

Supporting community action on AIDS in developing countries

EMERGING NETWORKS OF PEOPLE LIVING WITH HIV IN UGANDA: PREVENTION, VISIBILITY AND DISCLOSURE

[December 2010]

FACTS

- **2.6m** new HIV infections per year
- **5m** people now on ART – but many more in need of treatment (around 10m in total)
- Expanding access has led to a **19%** decline in deaths among people living with HIV (PLHIV)
- Demand for care and support is increasing now that more people are living with HIV



Source: UNAIDS Report on the Global AIDS Epidemic (2010)

Members of the PLHIV Multi-Purpose group, Nyimbwa, Uganda © Nell Freeman for the Alliance

RESEARCH SUMMARY AND BACKGROUND

The aim of this qualitative study, carried out in 2010, is to provide an evidence-based approach to understanding how networks of people living with HIV (PLHIV) are formed, their role in the prevention of HIV and improving access to care and treatment, and networks' impact on members and people directly and indirectly linked to them.

The study focuses on three key issues:

1. Understanding the relationships between people living with HIV and members of the networks
2. Understanding the roles of these networks on issues of visibility, and disclosure of HIV status, and how they contribute to shaping private and public experiences of living with HIV
3. The impact of networks of people affected by HIV on interventions, particularly positive prevention

The antecedents of this study include the Networks Project (2006-2009), exploring the role of networks in improving the treatment and care of PLHIV in Uganda, and especially the role of *network support agents* (NSAs) in coordinating connections and referrals to health facilities and NGOs so the specific needs of PLHIV can be better addressed.

Uganda over the last five years has seen a rapid growth in networks supporting PLHIV, engaging in advocacy, treatment and care and raising the profile of HIV in the public domain. Stigma and discrimination remain key challenges for PLHIV, and a key motivation for civil society has been to ensure that public perceptions of HIV and affected people are appropriate and non-judgemental – and this includes health service provision and promoting compliance with principles outlined in the GIPA guidelines.

It is imperative to gather evidence confirming the benefit of networks for PLHIV in order to effectively scale-up and sustain their impact. In addition, understanding how individual PLHIV access networks, and their motivation for doing so, will ensure that services appropriately meet their requirements – a key factor underpinning this qualitative study.

DESCRIPTION OF THE PROJECT

The study was designed to address a number of research foci, including: Role of PLHIV networks in positive prevention efforts; the nature of the relationships between PLHIV networks and PLHIV households; the role of PLHIV networks in relation to issues of visibility and disclosure.

Respondents were people of reproductive age living with HIV who are members of and utilize services from PLHIV groups; and The AIDS Support Organization (TASO) groups of people living with HIV within the project area were targeted for the study. Other participants were purposively selected for key informant and in-depth interviews based on their participation in PLHIV group work and utilization of services promoted by PLHIV networks. District Health Officers, district HIV/AIDS Focal Persons, district HIV/AIDS coordinators, community leaders, medical superintendents, ART clinic In-charges, leaders of PLHIV groups and key stakeholders at national level were also interviewed. Focus group discussions were held with Network Support Agents and other members of Alliance PLHIV and TASO groups. Selected records of PLHIV groups (TASO and others) and NSAs were reviewed to further inform the research on their activities.

Participatory data collection, analysis, report writing and dissemination of results were conducted and supervised by core and advisory research groups.

FINDINGS

Following qualitative analysis, the findings provide a number of insights into the impact of networks in the lives of PLHIV – their perceptions, attitudes, consideration of benefits and impact. In particular, factors encouraging a PLHIV to *join* a network were highlighted. A number of themes were evident in the data, including:

Why PLHIV join networks: For material support and skills (including income generating activities), due to stigma and discrimination, and for psycho-social support, treatment and care.

The impact of networks on the community: Members of the networks play an important role in the community – they are looked on as a source of basic household need, and also in supporting PLHIV not able to adhere to medical regimes.

Relationships between PLHIV and their family: It was observed that the relationship between networks of PLHIV groups and their family members has improved compared to previously. Now, family members do not fear PLHIV, instead taking a positive role in their support, such as reminding them to take drugs, attending sensitization meetings organised by PLHIV networks, and adopting a more positive attitude towards those who are affected.

Network collaboration: The study reveals that PLHIV network groups collaborate with other community groups, liaising on community activities and avoiding duplication of services. They also train community groups in the use of drama, and counselling.

Networks, disclosure and the community: Disclosure is a slow painful process, and one role of networks is to help communities realize that HIV is not about individuals but a community issue. Once a PLHIV has disclosed, respondents in this study spoke of becoming role models in the community. Disclosure has a strong, positive impact on the community in terms of health seeking behaviours, as well as increased demand for health, treatment and testing services.



Network support agents in Uganda © Alliance

DISCUSSION AND IMPLICATIONS

The study confirms that for PLHIV, networks provide a powerful mechanism for addressing a number of challenges in their day-to-day lives. Networks in the community – and key personnel such as Network Support Agents – are identified clearly as factors enabling PLHIV to disclose their HIV status, enhancing access to treatment, care, and other opportunities focused toward improving their health. Seeing those who have already disclosed their status – through the connections created by networks – can be a key motivator to other, more hesitant PLHIV.

However, respondents report being ‘pressurised’ to disclose, and disclosure is looked at more as a necessity than a choice – not about courage alone but also commitment to the prevention of harm to others.

This study was a valuable tool for gathering insights into the level of community, social and political involvement desired by PLHIV. Though respondents confirm that discrimination has reduced, there are still challenges towards universal access to prevention care and treatment and greater community involvement in HIV service delivery.

“After disclosing I felt like a load had been lifted, and people started giving me help, which had not happened before”

FEMALE PLHIV, UGANDA

DISSEMINATION

The final report will be released by January 2011. In addition, the study findings will contribute more broadly to advocacy, programming and the development of sustainable social mechanisms for ensuring that prevention, treatment, care and support for PLHIV and their families is delivered cost-effectively and with maximum benefit.

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A global partnership:
International HIV/AIDS Alliance
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ABOUT EVIDENCE FOR ACTION

Evidence for Action is an international research consortium with partners in India, Malawi, Uganda, UK and Zambia, examining issues surrounding HIV treatment and care systems.

The research is organised in four key themes:

1. What 'package' of HIV treatment and care services should be provided in different settings?
2. What delivery systems should be used in different contexts?
3. How best should HIV treatment and care be integrated into existing health and social systems?
4. How can new knowledge related to the first three questions be rapidly translated into improved policy and programming?

PARTNERS:

- **International HIV/AIDS Alliance, UK**
- **Lighthouse Trust, Malawi**
London School of Hygiene and Tropical Medicine, UK
- **Medical Research Council Uganda Research Unit on AIDS, Uganda**
- **Medical Research Council Clinical Trials Unit/University College London, UK**
- **National AIDS Research Institute, India**
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