Only connect – the role of PLHIV group networks in increasing the effectiveness of Ugandan HIV services

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In recent years, Uganda has experienced rapid growth in networked groups of people living with HIV (PLHIV) who provide support, engage in advocacy, treatment and care and raise the profile of HIV in the public domain. This qualitative study focused the benefits of joining a networked group, relationships between groups, impact of networked groups on the community and shaping private and public experience living with HIV. Data were collected from two Ugandan districts, using semi-structured interviews, focus group discussions (FGDs), observation and reviews of group records and archives. Respondents ($n = 46$) were adults living with HIV, and members of rural and urban PLHIV groups. Narratives from PLHIV ($n = 27$) were gathered, and records from PLHIV group service-registers ($n = 20$) reviewed. Key Informants ($n = 15$) were purposively selected for interview, based on participation in PLHIV groups, utilisation of network services and their positions as key stakeholders. FGDs were held with network support agents (NSAs), members of PLHIV groups, and their leaders. Following qualitative analysis, findings suggest that for respondents, PLHIV networks enhance the impact and effectiveness of individual groups: the whole is greater than the sum of the parts. For groups, being part of a wider network allows for diversity of service delivery, and well-defined roles for individuals to participate in community support and sensitisation, with a reduction in the experience of stigma. We conclude that networking PLHIV groups is an effective strategy for improving the quality and reach of community-based HIV services. Governments should be encouraged to support networks and include them in policy-making at the national level. Local and regional groups should explore further ways to collaborate and expand support to PLHIV in Uganda.

Keywords: networks; PLHIV; disclosure; health systems strengthening; HIV care

Introduction

Background

In Uganda, HIV prevalence and antiretroviral treatment (ART) coverage of those eligible is estimated at 6.5% and 39%, respectively (UNAIDS, 2010; World Health Organisation, 2010). In 2004, when Uganda first introduced ART, capacity for supporting counselling, testing and non-discriminatory care for people living with HIV (PLHIV) was limited (STD/AIDS Control Programme, 2007). There were significant levels of stigma, discrimination and other factors limiting access to HIV services.

Networks of PLHIV offer a key mechanism for enhancing support to those who are affected, and ameliorating negative experiences of living with HIV (Odhiambo & Gatua, 2008). As programmes encourage greater involvement of PLHIV (GIPA) (UNAIDS, 2007), there is increasing engagement of affected communities in national responses to HIV,

and PLHIV networks have the potential to maximise stakeholder contributions. In addition, approaches that increase engagement and empowerment can potentially shift the focus of PLHIV's roles from representation to the building of individual and community capacity to promote health (Kielmann & Cataldo, 2010).

The role of PLHIV networks in communities

Networks are social mechanisms connecting existing groups of PLHIV together, and to other systems including health services. Networks increase the potential for effective capacity building, communication and advocacy. Improved service access and autonomy of marginalised groups has been achieved in other contexts through pooling capacity and support, for example women's empowerment in India (APMAS, 2005). However, as Shumate, Fulk, and Monge (2005) show in their study of networking

between international HIV NGOs, competition for resources may stifle cooperation and divide rather than unite groups.

Nevertheless, literature suggests that networks are more than the sum of their parts, and influence the impact of individual PLHIV groups (Grbic et al., 2008; Health Policy Initiative-Task Order 1, 2009; International HIV/AIDS Alliance, 2009; USAID, 2007). Influential networks are becoming essential components of successful, owned and coordinated provision of HIV services for PLHIV (Wall et al., 2012).

Networking promotes a holistic, horizontal approach, often negating the constant risk of vertical, restrictive mechanisms, which deny the full range of assistance. Networks improve access to counselling and testing (Wall et al., 2012); ART and health services (International HIV/AIDS Alliance, 2009); promote advocacy and reduce stigma (Odhiambo & Gatua, 2008), and assist in disclosure (Medley, Kennedy, Lunyolo, & Sweat, 2009). Disclosure can have a significant impact on stigma, through declaration of HIV status and delivery of HIV prevention messages by PLHIV (Asia Pacific Network of People Living with HIV/AIDS, 2004).

Once a person has disclosed, networks provide opportunities for playing a specific role in the community. Disclosure can be an unburdening experience (Norman, Chopra, & Kadiyala, 2007), but the experience (or expectation) of stigma, social exclusion and risk of jeopardising relationships leads many PLHIV to be wary of disclosure. Factors likely to encourage disclosure include possibility of support (Ssali et al., 2010), being married, attending a support group (King et al., 2008), receiving counselling or seeing another person disclose (Kadowa & Nuwaha, 2009).

Networks in Uganda

The USAID-funded Networks Project was launched in 2006, and aimed to strengthen the capacity of PLHIV networks in Uganda and enhance community participation in the HIV response (International HIV/AIDS Alliance, 2009). Project activities included clustering 750 existing groups of PLHIV into 120 larger, sub-district networks. By the end of 2008, close to 40,000 PLHIV were registered members of the connected groups. Partnerships were established between the Ministry of Health, Uganda AIDS Commission, Tuberculosis Control Assistance Program, The AIDS Support Organisation (TASO) and these community-based PLHIV groups. The project provided organisational and technical support to clusters of PLHIV groups, to improve governance, leadership and management skills. These clusters served as service delivery points facilitating focused interventions to PLHIV.

Networks also facilitated income generation, music, drama and vocational skills development. A key element was the training of over 1300 "Network Support Agents" (NSAs), seconded to work alongside health care providers in 640 facilities. NSAs provided additional support for PLHIV and their families by sensitising communities, performing referrals, promoting counselling and testing and increasing access to HIV and general health services, for example by distributing anti-malarial medicines, following-up clients for TB and HIV treatment, and performing referrals to other services not provided by networks, such as PMTCT and TB testing (International HIV/AIDS Alliance, 2009).

Evaluations of the project (International HIV/AIDS Alliance, 2009) confirm that groups benefit from the collective strengths and skills offered by networks, in outreach and education activities and through links with health care providers, improved treatment service delivery, with shorter periods of stock-outs of ART and co-trimoxazole.

This study

Following the dramatic increase in PLHIV networks resulting from the Networks Project, further insights were sought into the benefits of joining a networked group; relationship between networked and non-networked groups; impact of PLHIV networked groups on the community; and role of PLHIV networks in shaping private and public experience of living with HIV. This was the focus of this study.

Methods

Study design

The study employed qualitative data collection and analysis methods to explore relationships, perceptions and understanding of PLHIV networks. Qualitative methods are helpful for giving explanations of complex phenomena (Denzin & Lincoln, 2005; Kuper, Reeves, & Levinson, 2008), and gathering individual perceptions and insights into peoples' lives.

Data collection and analysis

The study was undertaken in two districts of Uganda, among participants drawn from clusters of PLHIV groups with whom the Networks Project and TASO already work. Data were collected through semi-structured interviews, focus group discussions (FGDs), participant observation, and reviews of

records about group and NSA activities. Respondents ($n = 46$) were adults living with HIV, and members of rural and urban PLHIV groups. Narratives and testimonies of PLHIV ($n = 27$) were gathered, and records from PLHIV group service-registers ($n = 20$) reviewed. Key Informants (KI) ($n = 15$) were purposively selected for interview, based on their availability to participate. Additional KIs included District Health Officers and HIV advisers, community leaders, medical superintendents, and ART clinic workers.

Focus group discussions were held with NSAs and PLHIV group members and leaders. NSAs were observed during their routine work, meetings and testifying about their sero-status. Interviews and FGDs were conducted in local languages, recorded, transcribed and translated into English. All personal identifiers were removed and interview codes assigned to safeguard confidentiality.

Data analysis was managed using NVIVO software, a tool for sorting, coding and categorising large amounts of qualitative data (Bazely, 2007). Research questions were reviewed and allocated to broad themes corresponding to the study aims. These were then re-visited inductively (Silverman, 2001).

Ethics

The study was approved by the Science and Ethics Committee of the Uganda Virus Research Institute (UVRI), and the Uganda National Council for Science and Technology. Appropriate guidelines were followed for confidentiality and consent, consistent with recognised procedures (World Medical Association, 2008), and approaches for addressing sensitive topics (Dickson-Swift, James, & Liamputtong, 2008).

Limitations

Although data triangulation was employed to improve reliability, findings of this study may not be generalised beyond the respondents.

Findings

Personal and community impact

For most respondents, there are numerous benefits to being part of a networked PLHIV group.

> Another group works closely with our group. They come to learn and share with us, to inspect our work while giving advice. We have kept friends with such groups, so that they grow like our group has done. (FGD, PLHIV)

Specific activities facilitated by networks, such as forming a drama group for educational event around HIV, not only serve the community, but also benefit the individual by giving a role to play in the community. Sharing knowledge and skills between groups is a significant part of network functioning, and respondents noted that receiving training in music, drama, counselling and care enabled them to support members of their groups. Findings suggest that groups with particular skills offer significant benefits to other groups, and this pooling of knowledge (outreach activities, such as drama) and resources (including food, domestic assets and income-generating items such as sewing machines), is noted by respondents as enhancing the support they give to individual group members while increasing community literacy and capacity on HIV.

Respondents trained as NSAs describe their motivation for joining liaison groups as arising from a desire to impact their communities:

> Why not inspire others on the advantages of testing, and access to treatment, care and support services? (NSA)

With the evolution of PLHIV networks more information is shared, and NSAs describe their elevation to community role models and facilitators, being consulted for guidance and being treated with respect, a marked contrast with their previous experience of being stigmatised, and with fears of dying without proper burial. The transition from despair to community role offers insight into how networks – and ultimately individual groups – serve the dual purpose of improving the care of PLHIV and offering structured roles for members to interact with a range of stakeholders. For one:

> Disclosing my status, and going for training as an NSA has affected my life greatly. People are friendlier, and want me to counsel them. My life is now comfortable. (FGD, NSA)

Additionally, NSAs engage in capacity building and support:

> As NSAs, we do a lot of supervision. [We] live with our groups, sensitise the community and support our colleagues with counselling. They feel free to talk to us because we have the same problems as them. (NSA)

Findings suggest networks enhance treatment access – not only from NSAs encouraging PLHIV to attend facilities for treatment in the first place, but also in transporting ART:

Due to networking and good working relations with partners, [medications] are given out at the community centre. This has reduced expenses on transport, and improved adherence. (PLHIV, KI)

For one NSA, easier access to ART programmes not only assists the individual, but unites families and communities against stigma by bringing HIV into the open:

When I told my mother about the availability of ART to extend my life, she was so happy. She called everyone to tell them the good news. They all pledged to help me, and they encouraged me to disclose. They promised to support me whatever the community's reaction. (NSA)

Community mobilisation, which brings together PLHIV groups and their families, has an impact on perceptions of PLHIV. Respondents describe family members as no longer fearing them, but instead assisting with ART adherence and attending sensitisation discussions.

A third strength of networks confirmed in this study is enhanced material support, and training in life skills shared between groups:

Income for PLHIV and other group members has improved, from farming, mushroom and passion fruit growing, and bee keeping. (PLHIV, KI)

Respondents describe the sharing of resources and skills when groups are joined – for example agricultural skills:

We collaborate very well on improving agriculture. We visit [the other group] to learn more about their activities. Because of what they do, we decided to join them, and learn the skills they possess. (FGD, Household)

Impact on interventions and positive prevention

Community sensitisation is a key part of HIV prevention, and findings confirm that NSAs are involved extensively in arranging and delivering community events, and advising individuals and couples (especially if discordant) on safer sex and family planning. This includes onward referrals to testing and treatment services, using drama groups to improve messaging, and facilitating condom distribution to other groups and peer educators. Other groups, for example working in drama, connect with agencies as part of their community sensitisation:

As a drama group, we access condoms at the [main] centre and carry some with us. People know that we are actually health workers, and say, "You people have those condoms – can you also get us some?" So if we have we do. (Key Informant)

Relationships between groups

Sharing knowledge, skills and resources is predicated on groups being able to relate effectively. Respondents describe groups sending messages to one another regarding important community events. This interdependency often increases coverage and reach of services:

The relationships between PLHIV groups are good. They are networking with one another on needs of orphans and vulnerable children, and PLHIV. When [one group] gets funds, the beneficiaries come from the other three groups. (Key Informant)

However, there is also wariness about working with certain groups, and respondents describe suspected corruption, non-transparent leadership, and poor governance as reasons for this implicit cynicism:

Many groups are fraudulent because of having crafty leaders, and only become active if hear about funding opportunities. They are active during campaign seasons because politicians will go around asking for votes. (Key Informant)

Relationships between PLHIV and non-PLHIV groups were generally positive, except for a few instances cited by respondents of some unwillingness of non-PLHIV groups to engage with HIV groups. An illustrative example is of money-lending groups being unwilling to lend to PLHIV, fearful their money would not be returned. Community sensitisation efforts reduced some of these initially negative responses.

Private and public perceptions of HIV

Perhaps one of the key community roles of groups is empowering PLHIV around disclosure, which remains one of the central challenges of living with HIV:

I used to live in fear of disclosing, but people from the group would come and counsel me, and remind me always. I ended up disclosing. (Key Informant)

[When I was diagnosed] I felt devastated and I wanted to die. I contemplated suicide, until one lady from the network connected me to [another group], and that is why am alive. I managed to disclose my status openly and now I am free. (FGD, PLHIV)

Once a person has disclosed and joined a networked group, they profit from services provided by their own, or other groups in the network:

[Originally] I thought I would die. But after disclosure, I had no fear of getting my medication and swallowing it. That is why I have lived long. I joined the group, and it's through them I got the groundnut grinder [from another group] which helped me support my children, pay their fees and even pay the rent. I don't regret disclosing my status. (FGD, PLHIV)

Disclosure is often accompanied by a strong personal commitment to sensitise and educate communities and colleagues. PLHIV expressed commitment to giving open testimonies in-order to facilitate disclosure for other PLHIV, which, according to respondents, resulted in greater numbers of people disclosing, and subsequently enrolling into care.

Discussion

PLHIV networks, as perceived by respondents, enhance the impact and effectiveness of individual groups – the whole is indeed greater than the sum of the parts. This confirms other studies and evaluations (International HIV/AIDS Alliance, 2009; Odhiambo & Gatua, 2008; USAID, 2007). Individual groups certainly offer important support for PLHIV, and this study adds to our understanding of networks which, being part of a broader coalition, allow for diversity of service delivery, and (in particular) well-defined roles for individuals to participate in community-based support, mobilisation and sensitisation.

We found support for the notion that groups whose activities are supported and enlarged by connecting with other organisations are able to improve the availability and reach of services. While acknowledging that different groups have particular strengths – for example in stigma reduction, counselling, adherence support, or home-based care among others – networks enable PLHIV to learn from one another, share resources and encourage income generation. Respondents confirm that being part of a wider collective of organisations – even if this is only with a group in an adjacent village – can address a wider range of needs.

However, there are potential problems where there are scarce resources. Here, groups would be in competition, be less willing to share material resources, technology, information and learning. Although our study did not reveal significant challenges, this is plausible, and the initial reluctance of some non-PLHIV groups to interact with PLHIV suggests a dynamic the HIV sector should be aware of.

The role of networks in encouraging disclosure and improving community perceptions of PLHIV – hence reducing stigma – suggests that individual and collective empowerment is a significant product of an effective network, and connected with this is the capacity for improving self perception, and indeed hope – transitioning from a state close to despair, to one characterised by motivation to survive and share with others that it is possible to live with HIV.

Recommendations

A number of recommendations for policy and programming emerge from this study. The Ministry of Health should promote the GIPA principle further by involving PLHIV networks in the national HIV response at all levels, consistent with the National Development Plan (Ministry of Finance Planning and Economic Development Uganda, 2010). The ministry should adopt policies to strengthen the implementation of task shifting (World Health Organisation, 2008) and enable NSAs to provide additional support at health facility and community levels. This would implicitly professionalise their roles and strengthen their recognition and contribution. However, it also buttresses the call to provide stipends for NSAs and other volunteer network members. Voluntarism is not necessarily sustainable and may lead to high levels of attrition (Kironde & Klaasen, 2002).

While this study did not explore the day-to-day governance of networks, other studies suggest that networks with influential leaders and agents are more likely to achieve greater impact (Wall et al., 2012). Networks should explore ways to breakdown barriers between themselves, and work on strategies to strengthen groups perceived as "unpopular" (for example, those with poor management). Capacity building of networks to enable them to effectively function and engage at the national level is essential.

Further research regarding financing, long-term sustainability and the impact of networks on HIV prevalence and adherence is required.

Summary

The study highlights the role of networks in facilitating disclosure, access to services and shaping the private and public perceptions of PLHIV. It explores the relationship between groups and the motivation for PLHIV to join them. GIPA in service delivery through task-shifting and the adoption of approaches

to safeguard sustainability of PLHIV networks are called for.

Key Messages

- Networks of PLHIV groups play an important role in sensitising communities on HIV and AIDS, improving access of communities to HIV prevention and PLHIV to treatment and care; and support services.
- PLHIV groups maximise and support disclosure, and shared resources and capacity between PLHIV groups, which diversifies the range of services available for PLHIV
- Networks provide platforms for community roles and action against HIV by PLHIV

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