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Looking back, moving forward: Improving the lives of orphans and other children affected by AIDS, Horizons studies 1998 to 2007

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Looking Back, Moving Forward

Improving the Lives of Orphans and Other Children Affected by AIDS

Horizons Studies 1998 to 2007
In 1997, the Population Council initiated the Horizons Program—a decade-long USAID-funded collaboration with the Family Health International, the International HIV/AIDS Alliance, Johns Hopkins University, International Center for Research on Women, PATH, Tulane University, and the University of Alabama at Birmingham—designing, implementing, evaluating, and expanding innovative strategies for HIV prevention and care.

Horizons developed and tested ways to optimize HIV prevention, care, and treatment programs; worked to reduce stigma and improve gender-biased behaviors; and greatly expanded knowledge about the best ways to support, protect, and treat children affected by HIV and AIDS. In all its projects, Horizons strengthened the capacity of local institutions by providing support and training to colleagues.

This series of synthesis papers presents lessons learned and best practices on six key topics that Horizons investigated: HIV-related stigma, access to Antiretroviral Therapy, men who have sex with men, orphans and vulnerable children, HIV and gender, and prevention of mother-to-child transmission of HIV.
Improving the Lives of Orphans and Other Children Affected by AIDS

In 1997, the Horizons Program began studying the care and support of orphans and vulnerable children (OVC) in sub-Saharan Africa, focusing on large gaps in our understanding of how AIDS affects children and how caregivers were coping. The research showed that children understandably suffer considerable distress at the illness and death of their parents, but that succession planning, linking children with community resources, participation in mentorship programs, and other programs can significantly improve well-being. Horizons researchers developed tools for assessing the well-being of children affected by HIV and outlined key ethical guidelines for conducting research with children. The design, implementation, and evaluation of community-based OVC interventions continues to be a key gap in the evidence base.

Introduction

Studies conducted in sub-Saharan Africa in the early 1990s documented a rise in the number of orphans and the breakdown of protective social networks and supports for them as a result of the AIDS epidemic [1, 2]. A landmark study in 1997, revealed that globally the number of orphans was increasing and that experience responding to orphaning as a social problem was limited [3].

As an initial response, some international and local agencies established orphanages. Child advocates soon criticized this approach as inefficient and unsustainable, undermining traditional models of family and community care, and creating adverse psychological and social effects among children and families [4, 5]. At the same time, many program implementers began to recognize what communities had long noted, that children whose parents had died of AIDS were not the only children affected by the epidemic. The operational term “orphans and vulnerable children” or OVC was thus coined to include not only orphaned children but also children considered vulnerable to shocks (such as living with a parent who is chronically ill) that endangered their health and well-being.

As the numbers of vulnerable children steadily grew with the increasing numbers of adults infected with HIV, so did the demand for greater knowledge about the lives and needs of OVC, their families, and their caregivers. The UN’s Millennium Development Goals, the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR), and other important health and development initiatives incorporated
OVC programming into their platforms. Yet little research had been done and few tools were available to measure the psychosocial manifestations of vulnerability and to evaluate approaches to reduce associated negative outcomes. There were limited data available to answer the key questions of what works in providing care and support to children and families, and how best to offer it.

Against this backdrop, in 1997 the Horizons Program began an ambitious agenda of operations research, which included a focus on the care and support of orphans and other children rendered vulnerable by HIV and AIDS in sub-Saharan Africa. These studies (Appendix) were conducted in collaboration with numerous local and international research and program implementation partners in several countries.

This paper summarizes the key contributions of the Horizons research portfolio among orphans and vulnerable children in describing the impacts of the epidemic on children, assessing the effectiveness of community-based interventions, identifying insights from program implementation, and improving methods for researching OVC programs. Based on this information, this paper concludes with recommendations for future programming and research aimed at mitigating the negative effects of AIDS on children, families, and communities.

**Diagnosing the Problem**

As Horizons began to develop its research agenda, it became clear that there were large gaps in our understanding of how AIDS affects children and how caregivers were coping. Yet this information was critically important to identify which populations to target and develop interventions to address the most serious problems.

Prior to the Horizons Program, OVC research had emphasized material deprivation. Horizons research gave equal attention to psychosocial distress experienced by children affected by AIDS. In a study in Rwanda, 55 percent of youth heads of households reported symptoms of clinical depression, and said that their parents’ deaths had negatively affected their confidence in other people, the meaning they placed on their own lives, and their religious beliefs. Over one-half reported feeling that life was no longer worth living at least some of the time, and 4 percent had attempted suicide in the two months preceding the survey [6].

In a study in Zimbabwe, vulnerable youth reported experiencing multiple distresses, including stigma, rejection in times of need, and the absence of adults to talk to about relationships and problems (Table 1). More than half reported feelings of worry or stress, irritability, sadness, difficulty concentrating, being overwhelmed, and hopelessness during the past month [7].

Horizons studies identified adult support as an important missing link in the psychosocial well-being of vulnerable children and youth. In the study in Zimbabwe, youth emphasized the need to talk with adults about relationships,

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**Table 1 Traumatic and stigmatizing psychosocial life experiences among OVC in Bulawayo, Zimbabwe**

<table>
<thead>
<tr>
<th>Experience</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>People saying bad things about them or avoiding them because of their family’s situation</td>
<td>52</td>
</tr>
<tr>
<td>Being rejected, neglected, or abandoned by their relatives when they needed them</td>
<td>51</td>
</tr>
<tr>
<td>Losing the support of their friends when they needed them</td>
<td>49</td>
</tr>
<tr>
<td>Having too much responsibility or work</td>
<td>37</td>
</tr>
</tbody>
</table>
but many felt that adults did not acknowledge
the challenges young people face in dealing
with HIV. The youth felt belittled when trying
to discuss romantic relationships [7]. In some
cases, family disputes—often about property or
other resources—alienated them from the adult
relatives to whom they would normally go for
advice. Half of the respondents felt that they
were not consistently supported by the adults
in their lives [7].

Research highlighted the range of health
risks and limited access to material and social
resources experienced by children who have
been orphaned. At three rural sites in South
Africa, a Horizons study found that orphans
were more likely to leave school than non-
orphans and were more likely than their peers
to cite financial constraints and sickness as the
reason for dropping out [8]. Horizons also doc-
umented risky sexual behaviors among orphans
in communities in KwaZulu-Natal, South
Africa, including a younger age of sexual debut
and a higher rate of transactional or survival
sex, compared to non-orphans [9].

The death of a parent is not the only driver of
vulnerability; parental illness from HIV can
instigate such feelings in youth. An important
finding documented by Horizons and partners
is that children’s vulnerability often begins
once a parent is diagnosed as HIV-positive or
becomes ill. For example, in a Horizons study
in Uganda, about a quarter of teens with HIV-
positive parents reported a decline in school
attendance and performance when parents
became ill. The study also found that many
parents had not taken key steps to inform and
protect their children should they become ill
and die, such as disclosing their HIV status,
appointing a guardian, and writing a will [10,
11].

Horizons studies in several settings found that
being female increased vulnerability. In South
African communities highly affected by HIV,
girls were more likely than boys to be out of
school regardless of whether or not they had
been orphaned [8]. Similarly, Horizons stud-
ies among vulnerable youth in Rwanda [12,
13], Zimbabwe (Table 2) [7], and South Africa
[9] have shown girls are more likely than boys
to report depression, traumatic life events,
and low self-esteem, and to report their first
sexual intercourse as unwilling. Women and
girls also take on a disproportionate share of
the burden of caring for orphans and vulner-
able children in many settings, which can have
negative repercussions for their own health and
well-being [14, 15]. A Horizons study con-
ducted in eight districts in South Africa found
that female-headed households were more
likely than male-headed households to include
orphans and vulnerable children [8, 16].

Age is also important when considering vulner-
ability. A Horizons study in Zimbabwe found
that older youth had higher trauma scores and
exhibited more signs of psychosocial distress—
such as feeling “alone in the world,” hopeless,
and worried—than their younger peers [7].
These results may reflect the challenges and
responsibilities—such as unemployment and
caring for younger siblings—that befall many older youth.

In communities that are deeply affected by AIDS, care for orphans and vulnerable children often falls on the elderly, especially elderly women. In Kenya and South Africa, Horizons studies found that caring for OVC can compromise older caregivers’ emotional well-being and encroach on time available for involvement in social and economic activities. Elderly caregivers in South Africa reported feeling they have little influence on the behavior of youth, sometimes expressing a sense of confusion and hopelessness [17]. Despite these burdens, many caregivers interviewed in Kenya and South Africa cited a sense of satisfaction in caring for ill adults and their young family members [17, 18].

Still, children may face significant hardships when raised by elderly caregivers. In Kenya, Horizons found that children who depend upon elderly caregivers often drop out of school and are expected to complete heavy workloads in the home. Also, some children may experience inadequate or inappropriate levels of discipline [18].

A significant number of children whose mothers are HIV-positive are themselves infected with the virus. While still limited, pediatric HIV testing and treatment services are increasingly becoming available to help these highly vulnerable children. Horizons studies conducted with partners in Kenya and South Africa have documented several obstacles that interfere with access to pediatric HIV care and treatment. These include limited community awareness of the indications for HIV testing among children; parental fear that if their children test HIV-positive, their own HIV status will be publicly revealed; providers of home-based care not identifying potentially HIV-infected children or promoting testing; and feelings of fatalism and loss of hope among surviving parents and guardians [19, 20].

### Table 2  Sex differences among orphans and vulnerable children in psychosocial distress and well-being outcomes in Bulawayo, Zimbabwe

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosocial distress*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt irritable or bothered</td>
<td>43</td>
<td>54</td>
</tr>
<tr>
<td>Felt nothing in life interested them</td>
<td>34</td>
<td>45</td>
</tr>
<tr>
<td>Felt alone in the world</td>
<td>33</td>
<td>42</td>
</tr>
<tr>
<td>Spent a lot of time sleeping</td>
<td>56</td>
<td>68</td>
</tr>
<tr>
<td>Had headaches or stomachaches</td>
<td>56</td>
<td>68</td>
</tr>
<tr>
<td>Had no appetite</td>
<td>38</td>
<td>53</td>
</tr>
<tr>
<td>Felt sad</td>
<td>59</td>
<td>66</td>
</tr>
<tr>
<td>Cried</td>
<td>44</td>
<td>64</td>
</tr>
<tr>
<td>Had nightmares</td>
<td>53</td>
<td>59</td>
</tr>
<tr>
<td>Felt others are targeting them</td>
<td>50</td>
<td>58</td>
</tr>
<tr>
<td>Psychosocial well-being*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel confident in themselves</td>
<td>83</td>
<td>74</td>
</tr>
<tr>
<td>Feel hopeful about the future</td>
<td>81</td>
<td>75</td>
</tr>
<tr>
<td>Enjoy spending time with friends</td>
<td>94</td>
<td>90</td>
</tr>
</tbody>
</table>

*D Differences experienced sometimes or most of the time in the last month between males and females are statistically significant p < .05 for each type of psychosocial distress and psychosocial well-being.*

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**Pioneering Intervention Strategies**

These findings helped shape a number of intervention strategies that were developed and tested by Horizons and partners through opera-
Improving the Lives of OVC

In Uganda, Horizons researchers assessed a succession planning program that aimed to reduce uncertainty and fear among adults and children about the children’s future well-being. The program provided counseling to HIV-positive parents on disclosure to children, support for appointing standby guardians, training in legal literacy and will writing, and training and seed money for income-generating activities. The study documented significant increases among parents in the appointment of guardians, a doubling in the number of wills written, and an increase in parents telling their children they have HIV. These results prompted international agencies and donors to acknowledge the importance of this approach and recommend expansion of the program [10, 11].

Mentoring child-headed households

Horizons research in Rwanda found that through regular home visits, trained adult volunteers developed a stable, caring relationship with children and youth living without an adult caregiver. High levels of depression, maltreatment, and marginalization were reported at baseline. Follow-up data two years later indicated greater positive psychosocial changes among young heads of households who had been supported by adult volunteers, compared to young heads of households not in contact with volunteers. Data showed that youth household heads perceived the greatest benefits when the mentors visited them and their siblings at least twice a month [12, 13].

Training young people as volunteer caregivers

Horizons studies in Zambia and South Africa demonstrated the feasibility and value of training young people to serve as volunteer caregivers within their communities. Although a program in Zambia initially aimed to train young people to help care for adults suffering from chronic illness, it became apparent that many of the young caregivers spent considerable time supporting children in these AIDS-affected households by providing counseling, help with homework and chores, and assistance in navigating health and education services. Young caregivers also reported that regular visits to these households helped decrease stigmatization of their HIV-infected clients by family and community members [21, 22]. In South Africa, young people trained as caregivers provided psychosocial support and HIV education to primary school students living in vulnerable settings. Horizons research showed that this program was associated with improved HIV-related knowledge, more frequent communication about AIDS, and more accepting attitudes toward people infected and affected by HIV [23].

These studies also found that young caregivers reported gaining valuable skills and knowledge in first aid, counseling, and making contacts with healthcare facilities and schools [21–23]. In Zambia, survey data show that condom use increased among sexually active young caregivers after participating in the program (Figure

“Before, we had no hope for the future. After being advised, we felt courageous. . . .this program helped us a lot.”

—17-year-old male participant in the Rwanda community-based mentoring child-headed households program study
1) [22]. Qualitative data reveal that young caregivers gained satisfaction from serving their communities and earning respect from local leaders. Program staff and stakeholders reported that young people were easy to train as caregivers and were flexible about their availability and the type of household work they carried out, including domestic chores. Male caregivers showed a remarkable willingness to participate equally in caregiving activities traditionally carried out by females [21, 22].

**Addressing the needs of elderly caregivers**

Building on formative research in South Africa that described the substantial caregiving burden borne by the elderly [17], Horizons and partners piloted a community-based intervention to address the needs of elderly caregivers and barriers to providing high-quality care. The intervention consisted of a series of workshops on intergenerational communication, basic nursing care, how to gain access to social services and grants, and relaxation techniques. Study findings revealed that elderly caregivers who participated in the intervention experienced improved knowledge about HIV, increased self-esteem, less anxiety about the future, and reduced anger toward their dependents. Further, elderly caregivers reported gaining valuable new skills from the workshops, such as how to better communicate with young people [24].

**Linking children with community resources**

Horizons studies emphasized the importance of networking to link OVC programs with existing community resources and clinical services. In Zambia, partnerships with local health and social welfare institutions legitimized the efforts of young caregivers and extended the scope of activities beyond what they could have carried out alone [21, 22]. Partners provided supplies, school fees and materials for their clients’ children. Capacity-building activities developed the ability of young caregivers to generate resources. Partnerships with local community groups and institutions also provided crucial elements of support and reinforcement to other volunteer caregivers. For example, home-based care providers in Malawi sought communica-
tion and collaboration with village health committees, church groups, and traditional healers [25], while similar programs in Zambia provided valuable mentoring and support to volunteer young caregivers [22]. In South Africa, elderly caregivers benefited from workshops conducted as a result of collaboration between health, social development, and community organizations [24].

Horizons’ studies illustrate the importance of the participation of local community members and stakeholders at each step of program development and implementation, including community leaders, parents/guardians, and teachers. The mentorship program in Rwanda demonstrated that giving the volunteer adult mentors decision-making power to set direction for the program catalyzed broader community support for orphans and vulnerable children and helped sustain activities [12, 13].

Supporting volunteer caregivers

To reduce program costs and make the most of existing resources, many programs train volunteers as caregivers. Horizons’ evaluation data support the value of this approach but also emphasize the importance of providing ongoing training, support, and incentives to motivate caregivers and sustain high-quality programs.

In Zambia and South Africa, trained young caregivers reported experiencing stress and emotional distress when caring for AIDS-affected children, particularly when confronted by family disputes, funeral arrangements, and food shortages [21, 22]. These volunteers benefited from support provided to them by the programs and referrals to more comprehensive community services when needed. Training and ongoing support must prepare caregivers to best define their role, to be aware of limitations in what they can and cannot provide, and to be able to communicate this to their clients.

Lack of recognition and recompense for volunteer caregivers can be barriers to long-term program sustainability [23, 25, 26]. In South Africa, the attrition rate among volunteer young caregivers was high due to lack of financial reimbursement and transportation, and to “poaching” from competing NGOs [23]. But in Rwanda, very few adult mentors dropped out of the mentorship program for youth-headed households over an 18-month period. Program implementers found that factors contributing to these high volunteer retention rates included: involving volunteers in key program decisions, holding monthly support meetings, formally recognizing and appreciating the volunteers’ work, and providing access to income-generating opportunities [12].
Developing Ethical and Innovative Research Methods

Horizons recognized that there were methodological and ethical gaps in conducting research on issues regarding orphans and vulnerable children. Through its work in sub-Saharan Africa, Horizons has contributed to the development of research measures and ethical guidelines that have helped the field better understand and measure the psychosocial dimensions of vulnerability, develop and test responses to improve psychosocial outcomes, and protect children while collecting data for these purposes.

Measuring psychosocial well-being

In Uganda and Zimbabwe, researchers developed, tested, and refined measures of psychosocial well-being [7, 11]. This shaped later research in Rwanda that tested new measures of social support, grief, maltreatment, and marginalization [13]. Box 1 shows items from the grief and marginalization scales that were part of the instrument used to examine the impact of an adult mentorship program on youth-headed households.

Outlining ethical guidelines for research with children

Recognizing the need for guidance in the conduct of social and behavioral research among children affected by HIV, Horizons spearheaded the development of a document [29] that highlights the responsibilities of research staff to ensure that such activities are conducted ethically with the utmost regard for children’s health, well-being, and rights. This pioneering document identifies challenges confronting program implementers and investigators and proposes practical solutions [30]. Among topics covered by the publication are gaining meaningful informed consent from children and creating opportunities for children to partici-
Moving Forward: Research and Program Priorities

As Horizons ends a decade of research on orphans and vulnerable children, how will its pioneering efforts help shape and encourage future research and programs? Evidence from the Horizons OVC portfolio indicates that the practical and ethical challenges of conducting research among children in vulnerable circumstances are not insurmountable. Horizons demonstrated that diagnostic studies and sound evaluations of community-based interventions are not only possible but yield rich findings and that quasi-experimental research designs and process evaluations provide valuable and scientifically valid frameworks for building the empirical data on OVC care and support programs.

Horizons’ studies have documented a range of HIV-related impacts that critically affect the health and well-being of orphans and vulnerable children and demonstrated that programs can make tangible improvements to the lives of children and families affected by AIDS. Important findings highlight the value of adult support and guidance; the need to focus on the circumstances of girls, women, and the elderly; the importance of meeting ethical standards in research among children who are vulnerable; and the fundamental understanding of vulnerability as broader than orphanhood. They also underscore the potential of community members—including youth and adults—to be part of the solution to the problems facing AIDS-affected families.

While community-based psychosocial support programs and caregiving interventions—such as the interventions evaluated by Horizons in Rwanda, Zimbabwe, Zambia, and South Africa—have proven beneficial to many participants, these programs may not be able to improve all aspects of all participants’ health and well-being. Horizons’ research indicates that future program priorities must include the development of functional links between care and support interventions for orphans and vulnerable children and other key services for young people, such as HIV prevention and life-skills education, health services, including access to antiretroviral treatment, and livelihood support.
A focus on links, referrals, and, where appropriate, program integration can help service providers meet the many and diverse needs of vulnerable young people while safeguarding their rights. It may also contribute to greater program coverage and efficiency. Additionally, proactive engagement with community members, networking and capacity-building of local organizations, and systematic priority setting are key to long-term program sustainability.

Yet important work remains. The evaluation of community-based OVC interventions continues to be a key gap in the evidence base. Developing and scaling up appropriate interventions requires research guided by the input of community members and stakeholders to ensure that programs are achieving their desired goals without harming children or jeopardizing their rights. The resulting data will enable program implementers, policymakers, and donors to decide which strategies are most effective and how they should be implemented. While investment in rigorous evaluation is initially resource intensive, the long-term payoff of developing a solid evidence base will ensure that future spending is directed at producing better outcomes for more children.
## Summary of Horizons OVC research portfolio

<table>
<thead>
<tr>
<th>Study title and country</th>
<th>Dates</th>
<th>Horizons’ partners</th>
<th>Study design</th>
<th>Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Our hearts are willing, but…” Challenges of elderly caregivers in rural Kenya [18]</td>
<td>2003</td>
<td>Plan International Kenya</td>
<td>Community-based qualitative study.</td>
<td>Focus group discussions (FGDs) and in-depth interviews (IDIs) with community leaders and elderly caregivers.</td>
</tr>
<tr>
<td>Factors affecting access to ART and HIV care services for OVC: A situation analysis in the Mariannhill area of KwaZulu-Natal [19]</td>
<td>2007</td>
<td>Medical Research Council, St Mary’s Hospital</td>
<td>Diagnostic study. Mini-surveys and FGDs/IDIs among health service providers and caregivers for orphans and vulnerable children from the Mariannhill communities. FGDs/IDIs among community health workers and staff of local orphanages and institutions caring for OVC.</td>
<td></td>
</tr>
<tr>
<td>Study Title and Country</td>
<td>Dates</td>
<td>Horizons’ Partners</td>
<td>Intervention</td>
<td>Study Design</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Assessment of the community-based options for protection and empowerment program, Namwera, Malawi [25]</td>
<td>1998–1999</td>
<td>Save the Children US-Malawi</td>
<td>Village committees formed to catalyze community-based HIV prevention and care activities.</td>
<td>Retrospective, qualitative evaluation including FGDs and IDIs.</td>
</tr>
<tr>
<td>Succession planning in Uganda: Early outreach for AIDS-affected children and their families [10, 11, 31]</td>
<td>1999–2002</td>
<td>Makerere University, Department of Sociology, Plan Uganda</td>
<td>Counseling to help HIV-positive parents disclose to their children and appoint guardians, training on will writing, provision of school fees and vocational training, training for standby guardians.</td>
<td>Quasi-experimental study with intervention and comparison arms.</td>
</tr>
<tr>
<td>Orphans and vulnerable youth in Bulawayo, Zimbabwe: An exploratory study of psychosocial well-being and psychosocial support programs [7]</td>
<td>2003–2004</td>
<td>Regional Psychosocial Support Initiative (REPSSI), Catholic Relief Services-STRIVE Program, Salvation Army Masiye Camp</td>
<td>Community psychosocial support programs, including Kids’ Clubs, a residential camp, and peer leader training.</td>
<td>Qualitative research followed by a survey.</td>
</tr>
<tr>
<td>Assessing the psychosocial benefits of a community-based mentoring program for youth-headed households in Rwanda [6, 12, 13, 27, 32–34]</td>
<td>2004–2006</td>
<td>World Vision Rwanda, Rwanda School of Public Health, Tulane University</td>
<td>Adult volunteer mentors trained to provide guidance and support to children and youth living without an adult caregiver.</td>
<td>Quasi-experimental study with intervention and comparison groups.</td>
</tr>
<tr>
<td>A pilot community-based intervention program to address the needs of elderly caregivers in the Eastern Cape Province, South Africa [17, 24]</td>
<td>2006–2007</td>
<td>Medical Research Council</td>
<td>Four workshops focusing on HIV, intergenerational communication, home-based care, social services and grants, and relaxation techniques.</td>
<td>Quasi-experimental study with intervention and comparison groups.</td>
</tr>
<tr>
<td>Involving young people in the care and support of people living with HIV/AIDS in Zambia [21, 22, 26, 35]</td>
<td>2000–2002</td>
<td>CARE Zambia, Family Health Trust</td>
<td>Anti-AIDS clubs train youth to provide care and support to people living with HIV. Clubs also supplied with care kits and bicycles.</td>
<td>Quasi-experimental study with intervention and comparison arms.</td>
</tr>
<tr>
<td>---</td>
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</tr>
<tr>
<td>Training youth caregivers to provide HIV education and support to orphans and vulnerable children in South Africa [23]</td>
<td>2005–2006</td>
<td>The Valley Trust</td>
<td>18–24 year old youth trained to provide HIV education, homework assistance, and psychosocial support to OVC aged 11–15 years.</td>
<td>Pre-post test design.</td>
</tr>
</tbody>
</table>


Acknowledgments

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