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Meaningful involvement of people living with HIV/AIDS in Uganda through linkages between network groups and health facilities: An evaluation study

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While community-based groups are able to provide vital support to people living with HIV/AIDS (PLHIV), their organizational and technical capacities are limited, and they frequently operate in isolation from PLHIV groups. We evaluated a three-year project implemented by the International HIV/AIDS Alliance in Uganda to increase the involvement of PLHIV in the HIV/AIDS response and to improve access to and utilization of prevention, treatment, care, and support services for households affected by HIV/AIDS. Information sources included project monitoring data, interviews with 113 key informants, and 17 focus group discussions in 11 districts. The evaluation found that PLHIV groups reached large numbers of people with education and awareness activities and made a growing number of referrals to health facilities and community-based services. The project trained individuals living openly with HIV as service providers in the community and at designated health facilities. Their presence helped to reduce the stigma that previously deterred PLHIV from seeking care and encouraged individuals to disclose their HIV status to spouses and family members. The project has put into practice the widely endorsed principles of greater and meaningful involvement of PLHIV in a systematic manner and on a large scale. A wide audience – ranging from grassroots PLHIV networks and AIDS service organizations to national-level non-governmental organizations, government agencies, and international organizations – can benefit from the lessons learned.

Keywords: HIV/AIDS; meaningful involvement of people living with HIV; Uganda; Africa

Introduction

By the end of 2006, an estimated 2.3 million people in Uganda had been infected with human immunodeficiency virus (HIV), with about 1.4 million living with HIV and almost one million having died from AIDS-related illnesses (Ministry of Health [MOH], 2006). Despite efforts by the Government of Uganda and its development partners, many people living with HIV (PLHIV) – i.e. infected with the virus – are

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unable to access HIV treatment, care, and support services because of lack of awareness, long distances to service sites, cost, and stigma, among other factors (Uganda AIDS Commission, 2006).

Greater involvement of people living with HIV

Community-based initiatives that offer material and medical support to local families affected by HIV/AIDS are a common approach to increase access to services. However, these grassroots groups typically have limited organizational and technical capacities and frequently operate in isolation from associations of PLHIV (MOH, 2006). Involving PLHIV in HIV and AIDS services as active agents rather than passive recipients offers many potential benefits. It can improve their self-esteem and decrease their isolation, provide valuable insights to organizations, and combat fear and prejudice. Engaging PLHIV in policymaking and program development and implementation enhances the quality, acceptability, and effectiveness of the AIDS response (Roy & Cain, 2001; Stephens, 2004; UNAIDS, 2007).

The principle of greater involvement of people living with HIV (GIPA) was formalized at the 1994 Paris AIDS Summit and has been endorsed by over 190 countries. GIPA aims to realize the rights and responsibilities of PLHIV, including their right to self-determination and participation in decision-making processes that affect their lives (UNAIDS, 2007). It is important, however, that such involvement is meaningful, not token – giving rise to the companion principle of meaningful involvement of people living with HIV (MIPA). The intensity of PLHIV involvement varies: in theory, individuals living with HIV may support service delivery; design, deliver, and monitor services; manage or lead organizations; serve as advocates or public speakers; and influence policymaking and strategic planning processes (Castle et al., 2002; Horizons Program & International HIV/AIDS Alliance, 2003; UNAIDS, 1999, 2007).

Yet putting the GIPA principle into practice poses challenges. It raises fears about public disclosure of HIV status and the associated stigma towards PLHIV, their families, and friends. There is a dearth of organizations prepared to involve PLHIV, particularly at the health facility level. PLHIV may have limited technical and communication skills. Sustainability is also a concern (De Goei & Groverman, 2009; Morolake, Stephens, & Wellbourn, 2009; Roy & Cain, 2001; UNAIDS, 1999). As a result, official recruitment of PLHIV into the health system is limited. A study of 17 service organizations in Burkina Faso, Ecuador, India, and Zambia found that individuals living with HIV were most commonly involved by accessing and supporting services, for example, by participating in "positive living" courses, support groups, and counseling sessions, and by providing informal peer support and community outreach (Horizons Program & International HIV/AIDS Alliance, 2003). These roles are important. However, the failure to recruit PLHIV to senior positions reflects continuing discrimination and reinforces negative stereotypes about the capacities and abilities of people with HIV (Morolake et al., 2009).

The Networks Project

We conducted a qualitative and analytical process evaluation of a project designed to put the principles of GIPA and MIPA into practice in Uganda. In July 2006, the International HIV/AIDS Alliance in Uganda launched a three-year USAID funded project: "Expanding the Role of Networks of People Living with HIV/AIDS," which sought to:

- increase access to and utilization of prevention, treatment, care, and support services by households affected by HIV/AIDS,
- strengthen the organizational capacity of PLHIV networks, and
- empower and train PLHIV to deliver HIV/AIDS services.

PLHIV groups formed the backbone of the Networks Project (International HIV/AIDS Alliance in Uganda, 2009). They acted as community service delivery points, offering home-based palliative care, adherence counseling, HIV prevention activities, and client tracking. They promoted linkages between the community and health facilities. They also conducted community-based activities, including income generation schemes, the promotion of male involvement, and sensitization in schools.

One of the main goals of the project was to build the capacity of participating PLHIV groups, which totaled 420 at the time of the evaluation. The Alliance organized them into 55 network clusters, with an average of eight groups in each cluster. Alliance staff worked directly with one "lead" group in each cluster, providing training on home-based care and psychosocial support, HIV prevention, financial management, and other key topics. Each lead group, in turn, was responsible for liaising with and building the capacity of the other groups in the cluster. The lead group was also responsible for overseeing innovative activities funded by small grants for which PLHIV groups could apply.

The project also trained selected group members who lived openly with HIV to serve as Network Support Agents (NSAs). When the evaluation took place, there were 1302 NSAs serving 643 health facilities and surrounding communities. NSAs facilitated linkages from the home to the community to the health facility; counseled community members; coordinated referrals to health facilities and other community organizations; and worked alongside providers at designated facilities, receiving clients, conducting education and counseling, and assisting with registration and records.

Methods

Participants and data sources

The evaluation was conducted in 11 of the 40 districts that took part in the Networks Project. Districts were purposely selected to represent each of the five regions in which the project operated as well as high and low performing areas, as defined by project monitoring data on how many services and referrals were provided by PLHIV groups.

The evaluation employed rapid participatory assessment and appraisal techniques and collected information from three sources. A desk review of project documents abstracted service statistics from the annual reports issued by the Alliance in Uganda.

Interviews were conducted with 113 key informants regarding the management and achievements of the project. Key informants were selected for their knowledge of the project and to provide a range of perspectives. They included senior and mid-level managers of the Alliance in Uganda, as well as staff implementing project activities; officials at the Ministry of Health and the Uganda AIDS Commission; district health officers; representatives of district non-governmental organizations; district and local government officials; and service providers – including doctors, nurses, counselors, and the project's NSAs – at randomly selected health facilities.

Sixteen focus group discussions (FGDs) were conducted at the community level in randomly chosen districts: 11 with members of PLHIV groups and five with community members who were not part of PLHIV groups. Eight to 10 people were randomly selected to participate in each FGD. One additional FGD was conducted with the Alliance Advisory Committee. FGDs focused on the reach and effectiveness of project activities, including GIPA and MIPA, and solicited recommendations for improving activities and overall project design.

Procedures

An interviewer/moderator and note-taker were present for each interview and FGD. Interviews and FGDs were audiotaped with the permission of participants. Missing information or inconsistencies were identified and, where possible, promptly followed up, usually during a telephone conversation with the key informant.

Audiotapes were transcribed verbatim. Textual data were explored using content analysis (Riley, 1990). Transcripts were read and re-read to identify emerging themes (Glaser & Strauss, 1967). All information relevant to each theme was examined using the process of constant comparison, in which each item is checked or compared with the rest of the data to establish analytical categories. Typical quotes were selected to highlight responses while preserving the original context.

Results

Access to and utilization of services

The Networks Project has improved access to services in several ways. First, NSAs and PLHIV group members began offering educational and counseling services. Monitoring data show a dramatic increase in the provision of these services. For example, the number of individuals offered antiretroviral therapy adherence counseling and support increased tenfold, from about 17,000 to 170,000, over a one-year period (Table 1). With the assistance of the NSAs, the number of health facilities offering HIV palliative care rose from 43 to all 643 facilities in the project area. Monitoring data indicate that NSAs and other group members provided palliative care to around 70,000 PLHIV in each of the final two years of the project (International HIV/AIDS Alliance in Uganda, 2008).

Second, NSAs mobilized PLHIV to utilize existing services at health facilities as well as wraparound services provided by community-based and non-governmental organizations. During the interviews, health workers said that the referral system operated by the NSAs contributed to a noticeable increase in patient volume. The greatest impact was on voluntary counseling and testing and on accessing antiretrovirals and septrin (cotrimoxazole). Monitoring data confirm an increase in referrals, which rose from 5000 in the fourth quarter of 2007 to over 115,000 in the same period in 2008 (Table 1). Health workers also noted that the NSAs' presence at the health facilities contributed to greater service utilization.

Table 1. Number of client contacts made by PLHIV group members and NSAs.

Service or referral provided	Q3 (2007)	Q4 (2007)	Q1 (2008)	Q2 (2008)	Q3 (2008)	Q4 (2008)
ART literacy and education	30,922	35,124	50,756	326,009	425,233	*
ART adherence counseling and support	17,808	19,251	25,474	120,731	176,784	*
HIV/AIDS follow-up counseling	8365	8332	10,271	77,499	129,936	*
Community follow-up	7529	10,394	10,125	61,075	93,266	*
HIV/AIDS education, awareness, and prevention	55,836	81,762	74,456	500,532	573,295	633,233
Referrals to health facilities and community based services	4956	4649	6023	60,148	78,831	115,819

Note: Figures include people who accessed more than one service and clients who received a service more than once. *Data are not available due to a change in the monitoring form.

> [NSAs] have managed to convince the communities that HIV/AIDS is real, and the people believe them in a way they never believed the health workers. [NSAs] have helped to bridge the gap between the health care system and the community; people are more comfortable coming to the clinics since they know they will be finding their peers at the facility who will show them around. (Interview with Health Unit In-Charge)

Third, NSAs compensated for staffing shortages at health facilities, reducing client wait time and increasing attention to each client.

> Before the Alliance came people used to spend the whole day at the hospital, but these days they don't. The NSAs try to help us go through very fast. Also, people have increased in number coming to the health unit for various services. (FGD with community members)

Fourth, NSAs followed up clients in the community, for example, checking whether they were taking their medication and informing facilities when clients moved away or died.

> [NSAs] are helping a lot because we were few and they have helped us do many things we couldn't handle alone. For example we had failed in the following up of our clients on ART because of [lack of] manpower and now they are doing great here. They also do a lot in following up these patients. We now can tell who died, shifted, and who are alive especially with the defaulters which we were not doing before. (Interview with Health Center HIV Unit In-charge)

Stigma, discrimination, and disclosure

NSAs and other members of PLHIV groups have a wealth of experience dealing with HIV and AIDS as patients, family members, and neighbors. Their empathy and credibility, coupled with counseling skills acquired from the project, helped reduce stigma and discrimination against PLHIV. Previously, this had deterred individuals from seeking care.

> NSAs, unlike the health workers, are able to give the clients some practical experiences in their testimonies – not theory – which they find a lot more believable, getting very encouraged to take on their advice as a consequence. The public [and] community members find the NSAs much more approachable and are able to take them into their confidence. This has fostered confidence in the health system as a result. (Interview with District Medical Officer)

By serving as role models and offering encouragement, NSAs contributed to an increase in the disclosure of HIV-positive status to spouses, family members, PLHIV group members, service providers, and community members. NSAs also emphasized prevention with positives, through which people living with HIV are encouraged to avoid re-infection and to disclose their status (US President's Emergency Plan for AIDS Relief, 2009).

Role and self-image of PLHIV

The Networks Project helped transform the role and self-image of PLHIV, so that they no longer played a passive role as recipients of services, but assumed an active role as service providers in the community and at health facilities. NSAs felt that they had become respected sources of guidance, support, and knowledge on HIV and AIDS.

> We have reduced stigma and gained recognition for what we have done. I got a name as a health worker; any sick person, community people call on me to give advice. (Interview with NSA)

The interviews and FGDs revealed a high level of acceptance of PLHIV participation in HIV/AIDS care and treatment. More broadly, the project facilitated active community engagement and empowerment by enhancing PLHIV networks and facilitating linkages with health facilities and other community institutions. Community members felt a sense of ownership and believed that they were addressing real needs.

Discussion and programmatic implications

Success in achieving GIPA and MIPA principles

A recent exploratory study in over a dozen countries found little awareness and visibility of GIPA among PLHIV organizations, government institutions, and development organizations (De Goei & Groverman, 2009). These organizations often did not understand what GIPA is and how it could be applied.

The Networks Project supplied these essentials and largely succeeded in enhancing the involvement of PLHIV in service delivery, but it has not yet achieved the highest possible levels of GIPA. Of the seven categories of PLHIV involvement described by UNAIDS (2007), the Networks Project emphasized and was most successful in four: personal well-being; treatment roll-out and preparedness; leadership and support group networking; and sharing and advocacy. The project did less to advance the remaining three categories: campaigning and public speaking; policymaking; and program development and implementation.

Another way to analyze the project's achievements with regard to GIPA and MIPA is based on the intensity of PLHIV involvement, as described by the Population Council's Horizons Program and the International HIV/AIDS Alliance (2003). Intensity ranges from access (if PLHIV are simply using services), to inclusion (if they help with an organization's non-HIV related tasks and deliver services informally or occasionally), to participation (if they help plan and deliver services on a regular basis), and culminates in greater involvement (if they have influence over day-to-day management, policymaking, and strategic planning). The Networks Project reached the third level of intensity – regular participation in service delivery – by deploying NSAs to health facilities and exceeded levels of involvement found in Burkina Faso, Ecuador, India, and Zambia (Horizons Program & International HIV/AIDS Alliance, 2003).

The Networks Project appears to be following the model of Thailand, where the GIPA principle has been fully realized. Since the 1990s, PLHIV groups in Thailand have moved from offering psychological support and income generation to the provision of comprehensive services, including antiretrovirals, in collaboration with local health facilities. In the process, the Thai groups encouraged the social normalization of HIV and public disclosure of HIV status – as the Networks Project is doing. More recently, PLHIV groups in Thailand have become involved in advocating for basic rights to health and social equity at the provincial and national levels (Lyttleton, Beesey, & Sitthikriengkrai, 2007).

Promising practices

According to the aforementioned exploratory study, capacity building is essential if GIPA is to be realized (De Goei & Groverman, 2009). The Networks Project offers several promising practices for the organizational development of PLHIV networks.

Organizing the hundreds of PLHIV groups into small clusters, each with a designated lead group, was instrumental in extending the reach of capacity-building efforts. The approach helped roll out training in home- and community-based care, which resulted in greater access to and utilization of these services. Further, delivery of services by PLHIV to PLHIV heightened the sense of community ownership and the belief that services were addressing local needs.

Giving NSAs the opportunity to work in health facilities also built capacity and intensified PLHIV involvement in service delivery. The project trained NSAs on counseling skills and key HIV and AIDS-related topics, including antiretrovirals, tuberculosis, and nutrition. NSAs attended a refresher course twice a year and received supervision and on-the-job training from health workers at the facilities. The heads of these facilities verified the NSAs' service delivery reports. This approach enabled the NSAs to fully participate as members of the health team at facilities.

The NSAs also worked in the communities, where they provided a link to health facilities by making referrals, providing ongoing care to clients after they visited a facility, and tracing clients lost to follow-up. Because NSAs live openly and positively with HIV, their presence in the community helped encourage open communication and reduced the stigma that has historically deterred people with HIV from seeking care. A study of almost 15,000 PLHIV in sub-Saharan Africa and Thailand found that making services and resources available at the community level, as the Networks Project did, can shield against stigma and discrimination by relieving the burden borne by families and communities and reducing physical signs and symptoms of disease (Maman et al., 2009). In addition, NSAs may have contributed simply by breaking the silence surrounding HIV, as increased communication about HIV is associated with increased uptake of HIV testing services (Hendriksen et al., 2009). Other research in Uganda also has pointed to the importance of social support for PLHIV (Green, Atuyambe, Ssali, Ryan, & Wagner, 2010).

The job of NSA combines the roles of two different positions in the Alliance's earlier Zambia project. In that project, different individuals worked at antiretroviral therapy clinics and served as links between community partners and the clinics (Horizons Program & International HIV/AIDS Alliance, 2008). Combining the two roles is likely to have strengthened the linkage between the community and the clinic and also provided for the kind of follow-up that is essential to a true continuum of care.

Areas requiring strengthening

The project did not achieve all seven GIPA/MIPA principles. Experiences in other African countries found that success is more likely when communities are proactively involved in responding to the HIV/AIDS epidemic (Horizons Program & International HIV/AIDS Alliance, 2003). For this reason, involving people living with HIV in project development and implementation, as well as policy and advocacy, are crucial in improving a project's relevance, acceptability, and effectiveness. Future projects should promote PLHIV involvement in campaigning and public speaking as well as policymaking and program development and implementation.

Conclusion

The Networks Project has put into practice the widely endorsed principles of greater and meaningful involvement of people living with HIV in a systematic manner and on a large scale. A wide audience – ranging from grassroots PLHIV networks and AIDS service organizations to national non-governmental organizations, government agencies, and international organizations – can benefit from the lessons learned regarding the development of PLHIV networks. Promising practices include clustering PLHIV groups for the purpose of capacity building and recruiting individuals who live openly with HIV to offer services both in the community and at health facilities.

Building capacity and designing strategies to involve PLHIV at all levels is not easy. The International HIV/AIDS Alliance has drawn upon learning from the Networks Project and its work in other countries to develop a tool to assist the planning, implementation, and evaluation of HIV programs to meaningfully engage people living with HIV (International HIV/AIDS Alliance & GNP+, 2010).

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