Goosby E., El-Sadr W.M., 2014

Given these similarities, public health experts have recognized that the lessons learned in crafting an effective response to the HIV epidemic can be applied to other chronic disease programs. Rather than “reinventing the wheel,” countries may be able to jump-start programs for heart disease by building on these lessons.

### THE HISTORY OF THE HIV RESPONSE

Twenty-five million people have died from HIV/AIDS over the last 30 years, devastating families and communities across the globe. Effective treatment was available in wealthy countries by the late 1990s; a decade later its use was widespread, and the average survival for people with HIV rose from less than six months to more than 20 years. But the vast majority of people living with HIV in lower-income countries continued to go untreated: In 2003, only 400,000 had access to lifesaving treatment. The scale-up of HIV services presented a formidable challenge to the global community.

At the time, innovative programs showed that HIV treatment could be successfully provided in poorer countries. In 2001, Doctors Without Borders, an international medical humanitarian group, worked with the primary health centers of the Khayelitsha Township in Cape Town, South Africa, offering HIV care and antiretroviral treatment to people with advanced HIV infection. On the other side of the globe in Haiti, the Haitian Group for the study of Kaposi’s Sarcoma and Opportunistic Infections (GHESKIO) teamed up with Partners in Health, a nongovernmental organization based in Boston, to run a program that also provided comprehensive care for HIV/AIDS and related illnesses.

Shortly thereafter, Columbia University’s Mailman School of Public Health launched the MTCT-Plus Initiative, a program designed to demonstrate the feasibility of HIV care and treatment in low-income countries. This initiative offered HIV services to pregnant, HIV-infected women and their families in eight African and Asian countries, ensuring the health of individuals and families while preventing mother-to-child transmission of the virus. The Pangaea Global AIDS Foundation supported testing, prevention and treatment programs in Rwanda and Uganda. And slowly but surely, programs in impoverished communities around the world changed the way people thought about the disease. Together, these groundbreaking programs provided “proof of concept” that HIV/AIDS could be treated in some of the poorest places in the world.

The fact that millions of people were dying from a treatable condition inspired a historic movement for universal access to HIV treatment, and the response was profound. The Global Fund to Fight AIDS, Tuberculosis and Malaria was established in 2002 and the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) was launched in 2003, with $15 billion targeted for lower-income countries. These two initiatives signaled a transformation in support from the global community.

But money alone could not have stemmed the tide of the HIV epidemic. Health ministries and public health practitioners had to develop and introduce innovative ways to bring treatment to millions of people in countries with severe shortages of health workers, drug supply systems, laboratories and clinics. They engaged more personnel and brought testing, diagnosis
and treatment to people’s doorsteps. They navigated political imperatives and trade regulations to ensure access to low-cost and generic drugs. They put information systems in place to record and follow patients over time—and to track each program’s performance. And importantly, these efforts were incorporated into national-level strategies rather than functioning as stand-alone programs.

The results were remarkable: By the end of 2013, 9.7 million people in low- and middle-income countries had access to antiretroviral drugs. Although there is still a long way to go toward universal availability, enough progress has been made that the Joint United Nations Programme on HIV/AIDS (UNAIDS) has embraced a new goal of “zero new infections, zero discrimination and zero AIDS-related deaths.” Amidst that success are lessons on how to expand access to treatment for heart disease, diabetes and other chronic illnesses in the developing world.

THE PUBLIC HEALTH APPROACH

Many of the nations hardest hit by HIV have fragile health systems. Yet over the past decade, many of these countries have created their first large-scale chronic disease programs to successfully extend HIV services to millions in need. While other health assistance programs had historically focused largely on procurement—buying contraceptives or vaccines—the global investment in HIV programming launched one of the first large-scale, multifaceted chronic disease initiatives in history.

The key was to use a “public health approach” to service delivery. Public health focuses on big-picture thinking, bringing a population-level perspective to health challenges. Public health programs are designed to reach entire communities and countries with prevention, care and treatment services, in contrast to a “medical approach” in which efforts are focused on people who come to a clinic or hospital for care.

Access to effective medical care is, of course, critical to any health program. But where the medical model often starts with the sick patient who has come to a health facility, the public health model views such a patient as the tip of the iceberg—representing thousands more who have risk factors for an illness but have not yet acquired it, those who have the illness but do not yet have symptoms and those who have symptoms but are unable to reach help.

A program using the medical model might concentrate on how to help a young man with HIV coming to a clinic with a fever and a cough or his mother visiting a hospital with high blood pressure. In contrast, a program using a public health model would provide treatment for these patients, but would also bring services to community members who have not come to a health facility, including education about disease prevention (providing counseling on safer sex to prevent HIV or heart-healthy eating at schools, churches and community centers to prevent heart disease); diagnostic testing (providing screening for HIV or high blood pressure using mobile vans or local community health workers); and linkages to health services (providing information about when to seek care or assistance with transportation costs).

With this public health perspective, the architects of HIV scale-up realized that business as usual was not an option. In order to reach millions, things would need to change. Providing HIV treatment could not be limited to doctors. Engagement of patients and communities was a priority. Fragmented approaches would have to be coordinated. And standardized and streamlined guidelines and protocols were necessary.

MOVING BEYOND PHYSICIANS: TASK SHIFTING AND COMMUNITY ENGAGEMENT

More than 50 countries—including many of those hardest hit by HIV and heart disease—have what WHO describes as a “critical health workforce shortage,” with fewer than 23 doctors, nurses and midwives for every 10,000 people. Malawi, for example, has just one doctor per 50,000 people, compared with the United States, which has one per 390 people. Compounding the problem, most Malawian physicians live and practice in cities, beyond the reach of rural populations. More than a billion people will never see a health worker in their lives.

Given these statistics, it is clear that services delivered only by doctors will never reach the millions in need. A critical step in addressing HIV/AIDS was the recognition that other clinicians—nurses, medical officers, community health workers and trained laypeople—could effectively deliver HIV services. Because these clinicians are more plentiful and less concentrated in urban areas, shifting tasks away from doctors to other types of health workers—particularly nurses—has enabled some countries to reach many more people with lifesaving health services. And research shows that even complex protocols, such as administering antiretroviral drugs, can be delivered by nurses, rather than doctors, without sacrificing quality or health outcomes. By changing regulations about who can provide HIV treatment, some countries have swiftly increased the number of patients who can be treated—an approach that could also be used for heart disease and other chronic illnesses.

In order to be effective, chronic disease services need to be delivered in homes and communities as well as clinics and hospitals. Community leaders, community-based organizations, faith-based organizations and advocacy groups for people living with chronic illnesses are essential partners. In many countries, people living with HIV now work as “expert patients,” providing coun-
counseling and assistance to newly diagnosed peers. Community health workers provide ongoing emotional and practical support to patients and families, encouraging them to continue taking their medications and attending their appointments at the local health facility. Local organizations provide outreach, education and information about HIV, encouraging people to be tested and combatting stigma. New technologies, such as mobile phones, can be used to provide services and support from a distance. For example, HIV programs in Kenya use SMS text messages to remind patients to take their medications; people who were sent the texts did better than those who did not receive them.

STREAMLINING AND STANDARDIZING SERVICE DELIVERY

As funding for HIV services became available, governments quickly realized the dangers of fragmentation. It was not unusual to find two clinics, mere miles apart, using different forms, treatment algorithms and monitoring systems to treat the same disease. Although diversity can certainly breed innovation, it can also overwhelm fragile health systems by creating duplicated efforts, mixed messages, incompatible data and unsustainable programs. In 2003, UNAIDS proposed the “Three Ones” principles, which state that each country should have only one HIV/AIDS action framework, one national HIV/AIDS coordinating authority and one country-level monitoring and evaluation system.

If asked to describe the components of a health care program, most people would think of the health worker, the medications and the clinic or hospital where the services are provided. But behind the intersection of patient and clinician or doctor lies a health system. Medicines need to be ordered, paid for and transported to health facilities across the country. Laboratories need to be equipped, pharmacies need to be stocked, clinics need to be staffed and staff need to be trained, supervised and paid. Records need to be kept and new supplies ordered on time. And in order to do all of these things rapidly, effectively and at scale, systems need to be as simple
as possible—and standardized throughout the country.

Large, public health-scale programs need the support of national policies and step-by-step guidelines that establish evidence-based, cost-effective protocols at every level of the health system: prevention, screening, diagnosis, treatment and support. For example, a national system might identify the “essential minimum package” of HIV (for diabetes or heart disease) services that every program should provide to every patient. These guidelines can help program planners calculate staffing needs, purchase equipment, design monitoring and evaluation systems and provide standardized training to large numbers of clinicians, counselors, pharmacists and lab technicians.

LEVERAGING LESSONS FROM HIV

Health ministries and program planners in lower-income countries are facing a daunting challenge when it comes to heart disease. Patients who seek services are just the tip of the iceberg. Behind them, tens of thousands of people remain unaware of what may be a life-threatening problem, living with unexplained symptoms, possibly unable to seek help or afflicted by asymptomatic conditions that remain invisible to them—and to the health system. To identify and help these individuals, successful programs must maximize outreach by engaging patients and communities, launching large-scale health programs to diagnose people with heart disease and providing lifelong care to large numbers of people.

Addressing the epidemic of heart disease requires urgent and widespread intervention, and may move faster and more effectively by leveraging lessons learned from HIV programs and the public health approach they spearheaded. Creating simple and standardized guidelines—step-by-step instructions—for heart disease prevention, care and treatment would enable countries to run large programs efficiently and well. National heart disease programs could streamline and coordinate efforts using the “three ones” approach and by adapting already-existing tools and systems developed for HIV programs. Program managers could adapt HIV appointment systems, medical records and charting tools as well as strategies for tracking and supporting patients. Making simple diagnostics available and empowering nurses and other clinicians to prescribe and manage medications for heart disease and its risk factors would greatly facilitate diagnosis and treatment, especially in rural areas. And the involvement of patients and communities could be as effective for heart disease as it was for HIV.

Another strategy is to expand HIV programs into “chronic care clinics” that provide services for multiple chronic diseases. One program in Cambodia treats patients with HIV, diabetes and hypertension in the same clinics, using the same tools and medical record systems for all three conditions. A clinic in Uganda uses the same staff and systems to provide services for HIV on some days and for diabetes and heart disease the rest of the week.

Clearly, there are some important differences between the HIV and heart disease epidemics. Stigma is more of a challenge with HIV than with heart disease. In some countries, heart disease is more widespread than HIV, requiring broader outreach and different approaches. And a critical element in the success of HIV programs in low-income countries is that services are usually free to patients. Out-of-pocket fees and co-payments, no matter how small, have been clearly shown to reduce the likelihood that people will continue long-term treatment. Providing services free of charge and/or expanding low-cost or subsidized health insurance will greatly facilitate the fight against heart disease.

One of the most notable differences between the two epidemics is that they receive dramatically different amounts of funding. While official development assistance for the HIV response runs into the billions of dollars, funding for heart disease and other noncommunicable diseases remains extremely limited. According to the Center for Global Development, less than 3 percent of overall global assistance for health in 2007 went to chronic diseases, just $503 million out of $22 billion. Without additional resources, it will not be possible to scale up services for heart disease and to translate the lessons learned from HIV programs into action.

Overall, heart disease programs can benefit from the huge investments in HIV prevention, care and treatment programs. The global investment in HIV programming expanded health care programs; catalyzed health system innovations, such as empowering nurses and other professionals; decentralized services to reach people who previously had limited access to quality health care; and provided the analysis and evidence needed to demonstrate successful approaches to chronic disease services in lower-income countries. In this way, the response to HIV offers a critical platform to propel a rapid, effective scale-up of preventive and curative services to reach the millions who need them.

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