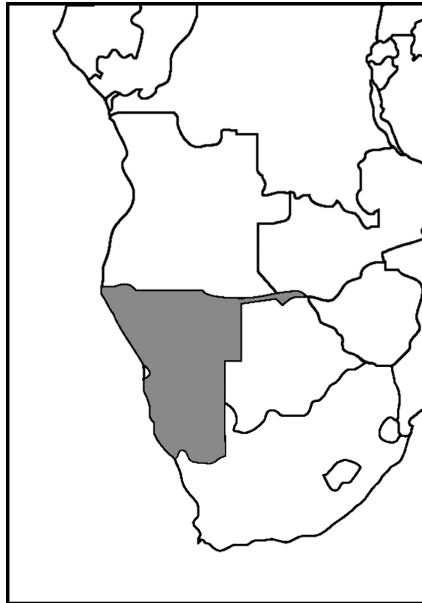


10

Namibia

Lessons from Patient Involvement in HIV Care: A Paradigm for Patient Activation and Involvement across Health Systems

Bruce Agins, Joshua Bardfield, Margaret K. Brown, Daniel Tietz, Apollo Basenero, Christine S. Gordon, Ndapewa Hamunime, and Julie Taleni Neidel



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Namibian Data

- Population: 2,479,713
- GDP per capita, PPP: \$10,585.0
- Life expectancy at birth (both sexes): 65.8 years
- Expenditure on health as proportion of GDP: 8.93%
- Estimated inequity, Gini coefficient: 61.0%

Source: All data are from the World Health Organization and World Bank. Latest available data used as of October 2017.

Background

The New York State Department of Health (NYSDOH) AIDS Institute was created in 1983 in response to the AIDS epidemic. The mission of the AIDS Institute is to protect and promote the health of New York State's diverse population through disease surveillance and the provision of quality healthcare, preventative measures, and support services for those impacted by HIV, AIDS, sexually transmitted infections, and viral hepatitis; intravenous drug users; the lesbian, gay, bisexual, and transgender (LGBT) community; and those with related health concerns. This includes eliminating new infections and improving the health and well-being of infected and affected communities. The AIDS Institute's HIV Quality of Care Program, launched in 1992, is responsible for systematically monitoring the quality of medical care and supportive services for people living with HIV (PLWH) in New York State to achieve patient-centered care and positive health outcomes (Agin et al., 1995).

At the epicenter of the AIDS crisis, New York became the birthplace of a vibrant culture of activism among PLWH, driven by a groundbreaking document entitled the "Denver Principles" (UNAIDS, 1983). A central recommendation of the Denver Principles is to involve PLWH at every level of decision making, setting the stage for consumers to provide recommendations in national HIV/AIDS policy and program development, service delivery, and evaluation. Involving consumers in these capacities also provided a basis for the Joint United Nations Programme on HIV and AIDS (UNAIDS) principles of greater involvement of people living with HIV (GIPA) (UNAIDS, 2007) (Figure 10.1).

Figure 10.1 presents the fundamental actions required to realize the rights and responsibilities of PLWH, formalized at the 1994 Paris AIDS Summit and endorsed by the United Nations in 2001.

Patient and Community Involvement

Community engagement and capturing the patient experience is key to understanding priorities for improving care. In low- and middle-income countries (LMICs), patients often have priorities that are very different from those in wealthier nations. For example, patients who prioritize mental health needs or food provision will not adhere to treatment until these needs are addressed. Gaining buy-in from communities and PLWH networks at local, provincial, and national levels or representing key populations is key to the success of improvement activities. Involving the community in code-signing measures and coproducing healthcare enhances participation and contributes important dimensions of quality and related experiences that are not accounted for otherwise.

In the context of LMICs, where patient and community involvement continues to evolve, it is important to examine the core elements of the NYSDOH HIV Quality of Care Program to understand how this model can be adapted—not only to stretch scarce resources to optimize treatment delivery, but also as a core component of a national quality program.

On a global scale, the World Health Organization (WHO) and others are adopting frameworks to ensure that public health systems promote and champion patient involvement as part of the people and family-centered care framework to improve patient outcomes and public health systems (Figure 10.1). As patient and community groups evolve from loosely organized structures into more formal designs, and as their role is integrated into health systems, resources can be stretched even further to bridge gaps in patient care and local capacity, as dedicated disease-specific funding wanes. As HIV-specific patient involvement programs advance, these models can subsequently be leveraged to build patient involvement across the health system. Today, the process of integration is underway in many LMICs, representing a unique opportunity to accelerate patient and community involvement in care.

The benefits and ultimate success of patient and community involvement in healthcare delivery are numerous, not only influencing patients and their families, but also providers and the system (Brett et al., 2014; Groene and Sunol, 2015). Advantages of this approach include better care coordination, improved health literacy, improved flow and self-management, better access to services, improved efficiencies and effectiveness, and improved patient safety (WHO, 2016e) (Figure 10.2).

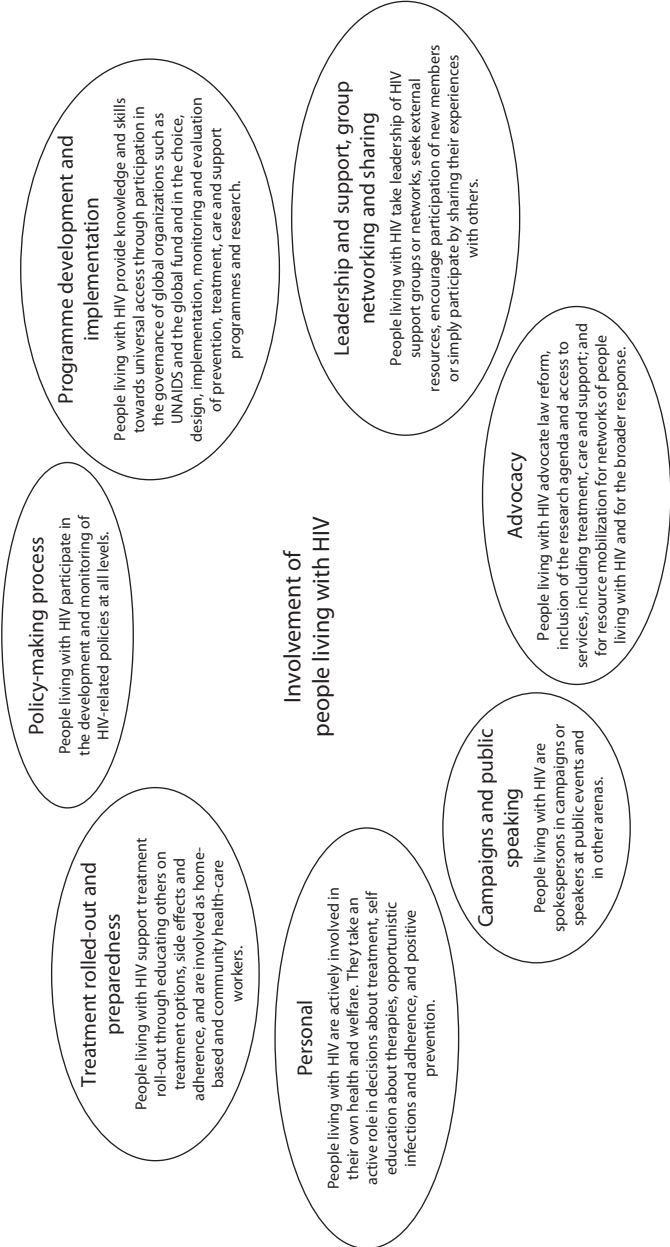


FIGURE 10.1 The greater involvement of people living with HIV (GIPA). (From UNAIDS, UNAIDS policy brief: The greater involvement of people living with HIV (GIPA), 2007. Retrieved from http://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf.)

The potential benefits of integrated people-centred health services	
<p><i>To individuals and their families:</i></p> <ul style="list-style-type: none"> • Improved access and timeliness of care • Better coordination of care across different care settings • Shared decision making with professionals with increased involvement in care planning • Improved health literacy and decision-making skills that promote independence • Increased ability to self-manage and control long-term health conditions • Increased satisfaction with care and better relationships with care providers 	<p><i>To health professionals and community health workers:</i></p> <ul style="list-style-type: none"> • Improved job satisfaction • Improved workloads and reduced burnout • Role enhancement that expands workforce skills so they can assume a wider range of responsibilities • Education and training opportunities to learn new skills, such as working in team-based healthcare environments
<p><i>To communities:</i></p> <ul style="list-style-type: none"> • Improved access to care, particularly for marginalized groups • Improved health outcomes and healthier communities, including greater levels of health-seeking behaviour • Better ability of communities to manage and control infectious diseases and respond to crises • Greater influence and better relationships with care providers that build community awareness and trust in care services • Greater engagement and participatory representation in decision-making about the use of health resources • Clarification of the rights and responsibilities of citizens towards health care • Care that is more responsive to community needs 	<p><i>To health systems:</i></p> <ul style="list-style-type: none"> • Enables a shift in the balance of care so resources are allocated where really needed • Improved equity and enhanced access to care for all • Improved patient safety through reduced medical errors and adverse events • Increased uptake of screening and preventive programmes • Improved diagnostic accuracy and appropriateness and timeliness of referrals • Reduced hospitalizations and lengths of stay through stronger primary and community care services and a better management and coordination of care • Reduced unnecessary use of health care facilities and waiting times for care • Reduced duplication of health investments and services • Reduced overall costs of care per capita • Reduced mortality and morbidity from both infectious and non-communicable disease

FIGURE 10.2 The potential benefits of integrated people-centered health services. (From WHO, Strengthening people-centered health systems in the WHO European region: Framework for action on integrated health services delivery, 2016. Retrieved from <http://www.who.int/servicedeliverysafety/areas/people-centred-care/framework/en/>.)

The Namibian Experience

The experience of Namibia provides an appropriate and insightful illustration of how components of patient and community involvement through a disease-specific program can be integrated into a national quality program at all health systems levels—national, regional, and local—even as implementation continues to evolve and spread.

With a population of approximately 2.4 million, Namibia is an expansive country located in southwestern Africa bordering the Atlantic coast. Namibia's HIV epidemic is generalized: transmission primarily occurs through heterosexual and mother-to-child transmission. The HIV prevalence is 13%, representing approximately 210,000 people over the age of 15 (Ministry of Health and Social Services [Namibia], 2015).

The Ministry of Health and Social Services (MoHSS) conducted a national assessment in 2012 to review the entire quality management (QM) system at health facilities across the country. As part of that assessment, healthcare workers, patients, and community members were interviewed. One specific objective of this review was to explore how patients and the community were involved in quality improvement (QI) activities and to capture their perspectives about quality of care in health facilities. The results of this assessment provided critical insight and facilitated relevant planning for integration of patient and community engagement into the broader health system.

National Level

Recognizing the importance of consumer and community engagement as a part of the new QM directorate, the MoHSS established a subdivision for patient and community engagement. This subdivision is driven by four primary objectives:

1. To establish mechanisms for active involvement of patients in their care
2. To encourage respect and dignified treatment of patients
3. To coordinate efforts to ensure continuity of care, reduction in delays, and access to the package of services
4. To disseminate information related to patient care, patient safety, and community engagement

At the national level, patients are represented in the National QM Steering Committee, where they attend monthly meetings. They have assisted in the development of terms of reference for the program and in updating the annual Quality Management Plan. This work has included establishing a subcommittee to design a consumer satisfaction questionnaire to be tested at

the health facility level, as well as developing guidelines and standard operating procedures around consumer and community involvement.

In January 2016, the MoHSS held QM training sessions for consumers at eight pilot sites, covering basic principles of QI and techniques for engagement. Consumers attended with providers from their agencies and developed plans to activate consumer participation at their respective sites. A formal consumer training curriculum is under review, which will be adapted to the Namibian context. Additional plans include training local PLWH to adapt course content and engaging community-based organizations to facilitate future training sessions.

Consumers are invited to attend regional HIV peer-learning sessions every 6 months with the goal of accelerating their QI knowledge and skills to function at the same level as other health workforce members. A patient charter was recently revised and nationwide patient education on consumer rights and expectations is in the planning stages.

The MoHSS has also engaged a public relations officer who provides health-related information to the public and responds to consumer questions and concerns that emerge either individually or through the media.

Regional Level

Program officers have received training on patient involvement and have attended regional HIV peer-learning sessions together with patients from healthcare facilities. This approach was designed to sensitize and prepare healthcare workers to more fully engage with patients, and to involve patients during regional meetings, such as the regional AIDS Coordinating Committee.

District and Facility Levels

Applying the regional approach at the district and facility levels, healthcare workers have been trained in patient involvement as part of the national QM curriculum. Patients have also gained representation within key administrative and management structures, such as hospital advisory committees, facility QI teams, and constituency coordinating committees.

Patient feedback is routinely solicited using suggestion boxes and through a customer care desk in referral hospitals. Some HIV clinics also engage patient experts to help PLWH navigate the clinical experience.

Namibia exemplifies the way in which a number of LMICs have begun the process of formally engaging patients and the community into routine improvement activities, and as noted, the process of integration is already underway elsewhere. Over the next 10–15 years, it will be critical to harness adaptable components of HIV quality programs, for example, by identifying key elements and considering how they can be integrated, especially for HIV patients who require general medical care and management of

noncommunicable diseases. In the context of patient and community involvement, this includes a list of core components previously described. In LMIC specifically, adaptation and integration will take time and require government structures and regulatory systems to support sustainable implementation. Namibia has made these steps possible through the recently approved QM directorate structure, which governs the national quality program. Patient and community involvement is embedded in administrative structures, technical working groups, and/or committees to ensure adequate management of these groups at various levels of government—local, regional, and national—and alignment of their work with national policies, frameworks, and priorities.

Prospects

Involvement of patients and the community in healthcare delivery is directly linked to the prospect of success of an improvement culture that encompasses the entire public health system, one that can truly improve quality of care and achieve patient outcomes in Namibia and beyond. This continues to be most evident in HIV care, and it will be critical to harness systems in that sector to build patient involvement beyond these disease-specific programs to ensure that similar successes can be achieved in the broader public health system. Namibia is now addressing this need by focusing on building the capacity of consumers to participate in the national QM program through the QM directorate.

Through a combination of leadership, the sensitization of healthcare providers, and the active engagement of consumers, Namibia's health systems can move beyond involvement, creating true partnerships in clinical care where the patient's voice receives equal consideration and is valued and applied in care decisions. Equality would also extend to relevant committees and governing bodies, allowing patient and community concerns to duly influence not only practice, but also policy.

Conclusion

True patient activation and patient-centeredness can only be accomplished by addressing existing challenges, which include transforming the traditional boundaries of the doctor–patient relationship and sensitization to the needs of patients and their role in care beyond token participation. In Namibia, the MoHSS is designing a well-structured approach, which is embedded in an

overall strategy of quality in the health sector. By building the capacity of and empowering consumer representatives to ensure that they understand their roles and responsibilities in care delivery, the MoHSS has committed to reinforcing systems and processes that will facilitate success.

Continued involvement of patients and communities in the improvement process will encourage ownership and further the spread of patient-centered strategies, while increasing the long-term sustainability of changes. Achieving sustainability will require multidisciplinary partnerships within future healthcare systems; adequate structures to support patient-centered care through committees and other formal mechanisms, as previously described; and opportunities to scale up and spread the concepts of patient involvement through training, recognition, and the promotion of success.

