

Involving Youth in the Care and Support of People Affected by HIV and AIDS

Young people in Zambia trained to provide care and support to individuals and families affected by AIDS have proven to be a vital resource to their communities. In a country where adult HIV prevalence is 13 percent among males and 18 percent among females, reaching 23 percent in urban areas (Zambia DHS 2001-2002), communities are seeking new ways of helping those infected and affected by the disease.

As the needs of people living with HIV and AIDS (PLHA) and orphans and vulnerable children (OVC) continue to escalate, results from an intervention study by the Horizons Program, in partnership with Care International and Family Health Trust, provide a promising picture of young peoples' potential to contribute to community-based care and support activities. The study also indicates that involving young people in the care and support of persons affected by HIV and AIDS may have a positive effect on their adoption of some protective behaviors.



KATIE SCHENK/POPULATION COUNCIL

Trained youth caregivers, Nchelenge district.

Study Description

This quasi-experimental intervention study sought to determine which care and support needs of PLHA and their families can be met by trained youth and to establish whether youth engaged in formalized care and support activities would increase their adoption of protective behaviors or reduce the level of stigma faced by members of AIDS-affected households.

The youth who participated in the study belonged to school and community anti-AIDS clubs. All schools in Zambia, from primary through secondary school, are required to form anti-AIDS clubs to give students the opportunity for involvement in HIV prevention education and related activities. Community anti-AIDS clubs represent a more diverse group of youth and address a broader range of social needs,

including income generation. Club members act as role models and peer educators within their school or community. Clubs are led by patrons and matrons, who may be school teachers, clinic officers, or community leaders. Both school and community clubs conduct recreational and HIV/AIDS activities, including football and netball games, drama, “red ribbon” HIV awareness campaigns, and distribution of information and condoms.

Horizons conducts global operations research to improve HIV/AIDS prevention, care, and support programs. Horizons is implemented by the Population Council in partnership with the International Center for Research on Women (ICRW), the Program for Appropriate Technology in Health (PATH), the International HIV/AIDS Alliance, Tulane University, Family Health International, and Johns Hopkins University.

community members for formalizing youth caregiving. This information was used to develop the care and support intervention activities. To assess outcomes, research staff conducted two rounds of structured interviews with club members, cross-sectionally sampled from 16 of the 30 clubs in each area, chosen at random. The quantitative results are considered statistically significant at the 0.05 level; p-values were calculated using Pearson’s chi².

The study was conducted in semi-urban and rural communities in two provinces of northern Zambia located up to 1,000 km from Lusaka. Thirty clubs in Mansa and Nchelenge districts in Luapula Province served as intervention sites; an equal number in Mporokoso and Kasama districts in Northern Province served as comparison sites.

Members, patrons, and matrons from all 60 clubs, which include groups based within schools and communities, received training in HIV/AIDS prevention and club management. In addition, clubs in the intervention area received training, materials, and ongoing support for caring for PLHA and OVC.

Data Collection and Analysis

The study began by collecting qualitative data that revealed enthusiasm among youth and

During the 18-month interval between rounds, training workshops and caregiving support activities took place. Qualitative data were also collected throughout the study by means of focus group discussions and in-depth interviews involving caregivers, patron/matrons, PLHA, and their family members. To help interpret data, club members and stakeholders participated in local results dissemination meetings.

The age range of survey respondents analyzed was from 13 to 25 years, almost all of whom were single (see Table 1). Club members include youth who are themselves orphaned or living in households possibly affected by HIV and AIDS, as evidenced by the fact that only about half of the sample at both rounds lived with both parents. Slight variations in mean age and school attendance limit comparability between the intervention and comparison groups; the final report explores age-stratified data.

Table 1 Respondent profile

	Intervention (Luapula)				Comparison (Northern)			
	Round 1 April 2001		Round 2 Sept 2002		Round 1 April 2001		Round 2 Sept 2002	
	Males n = 200	Females n = 165	Males n = 280	Females n = 216	Males n = 209	Females n = 222	Males n = 269	Females n = 218
Mean age (years)	18.0	16.2	18.7	16.7	17.7	16.5	17.8	16.2
% in school	75.3	90.1	72.6	89.7	84.4	91.7	80.6	89.7
% living with both parents	48.7	52.2	36.1	49.5	42.9	55.8	31.2	40.4
% single	94.0	99.4	89.6	96.8	96.6	98.2	92.2	95.0

Description of the Intervention

All 60 clubs in both intervention and comparison areas received basic training in club management and HIV prevention, and materials for recreational activities (e.g., footballs, netballs, drums). Clubs in the intervention area also received enhanced training in care and support, with an emphasis on how to network with existing resources and services, such as NGOs, OVC programs, clinics, and home-based care (HBC) teams (see Table 2). Kits provided to each club included items to help the caregivers treat sores and prevent infection (gloves, disinfectant, soap, cotton wool, gentian violet, bandages), document their experiences and collect data (pens and notebooks), and reinforce their group identity as youth caregivers (uniform aprons and badges). Replenishing the care and support kits every three months enhanced motivation among caregivers. Each club in the intervention area was also provided with two bicycles to help members reach PLHA in more remote areas.

Developing the care and support training curriculum¹ for youth and training the trainers who were drawn from local health professionals took approximately six months (Table 3). The

Table 2 Club activities in the intervention and comparison areas

	Intervention (Luapula)	Comparison (Northern)
Club management training	✓	✓
HIV prevention training and material support (e.g., condoms and educational materials)	✓	✓
Care and support training and provision of kits	✓	
Networking and building partnerships with community care and support services	✓	
Advocacy activities to reduce stigma and promote acceptance of youth caregivers	✓	

curriculum covered a wide variety of topics, including HIV voluntary counseling and testing (VCT), stigma reduction, community- and home-based care, needs of OVC, children's rights, protecting the caregiver, and gender and cultural issues in caregiving and prevention. Training also covered monitoring and reporting of activities and included a field component to gain first-hand experience.

Key Findings

Caregiving activities among youths increased in the intervention area.

At the first survey round, almost half of both males and females in both areas reported that they recently provided care to a family member or neighbor with a chronic illness, although few had the appropriate knowledge and skills to deal with the complex health needs and social issues

Table 3 Stages of care and support training

Stage	Time	Activities
Stage 1	March-June 2001	<ul style="list-style-type: none"> Curriculum development with youths and stakeholders.
Stage 2	August 2001	<ul style="list-style-type: none"> Training of 12 local health professionals as trainers.
Stage 3	September 2001	<ul style="list-style-type: none"> Training of 300 youth caregivers from 30 clubs and providing kits. Field component: opportunity to visit clinics, VCT centers, and HBC programs.
Stage 4	November 2001	<ul style="list-style-type: none"> Follow-on training to ensure that every club member had the opportunity to be fully trained. Commencement of ongoing training sessions to address specific needs and concerns raised by caregivers during the course of their work.

associated with HIV/AIDS. Little change in care activity by respondents was documented in the comparison area at follow-up, while the proportion of youth in the intervention area reporting that they provided care almost doubled by the second survey. For example, club members in the intervention area providing care increased from 47 percent to 82 percent for males and from 41 percent to 78 percent for females ($p < 0.05$).

Although high at the first round, trained youth caregivers' comfort level in providing care to PLHA increased, with females reporting the greatest gains (72 percent to 91 percent, $p < 0.05$) compared to males (81 percent to 90 percent, $p < 0.05$). By the follow-up survey, intervention area club members reported that they conducted one to two visits per week to families affected by HIV and AIDS, with females caring for an average of approximately four PLHA and four OVC and males caring for an average of four PLHA and five OVC in the last three months. In the comparison area, youths reported caring for fewer PLHA and OVC (Figure 1).

Trained youth caregivers successfully provided a wide range of services but were unable to meet basic material needs.

Youth caregivers reported that they were most able to provide help with cleaning, nursing care, counseling, and making clinic referrals, and PLHA reported satisfaction with these services.

However, both youth caregivers and PLHA reported dissatisfaction with the youths' inability to meet material needs, including food, medicine, and transportation. Contrary to early concerns that youths would only do tasks according to expected gender roles, researchers found that male and female caregivers provided similar kinds of care-giving services, including counseling and housework. Although same-sex caregivers were required for bathing, the only other activity in which a gender difference appeared was in contacting external organizations for assistance, which was reported by a greater proportion of males.

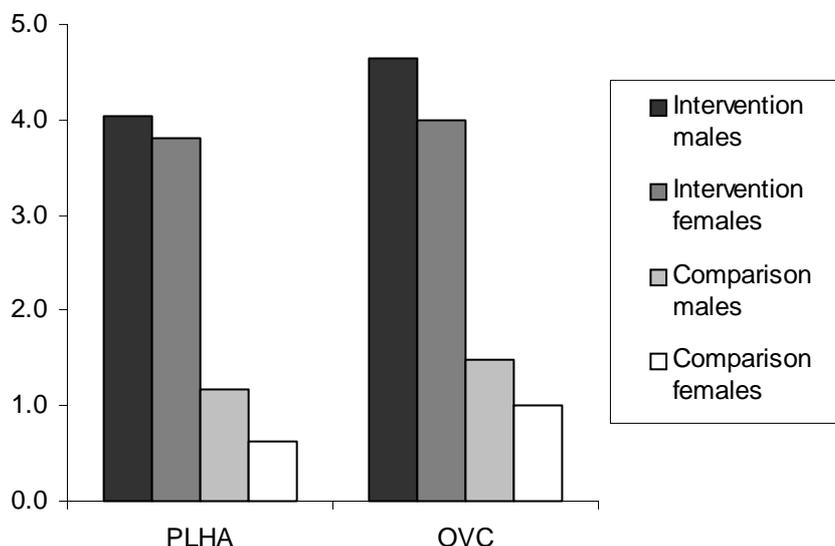
OVC emerged as a key concern for PLHA and caregivers.

The study originally focused on meeting the needs of PLHA, but trained youth caregivers soon began reporting that children of PLHA in the homes they were visiting also required care and support. As a result, the intervention was expanded to include the specific needs of OVC. The youth caregivers were encouraged to involve OVC in recreational activities in an attempt to reduce their sense of isolation, to contact schools to make sure that their needs are recognized, and to make referrals to NGOs working with OVC in cases where additional support is required.

Caregivers and PLHA felt positively about the program.

Male and female caregivers alike appear to have been well received by the PLHA; trained youth caregivers reported that PLHA were friendlier and requested more visits over time. Reported increases in disclosure of HIV status to them by PLHA indicated a growing level of trust of the youth caregivers. Trained youth caregivers reported a number of benefits, including achieving satisfaction from serving their communities, gaining the respect of communities and leaders, increasing their own knowledge and skills, undertaking income-generating activities, and achieving a new status that permitted access to institutions and services. Some also said that the caregiving activities had provided

Figure 1 Mean number of PLHA and OVC cared for in last 3 months at round 2



them with the motivation to change their own sexual behavior. Despite the benefits of the program, some youths said they experienced emotional distress when caring for PLHA and OVC with needs that were beyond their capabilities, such as dealing with rejection and family disputes, funeral arrangements, or severe food shortages.

Youth in the intervention area increasingly believe that they are at risk of HIV infection.

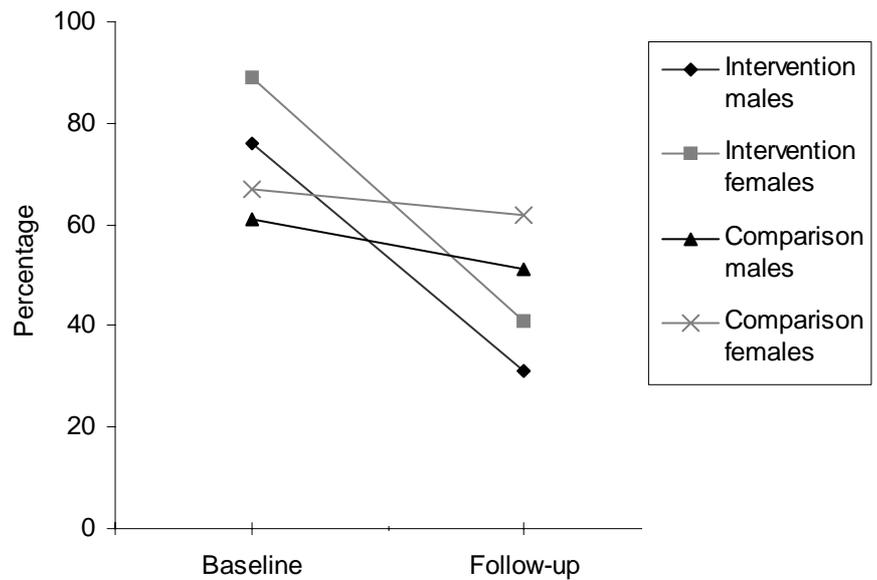
Youth in the intervention area became significantly more aware that they were potentially at risk of HIV infection during the course of the study. Figure 2 shows that in the intervention area, males believing that they were not at risk of infection dropped sharply from 76 percent to 31 percent ($p < 0.05$), and from 89 percent to 41 percent among females ($p < 0.05$). Smaller declines were apparent in the comparison area, where youth also received prevention training (males: 61 percent to 51 percent; females: 67 percent to 62 percent, NS). Discussion at the dissemination workshops revealed that the greater change in perception of risk in the intervention area could be attributed to respondents' enhanced awareness of the consequences of HIV through increased contact with PLHA, some of whom were close to their own age.

Perceptions of who is at risk of HIV infection changed in the intervention area, as youth increasingly recognized that females are more vulnerable (males: 61 percent to 74 percent, $p < .05$; females: 50 percent to 69 percent, $p < 0.05$). There was no statistically significant change in the comparison area, although baseline levels were similar.

Youth reported high levels of abstinence.

Recent sexual activity among anti-AIDS club members was low, with high levels of reported abstinence (including secondary abstinence²) among males and females. At the first round, 64 percent of males and 88 percent of females in the intervention area reported that they had not had sex during the three months preceding the

Figure 2 Proportion of youth who believe they are not at risk for HIV infection



survey, and this did not change significantly at the second round. Among respondents who said that they had had sex during this period, most of them (68 percent of males, 90 percent of females) claimed to have had only one partner, with no significant changes at follow-up. In the comparison area, 79 percent of males and 90 percent of females said that they had not had sex in the three months preceding the survey. Of those who had sex during this period, 74 percent of males and 100 percent of females reported that they had one partner.

Peer pressure and gift giving influence risk behaviors.

As with many young people, respondents in this study indicated that peer pressure is an important influence on risk behaviors, including their consumption of alcohol and drugs and having a boyfriend or girlfriend. Both males and females mentioned the exchange of sex for gifts as an added pressure on young people, allowing them to acquire food or money for basic needs or luxuries for themselves or their families. For example, in the first round, 6 percent of males and 16 percent of females in the intervention area, and 11 percent of males and 13 percent of females in the comparison area had exchanged sex for gifts. Participants in the dissemination workshops corroborated the existence of sexual exchange by females and males, and cited examples of boys pressured into sex with older women, often businesswomen. They also felt that

orphans might be particularly vulnerable to forced sex and highlighted the need to raise the issue of forced sex within the extended family.

Reported condom use increased only among trained youth caregivers, although it was already high in both areas.

Among the youths who reported that they had had sex, ever-use of condoms was similar between the two study areas at baseline, but increased significantly only in the intervention area: among males from 61 percent to 81 percent ($p < 0.05$), and among females from 67 to 81 percent ($p < 0.05$). Among those who reported that they had ever used a condom, reported condom use at last sex was high and changed little, fluctuating at around 80 to 90 percent of males and females.

Although the youths felt that their knowledge of condoms improved through the prevention training, and their motivation to protect themselves from HIV increased through the care and support activities, club members at the dissemination meetings revealed that condoms are still used inconsistently, reflecting respondents' limited ability to get condoms and some respondents' negative views of condoms within long-term relationships. These barriers call into question the accuracy of the high reported rates of condom use.

Youth in the intervention area increasingly acknowledged joint responsibility for providing a condom.

At baseline in the intervention area, 84 percent of males and 74 percent of females believed that supplying a condom should be the responsibility of males, and the frequency of this response dropped significantly by the second round (to 58 percent of males and 54 percent of females, both $p < 0.05$) as youth recognized that condoms were a joint responsibility. Little change in this indicator was observed in the comparison area, where approximately 70 percent of all respondents at both survey rounds said that supplying a condom was a responsibility for males.

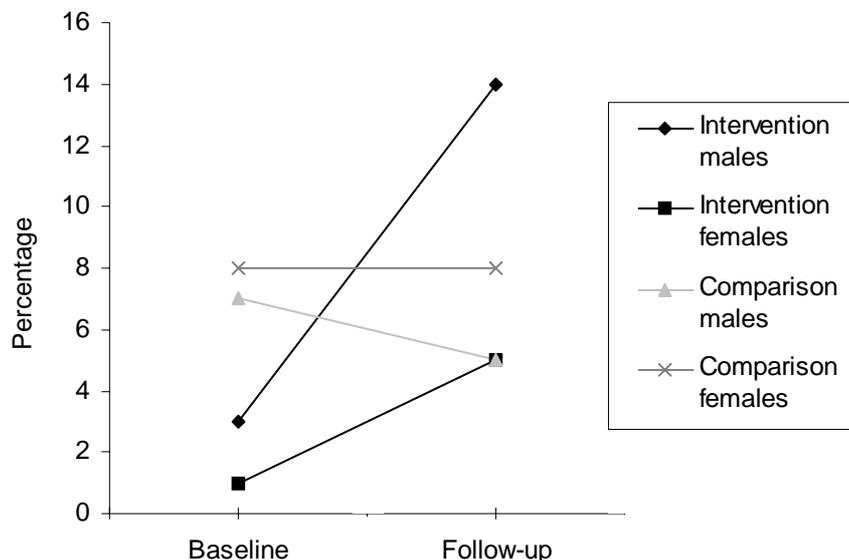
Anti-AIDS club members reported that they have changed their behavior.

In both study areas, youth were asked whether they had changed their behavior since joining the anti-AIDS clubs. Youth in both intervention and comparison areas reported statistically significant increases in ever-use of condoms and restricting sexual activity to one partner. Although these data may not reflect the same trends as the indicators above, they may represent respondents' intentions to change and improved prevention awareness. In the intervention area, there was a significant increase (although overall levels were low) in males and females who reported asking their partner to be faithful, indicating enhanced partner communication (see Figure 3), while youth in the comparison area remained virtually unchanged. At the dissemination workshops, the participants explained that being a member of an anti-AIDS club was a great motivation for behavior change, and that the behavior of club members was qualitatively very different from that of their non-club member peers.

There was no change in stigmatizing attitudes among trained youth caregivers, who already felt positive about PLHA.

Almost all indicators used for stigma showed high levels of acceptance of PLHA by youth in both study areas and survey rounds, with no gender differences, and this was not increased or eroded at follow-up. Most youths said they would feel

Figure 3 Youth who reported that they asked partner to be faithful





Anti-AIDS club members examine study findings.

comfortable about shaking hands with, using the same plate as, or working with PLHA. The only indicator that dropped significantly was whether PLHA deserved compassion, which fell among youth in the comparison area only, from 79 percent to 67 percent ($p < 0.05$). In the intervention area, where youth had closer contact with PLHA, 90 percent of youth felt that PLHA deserved compassion, which was maintained at 91 percent at follow-up.

Trained youth caregivers reported a decrease in perceived community stigmatization of families affected by AIDS.

In the first survey round, approximately one fifth of youth in both study areas said that PLHA are treated badly in the community. Examples cited in the dissemination workshops included verbal abuse, isolation, rejection, rumors, and gossip, which were felt to be worse in the villages than the semi-urban areas. The quantitative results did not change between surveys, but qualitative methods revealed that some PLHA and youth caregivers felt that the program was beginning to make a difference.

Our community is beginning to accept PLHA since youth caregivers started visiting; they are not as fearful as before.
PLHA, Kale Community

We have noticed that family members are beginning to take more interest in caring for relatives with HIV/AIDS.

Youth caregiver, Mantumbusa
Community Club

When survey respondents were asked about families who have lost members to AIDS, there was a significant increase in the proportion of youth in the intervention area who felt they were treated the same as others by the community (64 percent to 78 percent; $p < 0.05$). No similar improvement was recorded in the comparison area. This shift may be due to specific advocacy activities conducted by trained youth caregivers to encourage support of AIDS-affected families, as well as increased visibility of the program in the targeted communities (e.g., youth wore special aprons that identified the program) and involvement of village heads.

Headmen go ahead of time to inform the community of our care and support activities.

Mutiti Basic School
Club caregiver

Our village head gives us protection and if a problem arises, he is there to solve it.

Kampampi Basic School
Club caregiver

Lessons Learned for Replication and Scale-up

The study demonstrates that trained youth caregivers are able to meet a range of PLHA and OVC needs, to the satisfaction of their clients, and that their efforts may be laying the foundation for decreased isolation and stigmatization of AIDS-affected families. Lessons learned from the study include the following:

- Involvement of community leaders is important at the initial stage of the program to promote acceptance of youth caregivers, generate community support, and enhance access to PLHA and their families.
- The range of needs that youth caregivers can meet must be clearly communicated to PLHA to avoid raising false hopes of receiving food or medicines, or to lead them to expect nursing support beyond the capabilities of the caregivers.
- Ongoing monitoring and training are essential to strengthen capacity and improve services provided by youth caregivers. Youth caregivers may require psychosocial support to address stress and burnout.
- Collaboration with health centers, HBC and OVC programs, schools, and health and social welfare departments is vital to improve access to care for PLHA, as well as access to VCT for their household members. Youth caregivers can play a vital role in referral to these services.
- Providing bicycles help youths reach isolated PLHA living in remote areas and transport them to clinics. Use and ownership of and maintenance responsibilities for the bicycles must be clearly defined.

Next Steps

Horizons and partners are implementing an 18-month program to mobilize local resources and promote local management. The goal is to transfer ownership of the program to the community in order to sustain youth involvement in care and support activities.

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Notes:

¹ Horizons Program, Youth Caregivers Training Manual, Zambia, 2003. Available upon request by contacting horizons@pcdc.org

² Defined as formerly sexually active youths who had refrained from sex during the period under question in the survey (three months).

Acknowledgments

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