

‘We are no longer called club members but caregivers’: Involving youth in HIV and AIDS caregiving in rural Zambia

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Abstract

This study assessed the strategy of building young people’s capacity to provide care and support to people living with HIV and AIDS in rural Zambia. Members of youth anti-AIDS clubs in schools and communities were trained as adjunct caregivers using a locally developed curriculum that allowed them to explore and challenge gendered notions of caregiving and emphasized networking with existing resources. Results show that caregiving increased among males (47% to 82%) and females (41% to 78%). Both sexes provided similar caregiving services, including help with household chores and personal care tasks. Youth also undertook activities with children to decrease their isolation, help them stay in school, and reach additional services. While clients and caregivers reported positive aspects of the programme, both reported frustration with the youths’ inability to meet material needs. This study demonstrates that trained youth already involved in anti-AIDS efforts can meet a range of care needs and be valuable assets to their community. It also highlights the importance of communicating clearly what youth can and cannot do, ongoing monitoring and support of youth caregivers, and involving community leaders to give youth credibility and access to local resources.

Introduction

The growing number of people living with HIV and AIDS in Zambia strains health systems and places a great care burden on families and communities. HIV prevalence in rural areas is fast approaching national prevalence levels (17.8% females, 12.9% males): e.g. in predominantly rural Luapula Province (approximately 700 km from Lusaka) prevalence had reached 13.3% among females and 8.6% among males (Central Office of Statistics/DHS, 2003). Despite recent evidence suggesting a reduction in sexual risk-taking (Central Board of Health/MEASURE, 2000), care and support requirements for already HIV-positive people and their families will remain high. Antiretroviral drugs remain out of financial reach for most people in Zambia, although access is increasing.

The diverse care and support needs of individuals with symptomatic HIV infection vary according to factors including stage of illness and availability of services. As disease progresses and physical capacity diminishes, individuals require increased assistance with domestic chores (e.g. cooking, laundry, fetching water and firewood) and personal tasks (e.g. bathing,

dressing wounds) for themselves and their dependents, especially when the sick individual is a mother (Foster, 1998).

Family willingness to care is high in Zambia: 94% of urban respondents and 85% in rural areas expressed willingness to provide care to a family member living with HIV (Central Board of Health/MEASURE, 2000). However, family structures need additional help to respond to the needs of HIV-positive people and their households (Seeley et al., 1993). According to traditional stereotypes in Zambia, as in most African countries, it is women who take the lead in caring for sick household members, in addition to their other domestic and economic responsibilities (Panos, 1990). Females tend to perform tasks associated with nurturing, while male caregivers fulfil roles associated with physical strength or money, such as carrying (Akin-tola, 2004) or paying for medical expenses (Taylor et al., 1996). Although females provide most care needs in Zambia, they are ill-equipped to do so, due to limited earning capacity and low socio-educational status (Macwangi et al., 1994). Within the home, young people in particular are increasingly

taking responsibilities for caring (UNAIDS, 2000; Robson, 2004).

In Zambia, home-based care (HBC) has emerged as a well-established complement to hospital care for individuals with symptomatic HIV infection (Chela et al., 1989; Chela & Siankanga, 1991). Lessons learnt from HBC in Zambia include the importance of community mobilization, working within traditional leadership and health-seeking behaviour models, and forming linkages with community groups (Jordan & Haworth, 1995; Foster et al., 1996; Burnett et al., 1999). Home-based caregivers provide nursing and counselling to alleviate physical ailments and mental distress, helping the HIV-positive individual and easing the primary caregiver's burden.

Traditionally HBC programmes rely on adult volunteers. We investigated whether youth members of school and community anti-AIDS clubs could contribute to care and support for HIV-positive individuals and their families. Under a Government-supported initiative, every primary and secondary school has an anti-AIDS club, providing opportunities for pupils to get involved in HIV prevention. Many communities also have youth anti-AIDS clubs, representing a more diverse membership body, addressing a range of social needs, including income-generating activities. Club membership is voluntary, with activities conducted under the guidance of club patrons/matrons including teachers and community members. Notwithstanding resource restrictions, school and community clubs conduct HIV and AIDS-related initiatives including 'red ribbon' stigma reduction campaigns, peer education and condom distribution.

Prior to this study, clubs did not focus on care and support. Yet earlier research from Northern Zambia indicated that many young people were already caring for chronically ill individuals, despite being ill-equipped (Esu-Williams et al., 2002). This paper discusses results from an intervention study to build club members' capacity to serve as adjunct caregivers in their communities.

Study aims

We aimed to determine which care and support needs trained young people could meet, and to explore how young males and females would respond to the idea of active involvement in caregiving.

Methods

Intervention

The intervention took place among communities in Mansa and Nchelenge districts, Luapula Province,

Zambia. Club members and local stakeholders (including church and community leaders, government officials) were enthusiastic about the idea of youth caregiving. A training curriculum was developed in partnership with community groups, emphasizing opportunities for youth to network with existing resources, involve community leaders, visit local health facilities, and explore and challenge gendered notions about caregiving.

We trained 12 local health professionals, who then trained 300 youth club members from 30 clubs. We provided support for clubs' educational and recreational activities, badges and aprons to reinforce group identity, and supplied kits containing materials for caregivers (e.g. dressings, disinfectant), which were regularly replenished. Ongoing training and supervision sessions provided the opportunity for youth caregivers to share experiences and for trainers to refresh skills and address emerging needs.

A local advisory group was established to give input into programme design and management, and to advocate for community support. Members included representatives of the AIDS Task Force; Ministries of Education, Community Development, and Health; NGOs; community leaders; churches; and the Catholic Diocese. The first programme referrals came from club members themselves, based on knowledge of relatives and neighbours with chronic illness (a commonly used euphemism for suspected HIV-related disease). As youth caregivers became more trusted, health providers, community members and elders began to refer other chronically ill people to the programme, indicating the importance of community support.

Data collection and analysis

We present data from two cross-sectional rounds of semi-structured interviews with club members before and after the intervention (March 2001, September 2002), sampled from 16 of the 30 clubs. We also discuss data from qualitative research conducted at the second survey round, including in-depth interviews ($n = 14$ clients, 3 caregivers) and focus group discussions (FGDs) with clients and family members. We draw on insights from participatory data interpretation workshops with club members and stakeholders conducted after the second round.

Interviewers were locally recruited and trained. Quantitative data were entered using Epi Info 6.0 and EpiData and analysed in SPSS. Only respondents aged 13–25 years were included in the analysis. Pearson's chi-square test of independence was used to determine significance except when calculating the difference between median values, when the Wilcoxon rank sum test was used.

Results

Respondent profile

We analysed survey responses from 365 youths at round 1 (200 male, 165 female) and 496 at round 2 (280 males, 216 females). Most respondents (55%) ranged in age from 15–19 years. At baseline, the mean age of male respondents was 18.0 years, and 16.2 years among females. Almost all respondents were single and over 70% were currently in school. Approximately half of the males (49%) and females (53%) reported that they lived with both parents. Respondent characteristics remained comparable at the second cross-sectional round, as some new club members joined and others graduated and left club activities. Among males there were small but statistically significant changes in mean age (18.7 years) and in the percentage living with both parents (36%).

Involvement in club and caregiving activities

At baseline, interviewers asked youth respondents whether they had provided care to a family member or neighbour who was chronically ill in the past six months, reflecting local sensitivities to asking directly about HIV. At the second round, caregiving increased dramatically: from 47% to 82% among males ($p < 0.001$) and from 41% to 78% among females ($p < 0.001$). The median number of clients during the preceding three months was four (range 1–15) for male caregivers and three for females (range 1–15). Qualitative findings indicate that most club members visited clients weekly.

Respondents reportedly became more comfortable interacting with people living with HIV: those saying that they felt fine with caregiving increased between rounds from 81% to 90% among males

($p < 0.05$), and from 72% to 91% among females ($p < 0.05$).

Youth services and client needs

Recognizing concerns from formative research that male and female youths would feel pressure to carry out tasks in line with traditional expectations (Williams, 2002), trainers explicitly discussed gender norms with youth, and found that they were open to exploring and challenging them. Although youth and clients expressed clear preferences for same-sex help with bathing and personal care, they agreed that the most important factor was to make clients comfortable with quality care. According to a youth caregiver from Mabumba Community Anti-AIDS Club: ‘Some ... worry about whether they are cared for by a boy or girl. But their main concern is whether we do the things that help them, not which sex we are.’

By the second survey, male and female caregivers had overcome initial gender concerns and provided similar services to their clients (Figure 1). Qualitative research indicated that youth still felt some of the more physically demanding tasks (e.g. digging, cutting firewood, roof repairs) should be reserved for males whereas lighter domestic tasks (e.g. washing plates, clothes) are more suited to females. Tasks generally agreed to be suitable for carers of both sexes included dressing wounds and general cleaning.

Male and female respondents reported that the services for which they were most helpful were: cleaning/housework (87%), changing dressings and treating sores (50%), counselling (44%), and making referrals (25%). They perceived clients’ unmet needs to include food (71%), money (58%), medicines (52%) and transport (32%). Results showed no

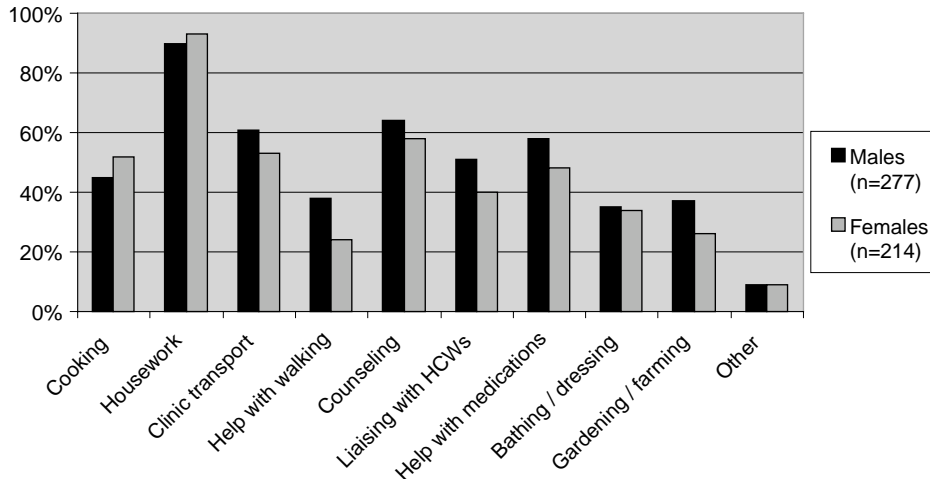


Figure 1. Services provided to clients by respondents in the last year (Round 2). Note: (HCWs =health care workers).

statistically significant differences between males' and females' responses. Survey findings were consistent with the results of in-depth interviews and FGDs with clients. Both youth caregivers and clients reported frustration with their inability to meet material needs including food, medicine and transportation. As noted by a client from Mantumbusa, 'The caregivers helped by cleaning the sores, and they have healed. My problem is that I can't afford to buy food and the necessary medicines'.

Youth caregivers desired additional training to improve the services they provided in counselling (57%), first aid (52%), nutrition (31%) and discussing HIV testing with family members (29%).

Meeting the needs of vulnerable children

During club meetings, youth caregivers reported that many clients' major anxiety was their children's welfare. In response, training was expanded to recognize the specific needs of children living in families affected by HIV. Trainers encouraged caregivers to devise initiatives involving children in recreational activities to reduce their sense of isolation, to contact schools to recognize their needs, and to make referrals to clinics and NGOs working with vulnerable children if additional support was required.

By the second survey, males had assisted more children affected by AIDS in the last three months (median:5, range: 1-30) than females (median:3, range: 1-30, $p < 0.01$). Respondents reported that services commonly provided were counselling, help with chores, and contacting clinics and schools. As shown in Figure 2, differences between males and females in the types of activities they carried out with children were small. However, qualitative findings

indicated that males felt confident and responsible conducting recreational activities for large groups of community youth (e.g. a football game), while females were more comfortable paying attention to individual children's needs.

Promoting care within the household

Youth caregivers were encouraged to build clients' and family members' capacity to carry out some tasks themselves. Clients reported that they and their families had learned much from caregivers, such as treating sores and rashes, and that youth caregivers had motivated family members and neighbours to be more accepting and supportive of client needs. Caregivers reported similar findings: as noted by a youth caregiver from the Muchinka Youth Club, 'We are teaching the families to care for patients. We monitor by watching if there is the right response to our teaching.'

Local Partnerships

Programme staff worked with local stakeholders to develop partnerships promoting active collaboration with youth caregivers. During training, youth gained first-hand knowledge of other services locally available through a field visit to a clinic providing care for people who are HIV-positive and HIV voluntary counselling and testing. Linkages with local health centres allowed youth caregivers to learn about services and when to refer clients. Clinic staff acceptance of youth caregivers, indicated by referrals, enhanced the community credibility of youth caregivers.

Community leaders' involvement was crucial during the programme's initial stages to generate

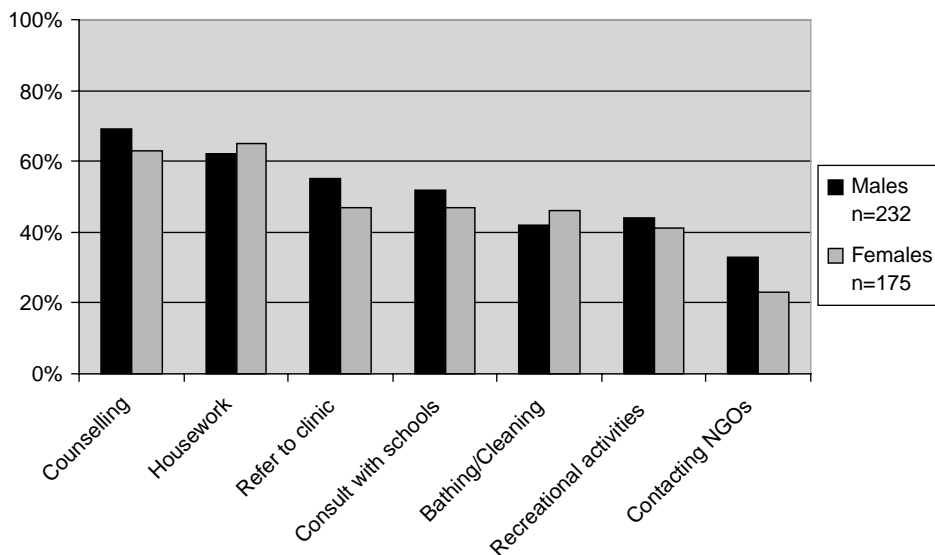


Figure 2. Services provided to children by trained youth caregivers in the last year (Round 2).

support and enhance access to new clients and existing services. Caregivers noted that endorsement by community leaders increased acceptance of their activities. 'Headmen go ahead of time to inform the community of our care and support activities,' said one youth from Mutiti Basic School Anti-AIDS Club. Another from Kampampi Basic School Anti-AIDS club noted, 'Our village head gives us protection and if a problem arises, he is there to solve it.'

Partnership with local HBC programmes was particularly important in developing training and mentorship. Youth caregivers worked closely with adults trained and experienced in providing HBC, who provided them with supervision, skills training, psychosocial support, and mentoring.

In FGDs, youth caregivers reported that these broad-based local partnerships helped promote community support for their new caregiving role, reinforcing their motivation, and helping to address challenges.

Responses to the initiative: clients and youth caregivers

Clients indicated that they appreciated the services, and perceived trained youth caregivers as respectful, well informed and well trained. Almost all (95%) respondents who provided care reported a change in clients' attitudes, including becoming more friendly and trusting, and increased disclosure of HIV status. Some clients requested more visits or referred others to youth caregivers' services.

Youth caregivers reported that they too experienced benefits; including achieving satisfaction from serving their communities, gaining respect of communities and leaders, increasing skills, and achieving a new status permitting access to institutions and services. However, some reported experiencing emotional distress when client needs were beyond their capabilities, such as dealing with rejection and family disputes, funeral arrangements or severe hunger, and required additional counselling.

According to one youth caregiver from the Kabuta Basic School Anti-AIDS Club, 'We are no longer called Anti-AIDS club members but caregivers ...' Another from the Mwililwa Community Anti-AIDS Club said, 'The communities are changing and becoming more involved. They no longer chase caregivers away, they prepare food for us and sometimes donate things which we give to [clients].'

Discussion

Anti-AIDS club members were particularly suitable to serve as adjunct caregivers because they were eager to learn and implement new skills, and keen to volunteer. Most youth were literate, attentive and already had basic knowledge of HIV and AIDS,

making them easy to train. Although this was a self-selecting group of young people already involved in HIV activities, youth caregivers showed striking openness to exploring traditional gender norms about appropriate caregiving roles and networking with community care resources.

Possible explanations for male caregivers' higher median value of orphans to whom they provided a service are that that males have more time and freedom than females. Researchers observed that males needed less parental consent to participate in activities outside home than females. Youth feedback also indicated that females' domestic responsibilities were spread out throughout the day (e.g. cooking, collecting foodstuffs), while males' responsibilities for farming activities are mainly concentrated in the morning, leaving more time to make caregiving visits. Discussion of caregiving tasks during FGDs indicated that while females were more likely to carry out tasks within the privacy of individual households, males rose to the challenge of active involvement in public service outside the domestic sphere.

Health care workers and clients reported that trained youth caregivers were flexible and helpful regarding work availability and the types of work they would undertake. However, home-based caregiving is a difficult and intensely personal task, whose effectiveness relies upon caregiver sensitivity and skill, client and family openness, and communication. Young people trained for these difficult tasks require more monitoring, encouragement and supervision than adult caregivers. Programme managers must clearly communicate to clients and community members the range of needs that youth caregivers are equipped to meet, and provide youth caregivers with support to deal with their inability to fulfil more material needs.

Training youth home-based caregivers requires wide participation, including local health facilities and community leaders. Linkages with local stakeholders extend the scope of services beyond what youth can provide alone, legitimize youth caregiving services, and increase partners' understanding of each other's capabilities. Developing local partnerships was instrumental in addressing youth caregivers' challenges, enhancing their credibility and motivation, and providing support in problem-solving and community mediation.

Conclusions

The study demonstrated that trained youth caregivers already involved in anti-AIDS efforts were able to meet a range of care and support needs of individuals and families affected by HIV, to the satisfaction of their clients. Their efforts may be laying the foundation for increased interaction

between individuals and families affected by HIV and their communities, even in relatively isolated areas. Moreover, young people in this study – particularly males – responded positively to responsibilities that required them to challenge traditional gender norms.

This study clearly showed that involving youth provided an appropriate and acceptable method for providing much-needed adjunct care services for people affected by HIV/AIDS – one that requires little external resources. With appropriate training and back-up, young people can provide a service making tangible improvements to clients' lives. Since caregiving is already a daily reality for many of these young people, challenging myths of childhood as dominated by play, schooling and innocence (Robson, 2004), we do not accept the argument that relying on the labour of young people as caregivers is exploitative or an abuse of their rights. In this context, we seek to build their capacity and provide support for voluntary work considered appropriate for young people in their communities.

Programme start-up relied on small-scale funding and technical assistance from two international NGOs. Costs were minimized by using existing resources to train and support youth already organized into anti-AIDS clubs. As the intervention progressed, the role of the international stakeholders diminished, and local partners increased their roles: club patrons are independently seeking engagement of additional stakeholders and resources. Partnerships with schools, social welfare organizations and local NGOs have been particularly successful, with many children now receiving support to attend school. Other local partnerships have stimulated income generation activities and linkages with treatment programmes. A follow-on study continues to investigate programme sustainability.

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