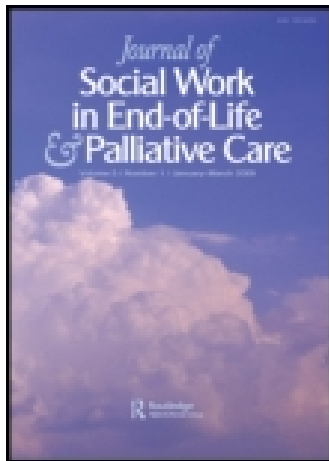


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Community Systems Strengthening for HIV Care: Experiences From Uganda

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Community Systems Strengthening for HIV Care: Experiences From Uganda

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The growing HIV burden on families and health systems is exerting a shift toward community caregivers, and is increasing the demand for functional community systems. In Uganda, where the number of people with HIV is increasing against a background of weak health systems, the role of community systems is poorly understood. We investigated the role of community systems in palliative care and the system elements required for an effective community response in Uganda. Qualitative interviews and focus group discussions were conducted among providers and recipients of palliative care, their family members, and governmental and community stakeholders in Mbale and Jinja, Uganda. Results showed that

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community systems play an important role in many aspects of palliative care—including personal, livelihood, nutritional and bereavement support—and often strengthen care linkages and referrals. For community systems to fulfill these roles effectively, multiple system elements—including leadership, training, partnerships, and enabling policies—are essential. Strengthening community systems could be an effective strategy to alleviate HIV burden on families and health systems. A systems approach could be a potent mechanism for determining which community structures to strengthen in order to maximize the impact of palliative care programs, and for guiding investments in HIV and health.

KEYWORDS palliative care, HIV, community systems, Uganda, Africa

INTRODUCTION

Progress in tackling the HIV epidemic has resulted in an unprecedented increase in the number of people living with HIV globally. This increase is partly attributable to the improved availability of antiretroviral therapy, declining rates of AIDS-related deaths, and ongoing, albeit diminishing, rates of HIV incidence (UNAIDS, 2012). At the end of 2011 there were 34.2 million people living with HIV globally (UNAIDS, 2012). The burden of HIV is particularly high in sub-Saharan Africa, where more than 69% of people living with HIV globally are located (UNAIDS, 2012).

In Uganda, where HIV prevalence at the end of 2010 was 6.7%, the total number of people living with HIV has doubled over the last decade (Ministry of Health, Uganda & ICF International, 2011; UNAIDS, 2010). At the end of 2008, 1.1 million people were living with HIV, of whom 60% were women (Uganda AIDS Commission, 2010). Men and women between the ages of 30 and 39 years are particularly affected (Ministry of Health, Uganda & ICF International, 2011; Uganda AIDS Commission, 2010). While the survival of people with HIV infection in Uganda has improved (Uganda AIDS Commission, 2010), the increasing number of people living with HIV is likely to have implications on the demand for palliative care. In this Ugandan context, tackling HIV demands a wide range of responses—including prevention, treatment for those who have acquired HIV, and care and support for those affected (Uganda AIDS Commission, 2010). Although these needs are all critical in the continuum of care for people living with HIV (Ogden, Esim & Grown, 2006; World Health Organization/UNAIDS, 2000), some appear to be prioritized over others, whether at home, in the community or at health facilities. For instance, while the number of adults and children accessing antiretroviral therapy in Uganda grew from 48% to 58% between 2008 and

2011 (Uganda AIDS Commission, 2012), the provision of other services such as palliative care during the same period was challenged by “inadequate political will and insufficient resourcing” (UNAIDS, 2010, p. 109). This is particularly notable in light of emerging evidence suggesting that despite the greater availability of antiretroviral therapy, significant physical and psychological problems requiring palliative care persist in many parts of sub-Saharan Africa (Harding et al., 2012). Moreover, the confluence of HIV and non-communicable diseases in sub-Saharan Africa has led to greater morbidity due to non-communicable diseases among older people living with HIV, which may increase palliative care needs among this population (Mills, Rammohan, & Awofeso, 2011). In addition, while home- and institution-based care remain the dominant palliative care paradigms, both appear to be inadequately resourced to meet the demands of an increasing number of people living with HIV in Uganda and elsewhere.

On the one hand, while families play a crucial role in filling the care gap resulting from the shortage of health care professionals and infrastructure (Kipp, Tindyebwa, Rubaale, Karamagi, & Bajenja, 2007), their ability to fulfill this role is often challenged by inadequate skills and an absence of systematic support to family units (Gysels, Pell, Straus, & Pool, 2011). In addition, due to poor linkages between formal and informal systems of care, the ability of family and other informal caregivers to provide care is often constrained by a discordant understanding of task shifting between different stakeholders, poor communication between caregivers and health care professionals, and caregivers’ personal competing priorities (Dambisya & Matinhure, 2012; Gysels et al., 2011; Lees, Kielmann, Cataldo, & Gitau-Mburu, 2012).

On the other hand, institution-based care is often undeveloped or non-existent in Africa (Harding & Higginson, 2005). In a systematic review of palliative care in sub-Saharan Africa, it was claimed that many patients do not necessarily prefer home-based care, despite women, children, and the elderly being the principal home caregivers (Gysels et al., 2011). Instead, home-based care, especially that provided by family members, was the dominant paradigm because there was not always the infrastructure or capacity to offer such support elsewhere. Palliative care other than that provided by the family within the precincts of the household was found to be “sparse across the continent” (Gysels et al., 2011, pp. 1–2).

These findings are consistent with the situation in Uganda, where a 2009 national audit of palliative care services found that institutional palliative care was only available in 32 of 80 districts (Palliative Care Association of Uganda [PCAU], 2009). Furthermore, while different models of palliative care service delivery existed in the 32 districts, most were either hospital-based (regional referral, district and mission hospitals) or home-based, with fewer community-based models (PCAU, 2009). This and other studies in Uganda have consistently concluded that institutional sources of palliative care—such as hospitals, free-standing hospices, and day care facilities—are

not universally available or resourced (Clark, Wright, Hunt, & Lynch, 2007; PCAU, 2009).

As the limitations of both family-led home-based care and institution-based care become more obvious, community groups and networks are gaining prominence as a potential alternative for Ugandans who need palliative services. Kim, Kalibala, Neema, Lukwago, and Weiss (2012, p. 3) found that community-based groups are acting as “service delivery points” for a range of services, including home-based palliative care. Jack, Kirton, Birakurataki, and Merriman (2011) further described how such voluntary community groups are mitigating the burden on patients, families, and hospices, and expanding the reach of palliative care in Uganda. Hodgson, Nakiyemba, Seeley, Bitira, and Gitau-Mburu (2012) and Mburu, Iorpenda, and Muwanga (2012) concluded that the provision of care to people living with HIV by groups of people who are themselves living with HIV is becoming increasingly organized in Uganda, and that these community groups are facilitating referrals and linkages between households, the community, and local health facilities. The scope, complexity, organization, and impact of community structures described in these studies suggest that adopting a systems approach to strengthening community-based care could be an effective strategy for alleviating the care burden on both families and health systems, as well as a potent mechanism for guiding investments in health and community systems.

Evidence of the effectiveness of community initiatives such as those launched by The AIDS Support Organization (TASO), an indigenous community-based organisation, has spurred interest in the potential role of community systems in the decentralized delivery of palliative and other HIV services in Uganda through task-shifting. An emerging body of work suggests that community models have particular strengths, such as a patient-centered approach, and an ability to strengthen the care continuum through wider, family-centered care and support (Abaasa et al., 2008; Hodgson et al., 2012).

Despite the demonstrated capacity of community models to improve HIV treatment outcomes related to access, coverage, adherence, viral suppression, retention in care, and survival (Abaasa et al., 2008; Fatti, Meintjes, Shea, Eley, & Grimwood, 2012; Wouters, Van Damme, van Rensburg, Masquillier, & Meulemans, 2012), it remains unclear how these models contribute to community-based palliative care. Yet as Bateman (2001) argued, community-based palliative care models are particularly needed to deal with the increasing HIV burden on formal health systems in southern Africa. This is particularly relevant as more people living with HIV in sub-Saharan Africa age and become increasingly susceptible to non-communicable diseases (Mills et al., 2011). This is a situation that could further exacerbate the burden on health systems. In addition, while care and support programming has become central to the work of community and nongovernmental organizations in Uganda

(PCAU, 2009), the concept of community systems strengthening, derived from a systems approach to the provision of health care (Global Fund, 2010), has not been adequately explored (Lees et al., 2012).

AIMS AND OBJECTIVES

This study examined the provision of community-based palliative care to Ugandans living with HIV, making specific reference to the role that community systems play in palliative care. The aim was to identify community system elements that facilitate care provision in such contexts.

METHODOLOGY

Study Design

A qualitative study design was employed to gather perspectives from participants on palliative care, using focus group discussions (FGDs), and interviews. Qualitative methods are particularly suited for developing explanations and collating individual perceptions and insights regarding complex phenomena (Greenhalgh, 2010).

Data were collected in Mbale and Jinja districts of Uganda between June and October 2010, where the International HIV/AIDS Alliance (the Alliance) had implemented a community-based HIV initiative known as the Networks Project between 2006 and 2009. The aim of the project was to increase access to a comprehensive continuum of HIV services by transforming groups of people living with HIV from passive service recipients to active service providers and facilitators (Kim et al., 2012; Mburu et al., 2012).

Study Participants and Recruitment

Study participants included members of rural and urban groups of people living with HIV, family members of people living with HIV, and HIV service delivery stakeholders (key informants). All participants, including people living with HIV, were involved in delivering a wide range of HIV prevention, care, and support services, as the premise of the project was to empower people living with HIV to be able to provide care to their peers. To strengthen representativeness of the sample, respondents were recruited from the Networks Project as well as other community-based care initiatives within the study districts. Participants were purposively sampled based on their involvement in service delivery, ability to consent, and availability to participate.

A total of 65 respondents participated in the study (Table 1), including people living with HIV who were providing palliative care to other people

TABLE 1 Sources of Study Data

Method of inquiry	Description
Key informant interviews	Key informant interviews with district health officers, district HIV focal persons, district AIDS coordinators, community leaders, medical superintendents of district hospitals, ART clinic supervisors, and leaders of groups of PLHIV ($n = 15$)
Focus group discussions	Focus group discussions with people living with HIV providing palliative care (3 sessions, $n = 30$) Focus group discussions with family members from households with PLHIV receiving palliative care (1 session, $n = 10$)
In-depth interviews	Narratives from PLHIV who received home-based palliative care from community groups ($n = 10$)
Retrospective record reviews	Review of records of PLHIV groups ($n = 20$)

living with HIV ($n = 30$); members of households with people with HIV who were receiving palliative care ($n = 10$); people living with HIV who were receiving care from community groups ($n = 10$); and key informants who included government officials, community leaders, and health care professionals involved in the delivery of HIV services in the study districts ($n = 15$).

Data Collection

A small team of local research assistants and coordinators were trained by two authors (IH and GM) to conduct interviews and facilitate and focus group discussions. Interviews and discussions were conducted in English, Luganda, or Lusoga depending on participants' preferences.

Interviews were conducted face to face and were audio recorded, transcribed, and translated into English. In some cases, where key informants had sufficient ability, interviews were conducted in English. Interview guides were used to safeguard consistency, and while researchers employed both closed and open-ended questions, the latter predominated to enable capturing of individual perspectives and experiences of providing or receiving palliative care. Semi-structured interviews with key informants lasted 25–30 minutes each. In-depth interviews with people living with HIV lasted 40–50 minutes, and captured longer narratives related to their experiences of living with HIV and receiving home-based palliative care.

Focus group discussions were conducted with people living with HIV who were providing palliative care to other people living with HIV (three sessions; $n = 30$) and, separately, family members of people living with HIV who were receiving palliative care (one session; $n = 10$). Four focus group discussions were held in total. Each session lasted between 45–60 minutes and included 8 to 12 participants. A facilitator asked open-ended questions

using probes to facilitate the discussion, and took short notes. Sessions were audio-recorded, transcribed, and translated into English.

Measures

Separate interview guides for the focus group discussions and interviews were formulated in English. These were later translated (and back-translated for validation) by the local research assistants into Luganda and Lusoga for use with participants who preferred being interviewed in a local language. The interview guides explored the role of networked groups of people living with HIV in HIV prevention and care; the relationships between groups of people living with HIV and households of people living with HIV; and the impact of organized groups of people living with HIV on visibility and disclosure of HIV at the community level (see Appendix 1 for full interview guides). Illustrative sample questions related to this article included the following:

- What activities are carried out by members of your group?
- What are some of the difficulties members of your group encounter as they provide and use HIV services from the group? What have members of your group done to overcome these difficulties?
- What motivated people living with HIV in this community to join and become members of your group of people living with HIV?
- How would you describe the relationships between the groups of people living with HIV and their households?

Although standardized phrasing and ordering of the questions was used, the interviewers allowed the participants' responses to guide the course of the interviews. This approach allowed emerging themes raised by participants to be explored as the interviews and group discussions progressed.

Data Analysis

All data were analyzed using the same thematic framework. Dynamics and interactions often explored in focus group discussions (Wilkinson, 2004) were not analyzed in this study; only narrative data were included. One author (AN) initially coded and searched data for consistently recurring themes (Silverman, 2001; Strauss & Corbin, 1998) using Nvivo[®] v.9 (QSR International Pty Ltd., Doncaster, Australia) software designed as a tool for sorting, coding, and categorizing qualitative data (Bazeley, 2007). Another author (IH) subsequently verified the codes independently. Two authors (IH and GM) discussed ambiguous data to reconcile potentially divergent interpretations. Theme selection was guided by the study objectives, as well as consistency of themes identified through constant comparison and analytic induction.

Respondent validation and peer debriefing techniques were employed through discussions with key stakeholders and, where appropriate, with respondents at in-country events such as research briefings, where participants were encouraged to comment on and validate the key narrative findings as reflected in their own experiences. Peer debriefing particularly reinforced the limitations and barriers of palliative caregiving. In addition, the interview data were complemented with a retrospective review of records of 20 community groups of people living with HIV to triangulate and validate data (Bhopal, 2008). These records contained the identity, location, and cumulative number of people reached with a variety of HIV services, including home-based palliative care, in the two study districts.

Ethical Considerations

Researchers employed appropriate approaches for obtaining informed consent and safeguarding confidentiality (Dickson-Swift, James, & Liamputtong, 2008; World Medical Association, 2008). Researchers explained the purpose of the study, and ensured that participation was voluntary and based on informed consent. Participants were informed of their right to end the interviews at any time. No incentives to participate were provided. All personally identifiable data were deleted, and coded data were stored in a password-protected computer. The study was approved by the Science and Ethics Committees of the Uganda Virus Research Institute and the Uganda National Council for Science and Technology.

RESULTS

Findings indicated that community groups and networks assume multiple roles in relation to HIV care and support. Besides identifying the dominant roles, the following results also describe community system elements that facilitated the performance of these roles.

Roles of Community Groups in Providing Palliative Care and Support

The study identified four interrelated roles that community groups and networks played in palliative care: personal care; treatment access and support; livelihood support; and bereavement support and care of children after the death of parents. Study participants reported activities aimed at providing comprehensive care for people living with HIV and their families:

When a client is helpless and bedridden, we support by helping to bathe them, offer [any] material support they need if we have it, and support the

family members to learn how to manage sores if present, and then referring them or taking them to hospital, if able, for further management. Before the clients start getting their ARVs [antiretrovirals], [we provide] adherence counseling to support and encourage members to take their treatment regimens. (Focus group discussion, person living with HIV)

Community-based caregivers saw themselves as able to make contributions that extended well beyond clients' direct HIV-related needs:

We visit each other to [assess] whether the mosquito net is used, whether [a] water guard is used for water purification or washing, whether one is adhering to treatment, the welfare in the home in terms of cleanliness and hygiene, nutrition issues in a home, and relationships in the household. We also used to provide material support like soap, food, and bedding, but have no finances currently. But we refer them to organizations that have those programs. (Interview, person living with HIV)

Descriptions of the role of community members external to the family unit in supporting family members in households with people living with HIV were common:

This group is useful because our father is now bedridden [with HIV] and [they] are the ones taking care of him. They come to visit him for moral support, and counsel us on how to care for him while encouraging us not to fear him. (Focus group discussion, family member of a person living with HIV)

Community groups were found to be an important source of bereavement support, often helping widows and their children when their spouses died of an HIV-related illness:

When my husband died my children were young and I was crying because I did not know what to do. So the chairperson of the group [said they] would support and comfort me, and even look after the children. (Focus group discussion, family member of a person living with HIV)

Narratives of how community groups linked people living with HIV to health services where they could access antiretroviral therapy were commonly encountered:

I was picked up from my home by other PLHIV [people living with HIV] for dead. These people did not give up. They took me to TASO. My CD4 [cell count] was 2 and there was no hope but through prayer and dedication from health workers to save my life. I am feeling okay after being bedridden for 1 year. Today ... I have a poultry farm and it's through [the] group that I started this. (In-depth interview, person living with HIV)

Narratives were also common of how community networks provided vocational skills that “enabled many households to be able to support themselves using incomes generated” (focus group discussion, person living with HIV) and “feed well at home” (focus group discussion, person living with HIV).

Study participants reported some limited involvement of men in palliative care. They had mixed views on the reasons for this phenomenon. They were asked what factors they thought influenced men’s involvement, and one participant responded: “At first it was for women alone, but now we involve men also in our group. We involved them because there are some jobs that we as women cannot do, like building” (focus group discussion, person living with HIV). The notion that men were particularly involved in physically demanding tasks was reinforced by another respondent who responded to the same question by asserting that: “If men are involved, they carry out heavy weight tasks” (focus group discussion, person living with HIV).

When participants were asked about their motivation to provide palliative care at the community level, many altruistic reasons emerged: “Why not inspire others on the advantages of testing and, if found HIV positive, be able to access treatment, care, and support services?” (focus group discussion, person living with HIV). However, community caregivers did not always feel adequately remunerated, immune from HIV stigma, or adequately resourced to fully meet the multidimensional needs of their clients. Expressions of a wide variety of barriers—including poor remuneration, limited training, and a lack of recognition—were frequently encountered during peer debriefing sessions. Participants were also encouraged to comment on and validate the key narrative findings based on their own experiences, as well as from group discussions: “We also have limited resources, especially funds for us to cover a wider [geographic] area. In some cases where many [of us] are volunteers, you can’t expect much” (focus group discussion, person living with HIV).

Community Systems for Home-Based and Community Palliative Care

Despite many challenges, it was clear that community groups had a structured organizational source of support and resources that facilitated the performance of their roles and mitigated some of their challenges. The data revealed a number of interrelated domains related to community groups’ ability to contribute effectively to palliative care. These included leadership; availability of training on HIV; community partnerships; involvement of community groups in monitoring and evaluation; and a policy framework that created an enabling environment for communities to engage in service delivery (Table 2).

TABLE 2 Requirements for Effective Community Systems Identified in Study

Theme	Subthemes
Organizational leadership	Leadership Transparency Equity
Resources and capacity-building	Training Financing Remuneration
Community partnerships and coordination	Partnerships with other community-based organizations Referrals and training from health facilities Logistical support to acquire and distribute medicines
Monitoring, evaluation, and planning	Community engagement in service delivery Accountability and reporting
Enabling policy environment	Inclusion of community activities in district data Registration of community groups by the government

Respondents alluded to the importance of leadership in determining the credibility and function of community groups, and in encouraging inclusion and participation of community members in service delivery: “Sometimes what attracts many people to join is the transparent leadership The group is transparent to an extent that if there is something to share it is done openly to seek people’s views” (key informant interview, community leader).

Right now, the chairman listens and possesses good leadership skills. He oppresses no one, is transparent, and treats us the same. He encourages us to continue helping to bring out more of our colleagues, although there are some people in the community still in denial and hiding. (Focus group discussion, person living with HIV)

Participants from community groups appreciated individual training, usually from trained health professionals, that increased their understanding of the palliative care needs of people living with HIV: “We were defeated by some logistics and resources. But when the Alliance came in, I think it was [easier] to find training opportunities from these HIV health facilities” (key informant interview, leaders of groups of people living with HIV).

Others saw partnerships with other organizations as an important element in skills transfer and a source of additional information and resources.

These partnerships also provided a framework for increasing access to treatment and care:

JPLWA [Jinja People Living with HIV AIDS—a local community group] has other groups that work together in the network to implement and monitor group activities. Like now, all members from the three groups who used to get treatment from TASO in Jinja are getting our drugs at the community support center belonging to JPLWA, which has helped us to easily get treatment near us without incurring transport costs. Unless you have some illness, that is when you go to Jinja. (Focus group discussion, person living with HIV)

Key informants and other participants alluded to “the government policy to support groups [which] has made many people come up and join these groups” (focus group discussion, person living with HIV). The coordinating role of the government at the district level and its inclusive approach in reporting the activities of community groups was also encountered: “The district has an overall role in providing technical advice and ensuring that all groups that are active in the health sector, not only in HIV programs, give us regular reports” (key informant interview, district health officer).

DISCUSSION

Study findings suggest that community systems and networks as an entity distinct from but linked to both family caregivers and palliative care institutions, play a significant role in the provision of palliative care to people living with HIV in Uganda. The findings also illustrate a set of system factors that are relevant to community-based palliative care.

Our study revealed that community networks contribute to personal care, treatment access and adherence support, financial support, bereavement support, and care of children after the death of their parents. Although few narratives regarding analgesia were encountered, interviews and focus group discussions revealed that these roles extend to include linking people living with HIV to a comprehensive range of services—including treatment, nutrition, and livelihood support. While these roles are broadly similar to those performed by family caregivers and facilities in Uganda and elsewhere in sub-Saharan Africa (Kipp et al., 2007; PCAU, 2009; Uys, 2002), community networks were perceived by study participants to be distinct from and external to both the family unit and the health system as a source of palliative care.

However, in fulfilling these roles, community members were confronted with challenges such as limited remuneration, competing personal needs, and HIV-related stigma. These challenges are similar to those facing other community caregivers elsewhere in sub-Saharan Africa (Schneider, Hlophe

& van Rensburg, 2008). Our study indicated that men were suboptimally involved in palliative care. Women were more involved in everyday caregiving activities, while men were more likely to perform specific, nonroutine tasks such as building. These findings echo those from other settings showing limited involvement of men in HIV services generally (Auvinen, Suominen, & Välimäki, 2010).

Nevertheless, our findings demonstrated that in Uganda, where there is a limited support system for family caregivers and low institutional capacity to provide palliative care (Clark et al., 2007; PCAU, 2009), organized community groups outside of family and institutional structures are emerging as an important provider of palliative care for people living with HIV. In particular, our findings showed that such community systems could alleviate the care burden on both families and health facilities, while increasing linkages to institutional care. As in other studies in Uganda (Dambisya & Matinhure, 2012), Haiti (Jerome & Ivers, 2010) and South Africa (Fatti et al., 2012), our results appear to suggest that the well-documented burden of HIV on the family unit and the formal health system (World Health Organization, 2007a) is exerting a shift toward community caregivers, a trend that may be increasing the demand for organized community systems.

Although palliative care is increasingly central to the work of community groups and nongovernmental organizations in Uganda (Hodgson et al., 2012; PCAU, 2009), this is an organically emerging phenomenon, and there is little understanding of the architecture and the requisite community system elements. Scholars have proposed that community service delivery calls for a systems approach (Jerome & Ivers, 2010), including “well-organized community support initiatives” (Wouters et al., 2012) that may require focused organizational development and capacity-building (Kim et al., 2012). Our study confirmed that community palliative care is dependent on complex, interrelated factors in the broad domains of leadership, capacity and training, partnerships, community engagement, and an enabling policy environment.

These community systems encompass both community infrastructure and actors supporting the delivery of health care (Jerome & Ivers, 2010; Lees et al., 2012). The Global Fund (2010) points out that effective community systems are those in which “community actors are also able to play a systematic, organized role in advocacy, policy and decision making and in creating and maintaining an enabling environment that supports people’s health” (p. 12). Consequently, community systems strengthening, which is derived from a systems-thinking approach to the provision of health care through community structures, aims to create strong community structures for “advocacy, community mobilization, demand creation and linkage of communities to services” (p. 12). This is particularly relevant in Uganda, where meeting the needs of an increasing number of people living with HIV against a background of limited institutional sources of palliative care

requires community mobilization and sustainable task shifting (World Health Organization, 2007a).

Our findings showed that in light of the varied psychosocial, medical, nutritional, and socioeconomic needs of people living with HIV, adopting a systems approach could be useful in strengthening community structures to respond to the demand for palliative care at the community level. In particular, identifying specific elements that may lead to better coverage and impact is an important step in guiding strategic investments in systems strengthening. This approach is particularly appealing, as our findings show that these informal community systems elements mirror the recognized building blocks of formal health systems, and perhaps should be seen as part of the same continuum. Formal health systems building blocks as described by the World Health Organization (2007b) include service delivery, health workforce, leadership and governance; health systems financing; medical products and technologies; and health information systems. In any case, “there is general agreement that the two sectors are, at least to some degree, dependent on each other” (Boros, 2008, p. 13). Lees et al. (2012) argue that strengthening linkages between formal and informal systems of care can enhance the contribution of communities to HIV care. Evidence suggests that in the context of Uganda this integration of community and health systems is feasible (Clark et al., 2007).

Finally, our findings revealed that strengthening community systems could alleviate some of the barriers that plague community-based HIV programs—such as an inability to train, retain, and remunerate community caregivers (Hermann et al., 2009; Schneider et al., 2008). These and other barriers may be mitigated through a community systems strengthening approach. This approach can increase the capacity of community groups and organizations in terms of their leadership, training, resources, and partnerships. It can also promote the formulation and legislation of decentralization and task-shifting policies that enable communities to participate in multidimensional palliative care. Evidence from studies in Ethiopia, Uganda, and elsewhere in sub-Saharan Africa shows that the presence of similar nontechnical characteristics—such as community leadership and management capacity (Bradley et al., 2012), partnerships between communities and health institutions (Bradley et al., 2012; Lees et al., 2012), and enabling policies (Hermann et al., 2009; Stjernswärd, 2002)—can positively influence the outcomes of broader primary health, maternal, and child health programs.

Limitations

One limitation of this study relates to the risk of bias in a purposive sample. Findings from a convenience sample may not be generalized to all community groups (Bhopal, 2008). Moreover, the findings relate to participants who

had been involved in a community-based HIV project. These results may not be generalizable to settings lacking such initiatives. Another limitation relates to the retrospective nature of data collected in the study, which often relied on recall of past events. However, the semi-structured approach of the interviews, coupled with in-depth probing, helped to refresh the memory of the participants and may have reduced recall bias.

CONCLUSION

While acknowledging that the preference regarding household, community, and institutional sources of support may vary among recipients of palliative care (Kikule, 2003), mobilizing communities and strengthening their capacity to identify and meet some of these needs through decentralized and sustainable task shifting is becoming increasingly necessary as the number of people living with HIV increases (Gysels et al., 2011; UNAIDS, 2012). Our study contributes to the understanding of a community systems approach as an alternative approach to palliative care provision in settings where family caregivers may not always be present (Williams, 2002) and health systems are weak (Harding & Higginson, 2005). Using a common framework to focus the efforts of all stakeholders in identifying and strengthening those systems elements that have the greatest impact on the reach and quality of community-based palliative care is now a necessity.

REFERENCES

- Abaasa, A. M., Todd, J., Ekoru, K., Kalyango, J. N., Levin, J., Odeke, E., & Karamagi, C. A. (2008). Good adherence to HAART and improved survival in a community HIV/AIDS treatment and care programme: The experience of The AIDS Support Organization (TASO), Kampala, Uganda. *BMC Health Services Research*, 8, article 241.
- Auvinen, J., Suominen, T., & Välimäki, M. (2010). Male participation and prevention of human immunodeficiency virus (HIV) mother-to-child transmission in Africa. *Psychology, Health & Medicine*, 15(3), 288–313.
- Bateman, C. (2001). Can KwaZulu-Natal hospitals cope with the HIV AIDS human tide? *South African Medical Journal*, 91(5), 364–368.
- Bazeley, P. (2007). *Qualitative data analysis with NVivo*. London, United Kingdom: Sage.
- Bhopal, R. (2008). *Concepts of epidemiology: Integrating the ideas, theories, principles and methods of epidemiology* (2nd ed.). Oxford, United Kingdom: Oxford University Press.
- Boros, K. (2008). *Clinics and home-based care: The interface between the formal and the informal health sectors* [Unpublished master's thesis]. University of the Witwatersrand, Johannesburg, South Africa.

- Bradley, E. H., Byam, P., Alpern, R., Thompson, J. W., Zerihun, A., Abebe, Y., & Curry, L. A. (2012). A systems approach to improving rural care in Ethiopia. *PLOS One*, 7(4), e35042.
- Clark, D., Wright, M., Hunt, J., & Lynch, T. (2007). Hospice and palliative care development in Africa: A multi-method review of services and experiences. *Journal of Pain and Symptom Management*, 33(6), 698–710.
- Dambisya, Y. M., & Matinhure, S. (2012). Policy and programmatic implications of task shifting in Uganda: A case study. *BMC Health Services Research*, 12, article 61.
- Dickson-Swift, V., James, E. L., & Liamputtong, P. (2008). *Undertaking sensitive research in the health and social sciences*. Cambridge, United Kingdom: Cambridge University Press.
- Fatti, G., Meintjes, G., Shea, J., Eley, B., & Grimwood, A. (2012). Improved survival and antiretroviral treatment outcomes in adults receiving community-based adherence support: 5-year results from a multicentre cohort study in South Africa. *Journal of Acquired Immune Deficiency Syndrome*, 61(4), e50–e58.
- Global Fund. (2010). *Community systems strengthening framework*. Geneva, Switzerland: Author.
- Greenhalgh, T. C. (2010). *How to read a paper: The basics of evidence-based medicine* (4th ed.). Chichester, United Kingdom: Wiley and Blackwell.
- Gysels, M., Pell, C., Straus, L., & Pool, R. (2011). End of life care in sub-Saharan Africa: A systematic review of the qualitative literature. *BMC Palliative Care*, 10, article 6. doi:10.1186/1472-684X-10-6
- Harding, R., & Higginson, I. J. (2005). Palliative care in sub-Saharan Africa. *Lancet*, 365(9475), 1971–1977.
- Harding, R., Selman, L., Agupio, G., Dinat, N., Downing, J., Gwyther, L., ... Higginson, I. J. (2012). Prevalence, burden, and correlates of physical and psychological symptoms among HIV palliative care patients in sub-Saharan Africa: An international multicenter study. *Journal of Pain and Symptom Management*, 44(1), 1–9.
- Hermann, K., Van Damme, W., Pariyo, G., Schouten, E., Assefa, Y., Cirera, A., & Massavon, W. (2009). Community health workers for ART in sub-Saharan Africa: Learning from experience—Capitalizing on new opportunities. *Human Resources for Health*, 7, article 31.
- Hodgson, I., Nakiyemba, A., Seeley, J., Bitira, D., & Gitau-Mburu, D. (2012). Only connect—The role of PLHIV group networks in increasing the effectiveness of Ugandan HIV services. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 24(11), 1368–1374.
- Jack, B. A., Kirton, J., Birakurataki, J., & Merriman, A. (2011). 'A bridge to the hospice': The impact of a Community Volunteer Programme in Uganda. *Palliative Medicine*, 25(7), 706–715.
- Jerome, G., & Ivers, L. C. (2010). Community health workers in health systems strengthening: A qualitative evaluation from rural Haiti. *AIDS*, 24(S1), S67–S72.
- Kikule, E. (2003). A good death in Uganda: Survey of needs for palliative care for terminally ill people in urban areas. *BMJ*, 327, 192–194.
- Kim, Y. M., Kalibala, S., Neema, S., Lukwago, J., & Weiss, D. C. (2012). Meaningful involvement of people living with HIV/AIDS in Uganda through linkages between network groups and health facilities: An evaluation study. *Psychology, Health & Medicine*, 17(2), 213–222.

- Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, T., & Bajenja, E. (2007). Family caregivers in rural Uganda: The hidden reality. *Health Care for Women International*, 28(10), 856–871.
- Lees, S., Kielmann, K., Cataldo, F., & Gitau-Mburu, D. (2012). Understanding the linkages between informal and formal care for people living with HIV in sub-Saharan Africa. *Global Public Health*, 7(10), 1109–1019.
- Mburu, G., Iorpenda, K., & Muwanga, F. (2012). Expanding the role of community mobilization to accelerate the progress towards ending vertical transmission of HIV in Uganda: The Networks model. *Journal of the International AIDS Society*, 15(S2), 173–186.
- Mills, E. J., Rammohan, A., & Awofeso, N. (2011). Ageing faster with AIDS in Africa. *Lancet*, 377(9772), 1131–1133.
- Ministry of Health, Uganda & ICF International. (2011). *Uganda AIDS indicator survey: Preliminary report*. Calverton, MD: Author.
- Ogden, J., Esim, S., & Grown, C. (2006). Expanding the care continuum for HIV/AIDS: Bringing carers into focus. *Health Policy and Planning*, 21(5), 333–342.
- Palliative Care Association of Uganda. (2009). *Audit report of palliative care services in Uganda*. Kampala, Uganda: Author.
- Schneider, H., Hlophe, H., & van Rensburg, D. (2008). Community health workers and the response to HIV/AIDS in South Africa: Tensions and prospects. *Health Policy and Planning*, 23(3), 179–187.
- Silverman, D. (2001). *Interpreting qualitative data: Methods for analysing talk, text and interaction*. London, United Kingdom: Sage.
- Stjernswärd, J. (2002). Uganda: Initiating a government public health approach to pain relief and palliative care. *Journal of Pain and Symptom Management*, 24(2), 257–264.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Newbury Park, CA: Sage.
- Uganda AIDS Commission. (2010). *UNGASS country progress report Uganda, January 2008-December 2009*. Kampala, Uganda: Author.
- Uganda AIDS Commission. (2012). *Global AIDS response progress report: Country progress report Uganda*. Kampala, Uganda: Author.
- UNAIDS. (2010). *Global report: UNAIDS report on the global AIDS epidemic 2010*. Geneva, Switzerland: Author.
- UNAIDS. (2012). *Together we will end AIDS*. Geneva, Switzerland: Author.
- Uys, L. R. (2002). The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *Journal of Clinical Nursing*, 11(1), 99–108.
- Wilkinson, S. (2004). Focus groups. In D. Silverman (Ed.), *Qualitative research: Theory, method and practice* (pp. 177–200). London, United Kingdom: Sage.
- Williams A. (2002). Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine*, 55(1), 141–154.
- World Health Organization. (2007a). *Task shifting to tackle health worker shortages*. Geneva, Switzerland: Author.
- World Health Organization. (2007b). *Everybody's business: Strengthening health systems to improve health outcomes: WHO's framework for action*. Geneva, Switzerland: Author.

- World Health Organization/UNAIDS. (2000). *Key elements in HIV/AIDS care and support*. Geneva, Switzerland: Author.
- World Medical Association. (2008). *WMA Declaration of Helsinki—Ethical principles for medical research involving human subjects*. Ferney-Voltaire, France: Author.
- Wouters, E., Van Damme, W., van Rensburg, D., Masquillier, C., & Meulemans, H. (2012). Impact of community-based support services on antiretroviral treatment programme delivery and outcomes in resource-limited countries: A synthetic review. *BMC Health Services Research*, 12(1), article 194.

APPENDIX 1: Interview Guide—Semi-Structured Interviews with Networks and Groups of People Living with HIV, Uganda

Interview guidelines

This interview guide indicates themes and topics that should be part of the interview. However, as mentioned during the training, please do not follow the questions too strictly. Most of them can be adapted, and should remain open-ended for the interviewee to respond. Also make sure that your questions are well understood—adapt your language to the age and understanding of the respondent.

Please also keep in mind the ethical issues we highlighted during the training. Approach the themes in a considerate manner, and do not force a response. Also be sensitive to any signs of anxiety, stress, or distress while conducting the interview, and be ready to take a break or end the interview if necessary. Please make sure you are able to refer adolescents to local services, if required.

Introduction

Example of introduction (please adapt as appropriate):

Good morning/afternoon. My name is _____. I am representing the research team conducting this study in collaboration with the Alliance Uganda, in partnership with TASO. The research focuses on networks of people living with HIV in Uganda. [See information sheet and consent form.] Your responses will be treated with complete confidentiality, and your name and identity will remain anonymous. The session will take about 60 minutes. Thank you in advance for your participation.

General background—family, friends, school, interests, hobbies

Ask the respondent questions about themselves and their background as an introduction to the interview. For example:

I thought we could begin the interview with you telling me about your background. It would be great if you could spend a few minutes talking about your family, friends, and household. It would also be nice to hear about your interests and what you like to do in your spare time.

Make sure you ask about the respondent's age, education, and household composition.

Topic 1: Relationships between networks and households of people living with HIV

1. What motivated people living with HIV in this community to join and become members of your group of people living with HIV?
2. How would you describe the relationships between the groups of people living with HIV and their households?
3. How would you describe the relationships among members of your group and members of similar groups of people living with HIV in the community? [Researcher: probe this response in particular.]

Topic 2: Role of networks in relation to disclosure and visibility

1. How do people living with HIV feel when they talk publicly about their HIV-positive sero-status?
2. What enables people living with HIV to disclose their HIV-positive sero-status to their partners, families, and other group and community members? How have community members responded to disclosure?
3. How has disclosure of HIV sero-status affected the lives of people living with HIV? How has it affected community members?

Topic 3: Role of networks in relation to HIV prevention and care

1. What HIV prevention and care activities are carried out by members of your group?
2. How have these activities reduced HIV transmission to community members who do not belong to your group?
3. What are some of the difficulties members of your group encounter as they provide and use HIV prevention and care services from the group? What have members of your group done to overcome these difficulties?

Close the interview

We have now reached the end of this interview. Is there anything else you think is important that we have not talked about today?

Do you have any questions about what we talked about? Is there anything you need more information about?

Thank the research respondent.

Researchers: Please identify whether the respondent needs any specialized support or to be referred to a specific health service.

APPENDIX 2: Interview Guide: Focus Group Discussions with Networks and Groups of People Living with HIV, and other Stakeholders in Uganda

1.1 Focus group discussion guide with members of groups of people living with HIV, Uganda

Focus group guidelines

This guide indicates themes and topics that should be part of the focus group. However, as mentioned during the training, please do not follow the questions too strictly. Most of them can be adapted, and should remain open-ended for group members to respond. Also make sure that your questions are well understood—adapt your language to the age and understanding of the participants.

Please also keep in mind the ethical issues we highlighted during the training. Approach the themes in a considerate manner, and do not force a response. Also be sensitive to any signs of anxiety, stress, or distress while conducting the focus group, and be ready to take a break or end the focus group if necessary. Please make sure you are able to refer adolescents to local services, if required.

Introduction

Example of introduction (please adapt as appropriate):

Good morning/afternoon. My name is _____. I am representing the research team conducting this study in collaboration with the Alliance Uganda, in partnership with TASO. The research focuses on networks of people living with HIV in Uganda. [See information sheet and consent form.] Your responses will be treated with complete confidentiality, and your name and identity will remain anonymous. The session will take about 60 minutes. Thank you in advance for your participation.

General background—family, friends, school, interests, hobbies

Ask the respondents questions about themselves and their background as an introduction to the focus group. For example:

I thought we could begin the focus group with you telling me about your backgrounds. It would be great if you could each spend a few minutes talking about your family, friends, and household. It would also be nice to hear about your interests and what you like to do in your spare time.

Now let's proceed and explore in detail a few questions relating to your roles. [Researcher, you do not have to follow the questions as ordered, but

allow the discussions to develop, as while you can refocus the discussions so that they are generally within the overall topics.]

Topic 1: Relationships between networks and households of people living with HIV

1. What motivated people living with HIV in this community to join and remain members of groups of people living with HIV?
2. How would you describe the relationships between members of these groups and their households?
3. How would you describe the relationships among members of your group, other groups, and similar groups of people living with HIV in the community?

Topic 2: Role of networks in relation to disclosure and visibility

1. How do people living with HIV feel when they talk publicly about their HIV-positive sero-status?
2. What enables people living with HIV to disclose their HIV-positive sero-status to their partners, family members, members of groups of people living with HIV and the community? How have community members responded to disclosure?
3. How has disclosure of HIV-positive sero-status affected the lives of people living with HIV? How has it affected community members?

Topic 3: Role of networks in relation to HIV prevention and care

1. What HIV prevention and care activities are carried out by members of groups of people living with HIV?
2. How have these activities reduced HIV transmission to community members who do not belong to groups of people living with HIV?
3. What are the difficulties members of groups of people living with HIV encounter as they provide and use HIV prevention and care services from groups? What have members of your group done to overcome these difficulties?

Close the discussion

We have now reached the end of this discussion. Is there anything else you think is important that we have not talked about today?

Do you have any questions about what we talked about? Is there anything you need more information about?

Thank the respondents.

Researchers: Please identify whether the respondent needs any specialized support or to be referred to a specific health service.

1.2 Focus group discussion guide with members of households of people living with HIV, Uganda

Focus group guidelines

This guide indicates themes and topics that should be part of the focus group. However, as mentioned during the training, please do not follow the questions too strictly. Most of them can be adapted, and should remain open-ended for group members to respond. Also make sure that your questions are well understood—adapt your language to the age and understanding of the participants.

Please also keep in mind the ethical issues we highlighted during the training. Approach the themes in a considerate manner, and do not force a response. Also be sensitive to any signs of anxiety, stress, or distress while conducting the focus group, and be ready to take a break or end the focus group if necessary. Please make sure you are able to refer adolescents to local services, if required.

Introduction

Example of introduction (please adapt as appropriate):

Good morning/afternoon. My name is _____. I am representing the research team conducting this study in collaboration with the Alliance Uganda, in partnership with TASO. The research focuses on networks of people living with HIV in Uganda. [See information sheet and consent form.] Your responses will be treated with complete confidentiality, and your name and identity will remain anonymous. The session will take about 60 minutes. Thank you in advance for your participation.

General background—family, friends, school, interests, hobbies

Ask the participants questions about themselves and their background as an introduction to the focus group. For example:

I thought we could begin the focus group with you telling me about your backgrounds. It would be great if you could each spend a few minutes talking about your family, friends, and household. It would also be nice to hear about your interests and what you like to do in your spare time.

Make sure you ask about the respondents' age, education, and household composition.

Topic 1: Relationships between networks and households of people living with HIV

1. What motivated people living with HIV in this community to join and remain members of groups of people living with HIV?
2. How do you interact with the members of groups of people living with HIV?

Topic 2: Role of networks in relation to HIV prevention and care

1. What HIV prevention activities are carried out by group members for community members?
2. What are the most important changes in the lives of community members that have resulted from activities implemented by the groups of people living with HIV?
3. What other impact has the networks and groups of people living with HIV had on your households, including and beyond care giving?

Close the discussion

We have now reached the end of this discussion. Is there anything else you think is important that we have not talked about today?

Do you have any questions about what we talked about? Is there anything you need more information about?

Thank the respondents.

Researchers: Please identify whether the respondents need any specialized support or to be referred to a specific health service.

1.3 Focus group discussion guide with key informants

Focus group guidelines

This guide indicates themes and topics that should be part of the focus group. However, as mentioned during the training, please do not follow the questions too strictly. Most of them can be adapted, and should remain open-ended for group members to respond. Also make sure that your questions are well understood—adapt your language to the age and understanding of the participants.

Please also keep in mind the ethical issues we highlighted during the training. Approach the themes in a considerate manner, and do not force a response. Also be sensitive to any signs of anxiety, stress, or distress while conducting the focus group, and be ready to take a break or end the focus group if necessary. Please make sure you are able to refer adolescents to local services, if required.

Introduction

Example of introduction (please adapt as appropriate):

Good morning/afternoon. My name is _____. I am representing the research team conducting this study in collaboration with the Alliance Uganda, in partnership with TASO. The research focuses on networks of people living with HIV in Uganda. [See information sheet and consent form.] Your responses will be treated with complete confidentiality, and your name and identity will remain anonymous. The session will take about 60 minutes. Thank you in advance for your participation.

General background—family, friends, school, interests, hobbies

Ask the participants questions about themselves and their background as an introduction to the focus group. For example:

I thought we could begin the focus group with you telling me about your backgrounds and how you interact with the networks and groups of people living with HIV. It would also be nice to hear about your interests and what you like to do in your spare time.

Make sure you ask about the respondents' age, education, and household composition.

Topic 1: Relationships between networks and households of people living with HIV

1. What motivated people living with HIV in this community to join and remain members of groups of people living with HIV?
2. How would you describe the relationships between members of these groups and their households?
3. How would you describe the relationships among members of groups of people living with HIV and other groups in the community?

Topic 2: Role of networks in relation to disclosure and visibility

1. How do people living with HIV feel when they talk publicly about their HIV-positive sero-status?
2. What enables people living with HIV to disclose their HIV-positive sero-status to their partners, family members, members of groups of people living with HIV, and the community? How have community members responded to disclosure?
3. How has disclosure of HIV-positive sero-status affected the lives of people living with HIV? How has it affected community members?

Topic 3: Role of networks in relation to HIV prevention and care

1. What HIV prevention and care activities are carried out by members of groups of people living with HIV?
2. How have these activities reduced HIV transmission to community members who do not belong to groups of people living with HIV?
3. What are the difficulties members of groups of people living with HIV encounter as they provide and use HIV prevention and care services from groups? What can be done to overcome these difficulties?

Close the discussion

We have now reached the end of this discussion. Is there anything else you think is important that we have not talked about today?

Do you have any questions about what we talked about? Is there anything you need more information about?

Thank the respondents.