

Lessons From Harlem: Relevance to a Global Epidemic

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Abstract: The HIV epidemic has challenged health systems around the world, including those in resource-rich countries. In Harlem, a disenfranchised community in New York City, poverty, mistrust of health care providers, and a frail health care system ill equipped to handle a chronic disease with profound psychosocial elements challenged the ability to mount an effective response to HIV. A step-by-step effort, initially conceptualized as an emergency response, was followed by a systematic approach to strengthen the health system and shape it to address the unique characteristics of the disease and the needs of the community. Lessons learned from this effort have been applied to other health threats in the community and could inform the global response to HIV.

Key Words: antiretroviral therapy, Harlem, health systems, HIV/AIDS, stigma, sub-Saharan Africa

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The global rollout of HIV care and treatment in low-resource, high-prevalence settings has been viewed as a response to a public health crisis. An emergency response was justified to confront this historic catastrophe. With more than 33 million people living with HIV infection and more than 2 million deaths attributed to HIV/AIDS annually, the urgency of preventing new infections and providing effective care and treatment warrants a rapid and effective response on the part of donors, national governments, and health care systems.^{1,2} Employing this emergency approach has enabled more than 3 million people worldwide to initiate antiretroviral therapy in an astonishingly short period of time while thousands more continue to access this lifesaving treatment each day.^{1–3} Although these remarkable achievements deserve acknowledgement and celebration, millions more have yet to access treatment, and for the millions engaged in care or who have initiated treatment, there is a need to assure access to lifelong health care services. Thus, an emergency response must continue in conjunction with efforts to establish durable, sustainable programs.

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How best to transform this emergency response into sustainable programs for this chronic hitherto incurable condition is an evolving effort. A transformation of health care systems is necessary from the current focus on acute care into systems that provide for the multiple health and psychosocial needs of adults, children, and families on an ongoing basis.

For many in resource-limited countries, it is difficult to imagine that resource-rich countries could have faced challenges similar to those they now confront with HIV. However, in central Harlem in New York City in the early 1980s, families were already grappling with multiple personal and societal challenges when HIV first appeared in the community. These included poverty, high rates of unemployment, teenage pregnancy, homelessness, alcohol and drug abuse, crime, poorly funded schools, and deteriorating housing stock. The image of Harlem as the historic center of black American culture and heritage had been eclipsed by a dark vision of dangerous streets, crime-ridden low-income housing projects, and doorways filled with drug users and drug dealers.^{4–7} Although AIDS cases were being reported in major US cities among gay men,^{8,9} men and women who used intravenous drugs were the first to succumb to this new disease¹⁰ at Harlem Hospital, the institution where we worked. By the late 1980s, HIV spread beyond gay men and intravenous drug users to involve whole families, including men, women, and children. Harlem became an epicenter for HIV infection, with amongst the highest seroprevalence rates in the United States. Of all women delivering babies at Harlem Hospital, between 3% and 5% were HIV infected, a seroprevalence rate triple that of New York City and 30 times higher than that of the national newborn population.^{11–13} The confluence of worsening social conditions in the community, the neglect and deterioration of tuberculosis control programs, and the increased vulnerability of people living with HIV led to a resurgence of tuberculosis, with rates in Harlem that again were several fold higher than those in New York City or the country as a whole.^{14,15}

The community response to HIV was laced with denial and distrust. Because HIV was perceived as a solely homosexual disease, people were slow to recognize that HIV would become one more trauma tearing the fabric of their already disenfranchised community. The infamous Tuskegee experiments had left an enduring legacy of distrust, not only of research but of the health care establishment as a whole.^{16,17} Denial, stigma, and discrimination kept people from learning their HIV status and accessing care. Exemplifying this mistrust was a widely held belief that death from AIDS was caused by zidovudine, the first available antiretroviral drug, rather than a result of advanced HIV disease.¹⁸

Discrimination was evident in how patients were treated even within health care facilities. Pregnant women with HIV admitted to labor wards were kept in isolation and their meals pushed across the threshold of their rooms by hospital staff wearing gloves, masks, and gowns. As for HIV-infected children, neither the foster care system nor the community was prepared to care for them or to properly address their medical and social needs. Many children became “boarder babies” spending months to years living on hospital wards.^{19,20}

Not unlike the experience in Africa, our early work at Harlem Hospital could be described as an emergency response to establish the most basic systems to identify HIV-infected individuals, manage life-threatening disease complications, and provide the few medications then available for treating HIV and, when treatments failed, pain management and end-of-life care. The health care system in Harlem was frail and maladapted to address the challenge posed by HIV. The unique characteristics of this condition, in addition to the community context and existing health care systems and practices, were critical to take into account in shaping the response. HIV causes multiorgan dysfunction warranting a holistic approach to the management of the disease. Its chronic nature and the multitude of its effects required the development of systems capable of providing continuity long-term care rather than those better suited to a short-term curative approach. Simple but fundamental issues such as the need to establish a dependable appointment system were explored and mechanisms established to ensure that patients would be consistently seen by the same provider. The multiple psychosocial dimensions of HIV had to be considered as well. Adults and children with HIV must cope with the psychological impact of having a stigmatized, chronic, and ultimately fatal disease that requires multiple daily medications, laboratory monitoring, medical visits, and trust of and reliance upon health care providers. As a result, it was necessary to enhance the few available psychosocial components of the clinical care structure. Finally, HIV, unlike most other infections, is transmitted within families, from mothers to their babies, between sexual partners, and, not infrequently, across generations within families made vulnerable by poverty and substance use. As in many African communities, bereaved grandmothers in Harlem witnessed the deaths of their sons and daughters and were left to care for grandchildren, who were often infected as well.¹⁹ These challenges compelled us to think beyond the walls of the institution to reach out to individuals and families in their homes, seeking to provide them with information and support and to link them to the few services available early in the epidemic and to enable them to take an active role in management of their health.

Incrementally, as both funding and effective therapies became available, we built systems and programs to care for large numbers of children, adults, and families living with HIV infection, successfully shifting from emergency management to a menu of programs responsive to the patient community's multiple complex medical and psychosocial needs. Step by step, we assembled teams of health providers with a variety of skills capable of addressing the full range of the biomedical and psychosocial needs of the patients and their families. Nurses, nutritionists, pharmacists, physicians, social workers,

counselors, and outreach workers met weekly as multidisciplinary teams to share their learning, insights, and collaborative patient management plans. Hierarchies within and between disciplines were vanquished. Cross-disciplinary activities were also initiated, bringing together obstetric, pediatric, and adult-medicine providers to discuss management of the health of pregnant women, their newborns, and their families.

The availability of increasingly effective antiretroviral therapies had a considerable impact. It resulted in a dramatic increase in the demand for and acceptance of HIV care and provided a new platform on which to build programs. However, successful engagement of patients in long-term care required more than medications. It required addressing the tangible needs of our patients, most of whom were very poor, with fragile social networks and many other complicating challenges, such as substance abuse, mental illness, and homelessness. Addressing food security, housing, and employment by building programs or linking to community-based activities enabled us to help families cope with many of their issues. In addition, creative methods were considered to make it easier for patients to adhere to multiple appointments and daily medications. Appointment systems, flexible clinic hours (including weekends and evenings), telephone reminders before clinic appointments, availability of providers during evenings and weekends by phone, tracking of missed appointments, and home visits—now considered routine in most clinics—were innovations that both staff and patients came to value and rely on.

We also witnessed the transformative power of people living with HIV when actively engaged as peer educators to work within multidisciplinary teams. In our first peer program at Harlem Hospital, “Positive Links,” we learned of their ability to communicate their experiences and to listen and understand the experiences of others. Supporting adherence and engagement in care, these peer educators relieved some of the burden on nurses attending to large numbers of patients with complex medical problems and at the same time highlighted and demonstrated the critical importance of both addressing both psychosocial and biomedical needs to ensure optimal health outcomes. The peers' inclusion in health services reverberated beyond the hospital campus: by openly and publicly acknowledging their HIV status, they contributed to the reduction of stigma and discrimination associated with HIV within the community. Slowly, but with great determination, people with HIV became the critical voice in shaping their own health care system, guiding program development, pointing to gaps in services, and demanding high-quality care.

Many more components were incrementally added to the model of care at Harlem Hospital in response to the population's emerging health concerns. Increasingly, we recognized the importance of addressing the holistic needs of the family in addition to those of the individual patient. For example, when we observed that mothers unwilling to come to clinic for their own health diligently brought their babies for care, we established a mother-baby clinic to allow parent and child to be seen together. Over time, to address the needs of those with mental illness, mental health services were

enhanced and a variety of counseling services and support groups organized for both adults and children. Harm reduction and drug treatment were vital components of the mosaic of services. And as both adult and pediatric populations aged and new clinical and psychosocial challenges arose, a special clinic was established to address the needs of adolescents transitioning into adulthood, and nutrition programs gained particular importance to manage risk factors and address cardiovascular disease and diabetes.

In hindsight, a transformation of the way health services were organized in Harlem resulted from HIV, in response to the unique features of this disease and urged by the profound needs of individuals and families affected by it. The question remains as to whether this response has had any impact on the response to other health threats. It is possible that the recent restructuring of asthma programs for children may have been informed by insights from the HIV response, conceptualizing it as a family disease with profound psychosocial elements.^{21,22} The rallying of community members around the cause of a clean environment and their vigorous challenge to established interests demonstrates the voice of advocacy reminiscent of the AIDS activist community.²³

Is it possible that there was a silver lining to the HIV epidemic? Although it has devastated some of the most vulnerable communities in the world, its unique characteristics have compelled us to reconsider and revamp the structure and function of health care systems.²⁴ The early experience in Harlem may yet prove valuable as the world grapples with how best to respond to HIV.

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