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The Well-Being of Children Affected by HIV/AIDS in Lusaka, Zambia, and Gitarama Province, Rwanda: Findings from a Study

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This publication was produced for review by the United States Agency for International Development. It was prepared by Minki Chatterji, Leanne Dougherty, Tom Ventimiglia, Yvonne Mulenga, Andrew Jones, Antoinette Mukaneza, Nancy Murray, Kathy Buek, William Winfrey, and Joseph Amon.



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Abbreviations

AIDS	Acquired immune deficiency syndrome
CHH	Child-headed household; Child heads of households
DHS	Demographic and Health Survey
FHI	Family Health International
HH	Heads of households
HIV	Human immunodeficiency virus
HBC	Home-based care
IMCI	Integrated Management of Childhood Diseases
IMPACT	Implementing HIV/AIDS Prevention and Control
IRB	Institutional Review Board
MTCT	Mother-to-child transmission
NGO	Nongovernmental organization
OVC	Orphans and vulnerable children
PABA	People affected by AIDS
PLHA	Person living with HIV/AIDS
SLI	Standard of Living Index
STI	Sexually transmitted infection
TB	Tuberculosis
USAID	U.S. Agency for International Development
VCT	Voluntary counseling and testing

Definition of Terms

Considerable variation exists in definitions of such terms as child, adolescent, youth, orphan, and “vulnerable.” The list below presents our definitions of these terms as used in this report.

Adolescent: Persons aged 13–19

Child-headed household: Household characterized by a child under age 20 acting as a guardian for siblings, relatives, and other children

Child: Persons aged 6–12

Children with chronically ill caregiver: Children and adolescents ages 6-19 who are not orphans, but have a chronically ill parent or caregiver

Comparison group: Households identified by nearest neighbor approach

Intervention group: Households identified by NGOs

Maternal orphan: Children 19 years old and younger who have lost their mother only

Orphans: Children 19 years old and younger who have lost either their mother or father (single orphan) or both parents (double orphan)

Paternal orphan: Children 19 years old and younger who have lost their father only

Primary caregivers: Parent, surviving parent, or guardian who is responsible for children’s welfare; specifically the person who prepares meals, bathes children (in the case of young children) and seeks medical attention when the child is ill

Sexually active adolescents: Adolescents ages 13–19 who have ever had sex

Youth: Persons aged 15–24

Summary

Introduction

In sub-Saharan Africa an estimated 12 million children under the age of 18 have lost one or both parents to AIDS (UNAIDS, UNICEF, USAID, 2004). Many more children live with one or more chronically ill parent. Despite the recognition of the magnitude and significant health, economic, social, and psychological consequences of this problem, and increasing attention and resources devoted to these children, few evidence-based answers are available to such basic questions as “which children are in the greatest need of assistance?,” “what interventions are most effective?,” and “which approaches are most appropriate in the different settings in which AIDS epidemics are seen?” Thus, donors, policymakers, and program managers have often been forced to make decisions regarding allocation of scarce resources for orphans, children with chronically ill parents, and other children affected by HIV/AIDS using little evidence about which children are most in need of assistance and what types of interventions would be most effective in helping them.

The Community REACH program is conducting an effectiveness study of selected interventions targeting orphans and children ages 6–19 with chronically ill caregivers.¹ This research is being implemented in collaboration with Community REACH grantees CARE Rwanda, Bwafwano, and PCI Zambia. Community REACH has also produced a companion report entitled, *A Costing Analysis of Community Based OVC Programs: Results from Rwanda and Zambia*, which provides information regarding the costs of these service delivery programs.

Objective of the report

The objective of this report is to analyze data from the first round of data collection in 2003 to compare differences in measures of educational, socioeconomic, health and nutritional, and psychological well-being among three groups of children in the comparison sample only: 1) orphans, 2) children who are not orphans, but have a chronically ill parent or caregiver, and 3) other children. This study does not use data relating to children from intervention households because these children were already exposed to interventions for 6–12 months prior to the survey and thus may have already derived positive benefits from the interventions.

As programs for orphans and children with chronically ill caregivers are designed in accordance with the belief that these groups of children are disadvantaged relative to other children, exploring differences among these groups is critical. Examining the variation in measures of well-being among these three groups of children will also suggest what types of children should be targeted and what criteria should be used by NGOs starting new programs or scaling up existing programs. Future research will examine the effectiveness of specific interventions.

The research questions examined in this report are:

- Do households with orphans and/or children ages 6–19 with a chronically ill caregiver have lower socioeconomic status than households that do not have orphans or children with a chronically ill caregiver in this age group?

¹ The Community REACH program conducted the baseline survey, and the endline survey will be implemented by MEASURE Evaluation.

- Do orphans and children with a chronically ill caregiver ages 6–19 have lower levels of educational, socioeconomic, health and nutritional, and psychological well-being as compared to other children in the same age group?

Methods

The research design used for the overall intervention effectiveness study is a modified quasi-experimental pre-test/post-test study design. In the design, which includes a baseline (reported here) and an endline survey, intervention group households with orphans or children with a chronically ill parent or caregiver receiving interventions (selected from project registers) will be compared to a comparison group of households selected using a “nearest neighbor” approach. The first round of data collection was conducted in mid-2003, and the same respondents will be interviewed in mid-2005. This report is based on analysis of data from the first round of data collection and only includes the comparison sample respondents.

The Zambia data used for the analyses in this paper includes 496 primary caregivers, 504 children ages 6–12, and 563 adolescents ages 13–19. The Rwanda data used for this report has 570 primary caregivers, 656 children ages 6–12, and 402 adolescents ages 13–19. Data were cleaned and analyzed using SPSS software.

For the analyses of the education, socioeconomic, and health and nutrition data, bivariate analyses and Pearson chi-square tests were used to test associations among the groups of children and various measures of well-being. Household-level socioeconomic measures were also calculated using standard of living indices (SLI). Scales intended to measure various aspects of psychological well-being were constructed, and the reliability of these scales was assessed using the internal consistency method.

Results applicable to both Zambia and Rwanda

- *Education:* Approximately 70 percent of 6–12 year olds in both countries was enrolled in school, but only about 50 percent of 13–19 year olds is in school. Findings did not suggest that there are any differences in school enrollment among orphans, children with chronically ill caregivers, and other children ages 6–19 in Zambia and Rwanda.
- *Socioeconomic status:* At the individual level, orphans and children with a chronically ill caregiver are worse off with regard to possession of a blanket, shoes, and an extra set of clothes compared to other children in both countries.
- *Health and nutrition:* Lower proportions of orphans and children with chronically ill caregivers ages 6–12 in particular have indicators of good health compared with other children in Zambia and Rwanda.
- *Risk behaviors:* Findings do not suggest any differences in age of sexual debut among orphans, children with chronically ill caregivers, and other children in Zambia and Rwanda.
- *Risk knowledge:* Higher proportions of orphans in both Zambia and Rwanda are knowledgeable about HIV/AIDS than are other children, yet these children may still be more vulnerable than other children to contracting HIV/AIDS and other STIs.

Key findings specific to Zambia

- *Socioeconomic status:* Households with orphans and children living with chronically ill caregivers have lower socioeconomic status, as measured by the SLI score, compared with households that do not have children from these groups in Zambia.
- *Health and nutrition:* Orphans and children with chronically ill caregivers have lower food intake than other children in Zambia.
- *Risk behaviors:* Higher proportions of orphans and children with chronically ill caregivers have ever consumed alcohol compared with other children in Zambia.
- *Risk knowledge:* Children with chronically ill caregivers are less knowledgeable about HIV/AIDS than are other children in Zambia.

Key findings specific to Rwanda

- *Socioeconomic status:* There is no difference in household wealth among households with orphans, children living with chronically ill caregivers, and other children in Rwanda.
- *Health and nutrition:* While the overall level of food intake appears low, there is no difference among the three groups of children in terms of food intake in Rwanda.
- *Risk behaviors:* Lower proportions of orphans and children living with chronically ill caregivers report ever having consumed alcohol compared with other children in Rwanda.
- *Psychological well-being:* Orphans and children with chronically ill caregivers ages 6–12 demonstrate slightly higher levels of worry than other children in Rwanda. Children ages 6–12 with chronically ill caregivers have higher levels of burden than other children in Rwanda.

Program and policy implications based on results that are consistent across both countries

- Educational programs should target all out-of-school children, not only orphans and children with chronically ill caregivers. Adolescents ages 13-19 in particular need encouragement and support to stay in school.
- Program implementers need to develop proven and sustainable interventions to help improve the individual material well-being of children. In addition, programs should consider providing assistance with basic needs and include children with chronically ill caregivers in such programs.
- Policies should ensure that national maternal and child health (MCH) programs give particular attention to orphans and children with chronically ill caregivers. In particular, the primary caregivers of these children, some of which are very young (15–24) or older (50+), need to be targeted by health promotion campaigns that typically reach mothers ages 25–49.
- Program implementers need to develop programs that help orphans translate their increased HIV/AIDS knowledge into safe behavior. These children should also be encouraged to educate their peers.

Conclusions

- *There appears to be no uniform approach to identifying children in need of assistance that is appropriate for all contexts in AIDS-affected communities in sub-Saharan Africa.* The results from this report do not present a simple story regarding children affected by HIV/AIDS in these areas of Zambia and Rwanda as many findings from this study are not consistent across both countries. Program implementers and policymakers must use existing data or collect additional data to ensure that programs for children affected by HIV/AIDS are context-specific.
- *Orphanhood status should not be the sole criterion for eligibility for interventions.* The findings from this report suggest that, in general, the magnitude of differences in well-being among orphans, children with chronically ill caregivers, and other children is not large. NGOs should identify target groups through the use of a variety of measures.
- *Children with chronically ill caregivers should be treated as a distinct group from orphans.* The results from this report suggest that these children may have needs and vulnerabilities distinct from those of orphans. Children in AIDS-affected areas are often referred to as “orphans and vulnerable children” or “OVC.” Use of this terminology, however, is not very descriptive for the non-orphans in this group of children, and policymakers and program implementers may not make necessary distinctions among orphans, children with chronically ill caregivers, and other vulnerable children in the community as a result.
- *Measurement of psychological well-being of children in HIV/AIDS-affected areas in sub-Saharan Africa should be further investigated and refined.* Given the possible adverse psychological consequences on a child of a parent’s illness and death, program implementers desperately need reliable and valid methods to measure the psychological well-being of children and determine their needs.

Chapter 1: Introduction

In sub-Saharan Africa an estimated 12 million children under the age of 18 have lost one or both parents to AIDS (UNAIDS, UNICEF, USAID, 2004). Many more children live with one or more chronically ill parent. Despite the recognition of the magnitude and significant health, economic, social, and psychological consequences of this problem, and increasing attention and resources devoted to these children, few evidence-based answers are available to such basic questions as “which children are in the greatest need of assistance?,” “what interventions are most effective?,” and “which approaches are most appropriate in the different settings in which AIDS epidemics are seen?” Thus, donors, policymakers, and program managers have often been forced to make decisions regarding allocation of scarce resources for orphans, children with chronically ill parents, and other children affected by HIV/AIDS using little evidence about which children are most in need of assistance and what types of interventions would be most effective in helping them.

The Community REACH program is conducting an effectiveness study of selected interventions targeting orphans and children ages 6–19 years with chronically ill caregivers.² This research is being implemented in collaboration with Community REACH grantees CARE Rwanda, Bwafwano, and PCI Zambia. These organizations provide a wide range of services for orphans and other vulnerable children including educational support, income generation, food assistance, behavior change communication interventions, and psychosocial support.

Community REACH is using the same research design and survey instruments to examine these interventions in two contrasting contexts. The objective is to identify and compare those characteristics that appear successful within the specific context of one country or across two diverse settings. In Rwanda, the research team is examining the effectiveness of service delivery interventions in Gitarama province, a post-conflict rural setting in the Great Lakes region. Community REACH is also assessing interventions conducted in peri-urban areas in Lusaka, Zambia, a Southern African country that has not recently experienced war, but is in an advanced stage of the HIV/AIDS epidemic with a prevalence of 16.5 percent (UNAIDS, 2004). The samples in both countries consisted of children living in households that were currently receiving support services (intervention group) and children living in households that were not being targeted by interventions (comparison group). Local NGOs identified and provided services to eligible households. Community REACH has also produced a companion report entitled, *A Costing Analysis of Community Based OVC Programs: Results from Rwanda and Zambia*, which provides information regarding the costs of these service delivery programs.

The objective of this report is to analyze data from the first round of data collection in 2003 to compare differences in measures of educational, socioeconomic, health and nutritional, risk behaviors and knowledge, and psychological well-being among three groups of children in the comparison sample only: 1) orphans, 2) children who are not orphans, but have a chronically ill parent or caregiver, and 3) other children who are neither orphans nor have a chronically ill parent or caregiver. This study does not use data relating to children from intervention households because these children were already exposed to interventions for 6–12 months prior to the survey, and thus may have already derived positive benefits from the interventions.

As programs for orphans and children with chronically ill caregivers are designed in accordance with the belief that these groups of children are disadvantaged relative to other children, exploring differences among these groups is critical. Examining the variation in measures of well-being among these three groups of children will also suggest what types of children should be targeted and what criteria should be

² The Community REACH program conducted the baseline survey, and the endline survey will be implemented by MEASURE Evaluation.

used by NGOs starting new programs or scaling up existing programs. Future research will examine the effectiveness of specific interventions.

Literature review

Most information on orphans is contained in program documents, although some descriptive studies have been published in peer-reviewed journals. These studies have compared measures of educational, economic, health, and psychosocial well-being among orphans and other children. Research in this area is still developing and consistent patterns of results have not emerged from the evidence available to date. There has also been little research on differences among children with chronically ill caregivers and other children in developing countries. In this section, the current literature regarding the circumstances of orphans and other children is summarized with respect to five areas of well-being: 1) education, 2) socioeconomic status, 3) health and nutrition, 4) risk behaviors and knowledge, and 5) psychological well-being.

Education

Several small studies (Kamali et al., 1996; Muller and Abbas, 1990; Nyambedha Wandibba and Aagaard-Hansen, 2001; Konde-Lule et al., 1996; Nyamukapa et al., 2003) have found that orphans are less likely to be in school than non-orphans.

Some larger studies have also found that orphans are less likely to be enrolled in school than other children. For example, Case and colleagues (Case et al., 2003) used DHS data from 10 countries in sub-Saharan Africa to examine the impact of orphanhood on school enrollment and found that orphans are significantly less likely than non-orphans to be enrolled in school. This study included Zambia, but not Rwanda. According to the study, non-enrollment of orphans is not explained by poverty but rather by relationship (i.e., biological closeness) of the orphan to the household head. The authors conclude that the study results are consistent with Hamilton's rule that posits that altruistic behavior between any two individuals depends upon the degree of genetic relatedness between them. Investments in children thus would decrease as the relationship between the child and the guardian adult becomes more distant.

Bicego and his colleagues (Bicego et al., 2003) also found that an orphan is less likely to be at his/her proper educational level than a child who has both parents living. The effect was found to be stronger at younger ages (ages 6–10) than at older ages (11–14). Furthermore, double orphans are less likely to be at their proper level than are single orphans. For single orphans, a mother's death causes more deterioration in education at the primary school ages as compared to a father's death. The authors indicate that more data and research would be required to understand the issues regarding decisions to educate or not educate an orphan child. Monasch and Boerma (2004) also found that orphans had lower school attendance in their study of 40 countries in sub-Saharan Africa, but the magnitude of the differences between orphans and non-orphans was not great.

Despite these results from large studies indicating substantial educational disadvantage accruing to children who have at least one deceased parent, two other large studies (Ainsworth and Filmer, 2002; Deininger et al., 2001) found that poverty,



Zambian children in their school uniforms. (*PCI Zambia*)

rather than orphan status, was the primary determinant of school attendance. In the Ainsworth and Filmer study, which is based on data from 28 countries, findings related to school enrollment were inconsistent. In some countries, no significant difference in enrollment between orphans and non-orphans was found; whereas in other countries orphans were disadvantaged, and in some they had higher enrollment rates than non-orphans. Zambia was included in this study, but not Rwanda. The authors suggest that the reasons why poor orphans are not in school are the same as those for other poor children not attending school. The rate of enrollment for orphans correlates highly with the overall enrollment rate. For example, in countries with general under enrollment, the under enrollment of orphans was not significantly greater than non-orphans. In countries with moderate enrollment, there were significant gaps between enrollment for poor and non-poor children, and poor orphans were more disadvantaged than other poor children. Policies in countries such as the Dominican Republic, Uganda, and Kenya have been successful in reducing this enrollment gap.

Deininger and his colleagues (Deininger et al., 2001) suggest that policies can have an impact on school attendance rates for orphans. Their study examined education and health outcomes among orphans in Uganda. Their findings suggest that orphans were not discriminated against in terms of school enrollments in settings where sectoral policies were adequate but may face discrimination where policies such as universal primary education (UPE) were not in place.

Socioeconomic status

Findings from studies on socioeconomic status of households with orphans versus those without orphans have found mixed results. One small study found households with orphans to be worse off than households without orphans (Konde-Lule et al., 1996), whereas another larger study (Ainsworth and Filmer) did not find this to be the case. For example, Ainsworth and Filmer (2002) found no statistically significant difference in the prevalence of orphanhood between poor and non-poor households. In some countries the poorest households were found to be less likely to have orphans. This could be because households with the most resources were more likely to take in orphaned children or this finding could reflect the socioeconomic distribution of HIV infection.

Deininger and his colleagues (Deininger et al., 2001) examined the socioeconomic impact of orphanhood at the micro- and macroeconomic levels. Their findings indicate that at the microeconomic level, receiving an orphan into the household can have a large negative impact on the household's consumption and on their capital accumulation in the long term. Because fostering reduces savings and investment at the household level, this can have an indirect impact on aggregate savings at the macro level.

Health and nutrition

Most studies on physical well-being of orphans (Lindblade et al., 2003; Hess, 2002) have focused on children under five years of age. Results from these studies, like those reviewed above, have been contradictory. In one (Lindblade et al., 2003) the authors found little difference in physical well-being, while in another (Hess, 2002) there were key differences. Deininger and his colleagues (Deininger et al., 2001) also found the health and nutritional status of orphans to be worse than non-orphans.

As did the Case study referenced in the previous section (Case et al., 2003), Bishai and his colleagues (Bishai et al., 2003) used Hamilton's rule to hypothesize that a child's relationship to the household head would affect his or her probability of survival, with more closely related children having greater longevity. The study hypothesis was confirmed using data from Rakai, Uganda. The findings indicated that the presence of both parents in the household increased the odds of survival of a child. Lower biological relatedness of a child was associated with statistically significant reductions in child survival.

Risk behaviors and knowledge

Several program documents, including Burnet's study in Rwanda (2002) and a Human Rights Watch study in Zambia (2002), have suggested that orphans and children with chronically ill caregivers are particularly vulnerable to sexual, physical, and psychological coercion and abuse. While there is empirical evidence that children of parents with AIDS in the U.S. are more vulnerable to engaging in risk behaviors than are other children (Rotheram-Borus et al., 2001), there have been no quantitative studies on the issue of orphans and children with chronically ill caregivers and risk behaviors in sub-Saharan Africa.

Psychological well-being

There is little empirical evidence on psychological well-being of orphans and children with chronically ill caregivers in sub-Saharan Africa. Literature in this area is mostly contained in program documents. These reports and articles strongly suggest that orphans and chronically ill caregivers suffer from a range of psychological problems. One of the few empirical studies on this topic was conducted in Tanzania (Makame et al., 2002). The authors found that orphans ages 10–14 were more likely to exhibit more problems with internalization of stress and suicide ideation than were non-orphans; however, this study was based on a relatively small sample of only 41 orphans and 41 non-orphans.³ The SCOPE study, conducted in several areas in Zambia, also found that orphans suffer from poor psychological well-being, but did not include a non-orphan control group (SCOPE-OVC/Zambia, 2003).

Contribution of this study to the existing literature

As discussed above, findings relating to differences in status between orphans and other children are not consistent across studies, and there is little information about children with chronically ill caregivers. However, interventions targeting orphans and children of chronically ill caregivers are based on the assumption that there are differences between these groups. Thus, it is important to determine whether there is sufficient evidence to support the hypothesis that orphans and children with a chronically ill caregiver are worse off than are other children.

This report will contribute to the existing knowledge base in this area and differs from prior studies in a number of ways. Unlike most existing studies, with the exception of analyses of DHS data, Community REACH is using the same research design and survey instruments in two vastly different contexts in sub-Saharan Africa. The research team is examining a wide variety of measures in the following five areas: 1) education, 2) socioeconomic, 3) health and nutrition, 4) risk behaviors and knowledge, and 5) psychological well-being. This report is unique in that it studies socioeconomic status at both the household and individual (child) levels. This study analyzes the health status of children ages 6–12 and risk behaviors and knowledge among adolescents ages 13–19 in the sub-Saharan African context. In contrast to existing studies on the psychological well-being of children in sub-Saharan Africa, this study has the advantage of having a relatively large sample size.

Additionally, this research examines different groups of children that are not well-represented in the existing literature. First, the study focuses on children over six, a group that has been neglected in the past. The study will examine children with a chronically ill caregiver as distinct from orphans. In this report, children with a chronically ill caregiver are defined as those who are not orphans, but have a chronically ill parent or caregiver. Orphans and children with a chronically ill caregiver are compared to other children, non-orphans that do not have a chronically ill caregiver, living in the same communities.

³ The internalization problem scale included constructs such as mood, pessimism, somatic symptoms, sense of failure, anxiety, positive effect, and emotional ties.

Study objectives

This report will explore the following questions:

Research Questions

- Do households with orphans and/or children ages 6–19 with a chronically ill caregiver have lower socioeconomic status than households that do not have orphans or children with a chronically ill caregiver in this age group ?
- Do orphans and children ages 6–19 with a chronically ill caregiver have lower levels of educational, socioeconomic, health and nutritional, and psychological well-being as compared to other children in the same age group?

The report focuses solely on children ages 6–19 from the comparison sample households to answer the above questions. This study does not use data relating to children from intervention households. These children were already exposed to interventions for 6–12 months prior to the study, and thus may have already derived positive benefits from the interventions. For example, comparing orphans who are receiving educational benefits with non-orphans not receiving any interventions may lead to the conclusion that orphans are generally better off with regard to educational status than non-orphans. Thus, the study compares measures of well-being among three mutually exclusive groups of children from the comparison sample only: 1) orphans, 2) children with a chronically ill caregiver, and 3) other children.

Context

Zambia, with an HIV/AIDS prevalence rate of 16.5 percent, is at a relatively advanced stage of the HIV/AIDS epidemic as compared with other parts of sub-Saharan Africa (UNAIDS, 2004). As a result, Zambia has a high rate of orphanhood with 19 percent of all children under 18 years of age having lost at least one parent. An estimated 60 percent of these orphans are due to AIDS (UNAIDS, UNICEF, USAID, 2004). Partly because Zambia has had a large number of orphans and other vulnerable children earlier in the course of its epidemic than have other African countries, and also because Zambia has been proactive in terms of developing programs for orphans and other vulnerable children, the country is in the vanguard of programming in this area.

Bwafwano Community Home-Based Care Organization (hereafter referred to as Bwafwano) is working in the Chipata and Ngwerere catchment areas in peri-urban Lusaka. The NGO is receiving technical assistance from PCI Zambia and working in collaboration with JHPIEGO with three years of funding from Community REACH. Similar to much of Zambia, HIV prevalence in these areas is high, and there are large numbers of orphaned children. The Bwafwano program, however, is one of the most comprehensive of its kind. Bwafwano operates a community school, health clinic, income generation for orphans and children with chronically ill caregivers ages 15–19, and counseling service at its community center.

Rwanda has a rate of orphanhood comparable to that of Zambia with 17 percent of children under the age of 18 having lost at least one parent (UNAIDS, UNICEF, USAID, 2004). However, only about 20 percent of these orphans were orphaned by AIDS. The genocide in 1994 is also partially responsible for the high proportion of orphans in Rwanda.⁴

⁴ In this report, however, the authors do not distinguish among orphans resulting from AIDS, the genocide, or other causes.

CARE Rwanda has received funding from Community REACH to work with orphans and PLHA in Gitarama province for three years. Gitarama province is an impoverished rural region with problems such as food insecurity and lack of access to health services. Similar to other areas of Rwanda, the catchment area has a large number of orphans resulting from AIDS as well as the genocide that took place there recently, many of whom are heading households (CHH) in Gitarama. Thus, CARE has chosen to focus its interventions on CHH and their siblings. CARE has developed a very innovative approach whereby children heading households are paired with adult mentors, also known as *Nkundabanas*, in the community. The model adopted by CARE is also being replicated by other organizations in Rwanda such as World Vision Rwanda, Tulane School of Public Health and the Rwandan School of Public Health in Gikongoro, Rwanda.



A young woman in Gitarama Province, Rwanda. (CARE Rwanda)

Methods

Study design

The research design used to assess the effects of the intervention is a modified quasi-experimental pre-test/post-test study design. In the design, which includes a baseline (reported here) and an endline survey, intervention group households with orphans or children with a chronically ill caregiver receiving interventions (selected from project registers) will be compared to a comparison group of households selected using a “nearest neighbor” approach. The first round of data collection was conducted in mid-2003, and the same respondents will be interviewed in mid-2005. This report is based on analysis of data from the first round of data collection and only includes the comparison sample respondents.

Design of survey instruments

The survey was comprised of five questionnaires: a primary caregiver questionnaire, a questionnaire for children heading households (administered only in Rwanda), a questionnaire for primary caregivers regarding their 6–12-year-old children, a questionnaire for 6–12-year-olds, and a questionnaire for 13–19-year-olds. A list of the modules included in each questionnaire is included in Appendix 3. The complete set of Community REACH survey instruments can be accessed at www.pactworld.org/reach/OVCResources/.

There are a number of survey instruments that were developed for other studies that proved helpful in the design of the questions and format for the Community REACH survey instruments. The household and child rosters in the Community REACH survey instruments were based on those of the Rapid Knowledge, Practices, and Coverage Survey from the Child Survival Technical Support Project (CSTS). The household financial security and socio-demographic and community characteristics modules were adapted from the Rwanda and Zambia Demographic Health Surveys. Education and food intake questions were derived from the education module of the DHS survey. Family Health International’s SCOPE study in Zambia was helpful in the design of the psychological well-being and risk environment modules. Also influential in the development of risk environment questions was a study conducted by Population Council, Horizons Project, Washington, D.C. in cooperation with PLAN/Uganda. Risk knowledge and behaviors and health modules of the Community REACH questionnaire were adapted from similar questions used in the Women’s Health and Action Research Center study conducted in Edo State, Nigeria, in collaboration with Futures Group, Washington, D.C. Jeremy Johnson Hess’s work in

collaboration with CARE Rwanda was helpful in the development of the mentors module in the child-headed household and adolescent questionnaires used for this study. Numerous instruments used in the United States were consulted for the psychological well-being sections of the questionnaire. These instruments are listed in Appendix 4.

Surveys were compiled in English. The instruments were translated into Bemba and Nyanja in Zambia, and in Rwanda the survey was translated into Kinyarwanda. The instruments were discussed and revised by the data collection team and pilot tested. Instructions and explanations for all questions were included in the interviewers' manual. Data were collected using interviewer-administered face-to-face surveys.

Ethical review, confidentiality, and referrals. The research protocols and survey instruments were approved by local Internal Review Boards (IRBs) in both Rwanda and Zambia. Interviewers were asked to read an informed consent form to the respondent and obtain consent prior to administering the questionnaires. In the event that the interview was upsetting to a child, the interviewer was instructed to suspend the interview and make a referral. In both countries, a counselor was available for children experiencing problems during or after the interview. In both countries, a referral system was in place in the event that the respondent or his/her family needed assistance and the respondents were given a card with the organization's contact information at the end of the interview.

Description of study sample and selection of respondents. CARE Rwanda, PCI Zambia, and Bwafwano recruited households with orphans, children with a chronically ill caregiver, and other children for this study through both: 1) consulting a registry maintained by the research partner NGOs in each site (intervention households), and 2) by using a single, household matched, "nearest neighbor" approach to interview children, adolescents and caregivers from adjacent households, (comparison households). In Zambia, a double-matched approach was used to increase the sample size of adolescents in a minority of cases (128 households), but only adolescents ages 13–19 from these households were interviewed.⁵

In Zambia and Rwanda, all households on the project register were included in the intervention household sample. For all children ages 6–19, a primary caregiver in the household was identified. For the purposes of this study, the primary caregiver was defined as the parent, surviving parent, or guardian who is responsible for a child's welfare. Specifically, the primary caregiver is the person who prepares meals, bathes young children, and seeks medical attention when the child is ill. All children ages 6–19 inclusive in the intervention and comparison households were interviewed, as were their primary caregivers.

To be included in the study, intervention and comparison households had to have at least one child (6–12 years) or one adolescent (13–19). In total, 985 primary caregivers, 1,437 children ages 6–12 and 1,130 adolescents ages 13–19 were interviewed in Zambia from a total of 857 households. In Rwanda, 1,328 primary caregivers, 1,158 children ages 6–12, and 1,364 adolescents ages 13–19 were interviewed from 1,062 households.

Data collection. In each intervention and comparison group household, the interviewer first asked to speak to the primary caregiver in the household. The interviewer then asked for some basic demographic information and survival status of parents for all children and adolescents between the ages of 6 to 19 inclusive living in the household. The interviewer then asked the respondent to identify the primary

⁵ Interviewers identified the "matched" comparison household by selecting the household that was closest to the intervention household. If this household contained any children in the 6–19 age group, the household was selected as the comparison household. If the household did not have any children in this age group, the interviewer selected the next closest household to find out whether this household had any children in the 6–19 age group. This process continued until the interviewer identified a comparison household with a child in the 6–19 age group. In the cases where the "double matched" approach was used, two comparison households were selected for each intervention household.

caregiver for each child and adolescent ages 6–19 in the household. Thus, in some cases there was more than one primary caregiver per household.

All primary caregivers of children and adolescents ages 6–19 were then interviewed. During the interviews, primary caregivers of children ages 6–12 were also administered a questionnaire about each child 6–12. Each child ages 6–12 was then interviewed separately. All adolescents ages 13–19 were also administered a questionnaire. In Rwanda, 404 adolescents ages 13–19 who were heading households were interviewed both as primary caregivers and adolescents. In Zambia, there were no adolescents under age 20 heading households in the sample.

In Zambia, data collection was completed during July and August 2003. Data collection started in July 2003 in Rwanda, but local leaders requested that data collection be suspended during the month of August leading up to the 2003 presidential elections. Therefore, there was a six-week gap between when data collection started and when it was completed.

In Rwanda the data collection team also found that many of the intervention households were not child-headed households (defined as households where the primary caregiver was under age 20), as expected. Instead, many of the primary caregivers in the households receiving interventions were over the age of 20 but under the age of 25. During data collection, therefore, the local supervisor asked interviewers to begin interviewing a person in the household under the age of 20 as the primary caregiver. The change in study protocol was detected by the principal investigator in Washington, D.C., and data relating to the primary caregiver collected during this two-week period were dropped. Interviewers were asked to return to these households and interview the primary caregiver as defined in the study protocol at the end of the study to recover the lost cases.

Data entry. The data were entered in Rwanda and Zambia into an ACCESS database. In Zambia, double data entry was employed to ensure data quality. A web-based database was developed and used during the first data entry in Zambia. Zambia employed the stand-alone ACCESS database during the second data entry. Rwanda was unable to use a web-based system because of poor internet connectivity.

Statistical analyses

All the respondents from the three comparison groups (orphans, children with a chronically ill caregiver, and other children) were used in the analyses, but observations from the intervention group were not included in the analyses for this report. Thus, the three groups of children included in these analyses were 1) comparison orphans, 2) comparison children with a chronically ill caregiver, and 3) comparison other children. Hereafter, in this report these children are simply referred to as “orphans,” “children with a chronically ill caregiver,” and “other children.”

The Zambia data used for the analyses in this paper includes 496 primary caregivers, 504 children ages 6–12, and 563 adolescents ages 13–19. The Rwanda data used for this report has 570 primary caregivers, 656 children ages 6–12, and 402 adolescents ages 13–19. Data were cleaned and analyzed using SPSS software.

Analysis of individual-level educational, socioeconomic, health, and nutritional well-being, and risk behaviors and knowledge data

For the analyses of the education, socioeconomic, health, and nutritional well-being, and risk behaviors and knowledge data, bivariate analyses and Pearson chi-square tests were used to test associations among the groups of children and various measures of well-being. Statistical significance of p -value < 0.10 were reported. Frequencies were generated for characteristics of primary caregivers, children, and adolescents.

Cross-tabulations were done for orphans, children with chronically ill caregivers, and other children for several individual-level measures of educational, socioeconomic, health, and nutritional well-being and risk behaviors and knowledge.

Analysis of household-level socioeconomic data

Household-level socioeconomic measures were also calculated using standard of living indices (SLI). These indices were constructed using the household asset data listed in Appendix 5. The first step in creating the index was to construct dichotomous variables (0,1) for each of the household assets collected in the caregiver's module of the survey. Factor analysis was then used to attribute scores to each of the variables. The SLI variable is based on the sum value of the scores assigned to each independent variable. For example, if a household answered yes to the question "Does your household have electricity?," it received a higher score for that variable than if it had responded no. Households with a higher standard of living were more likely to answer yes to certain assets and receive a higher total score. Once the SLI variable was created and a value was assigned to each household, the households were divided into quintiles. The households with the top 20 percent scores were assigned a value of 5, households with the next 20 percent were assigned a value of 4, etc. The scores assigned to each household were then matched to the household identifier in the primary caregiver's dataset and merged accordingly.

Because the Rwanda data contained very little variation among the poor households, the top quintile was set aside and the factor analysis was run again to differentiate among the poor households. The top richest households from the first factor analysis were labeled the highest quintile, or "5," and the households from the second factor analysis were split into quartiles and contributed to the lower four quintiles.

Cross-tabulations for type of household—1) households with orphans, 2) households with children with a chronically ill caregiver, and 3) households with no orphans or children with a chronically ill caregiver—by percentage having SLI scores in the top quintile of the entire sample of households were calculated to provide household-level measures of socioeconomic status.

Analysis of psychological well-being data

As discussed in the literature review, little empirical data has been published on psychological well-being among orphans and children with chronically ill caregivers in sub-Saharan African settings. The analysis presented in this report is a preliminary attempt to improve understanding in this important area and examines measures of psychological well-being of orphans, children with chronically ill caregivers, and other children. The results are presented in relation to psychological well-being scales constructed according to psychological theories of childhood psychological development and the internal consistency of responses to the questionnaire as well as in bivariate terms—the proportion of respondents answering specific survey questions.

Because there are currently no scales of child or adolescent psychological well-being that have been thoroughly validated in an African population (Ward CL et al., 2003, conducted a limited reliability assessment of the Beck Depression and Self-Rating Anxiety Scale in South African adolescents), questions for this study were chosen from a variety of established measures (listed in Appendix 4), with the intent of representing a range of different aspects of psychological well-being potentially relevant to the study population and with attention paid to the significant time constraints for this section and other objectives of the study. The psychological well-being questions used in the Community REACH survey are included in Appendix 4.

The method used was based on Bolton's (2001) work on developing mental health assessment tools in Rwanda where no "gold standard" for diagnostic categories exists. A vital component of this method was

analyzing the data for evidence of internal consistency. This study generated and interpreted Cronbach's alpha scores. The authors then used the reliability results to decide which questions were useful and should be included in the scale and which should not be used. Questions that had low correlation or internal validity were eliminated from scale construction. Some aspects of psychological well-being, such as self-esteem, which were incompletely represented (i.e., too few questions to robustly support scale construction) were also eliminated. Statistical significance of the results of the scales by population groups was assessed through the use of the analysis of variance (ANOVA) method, and p-value < 0.10 were reported. Higher scores on the scales indicated worse well-being.

For children 6–12, two scales representing Worry/Stress and Overburden/Responsibility were created. The Worry/Stress scale consisted of seven items: feeling worried, feeling unhappy, refusing to eat at mealtimes, feeling frustrated, feeling like running away, having no time to play, and having nightmares. The Overburden/Responsibility scale consisted of four items: lack of free time (to play outdoors), too many responsibilities, taking care of family, and concern about the health of family members.

The two factors assessed in adolescents ages 13–19 were locus of control (LOC) and overburden/responsibility. The LOC scale consisted of four items: having little control over events, having little to be proud of, feeling helpless, and feeling that little can be done to change things. The Overburden/Responsibility scale consisted of four items: lack of free time, too many responsibilities, feeling burdened by taking care of family, and feeling bothered by concern about the health of family members.

In this study, the internal consistency method is used to assess the reliability of each of the four scales presented in this section. The reliability estimate used with this method is Cronbach's alpha. Typically, most references on this topic advise that estimates should not be below 0.70 for widely used scales (Nunnally and Bernstein, 1994), but due to the state of this field, results for all scales are presented.

Limitations of the study

A few limitations to this study should be noted. The nearest neighbor comparison group used in this study represents a purposively selected sample. Thus, the data are not intended to be representative of all children in Rwanda and Zambia. Throughout this report, the terms “in Rwanda” and “in Zambia” are often used, but the reader should keep in mind that the sample is not nationally representative. Thus, the results can be considered illustrative of the Bwafwano and CARE Rwanda project catchment areas and other similar surrounding areas in these countries.

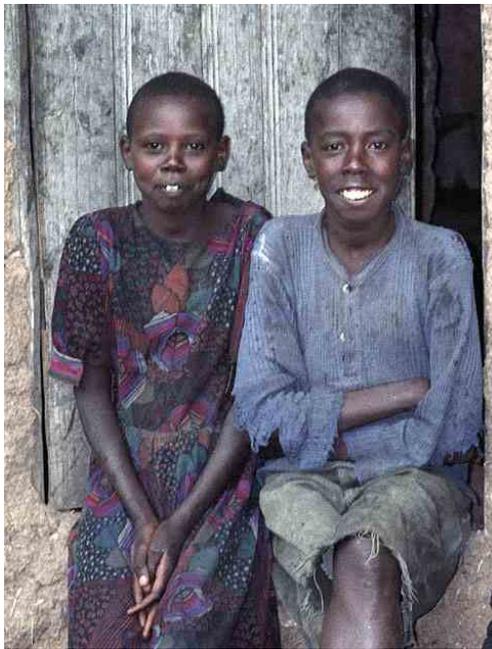
Additionally, because more than one child and/or adolescent was potentially interviewed from one household, there will be intra-household correlation among measures of well-being for children and adolescents from the same household. This report also contains only bivariate analyses of the explanatory variable orphanhood status (orphan, children with chronically ill caregiver, and other children) and several measures of educational status, socioeconomic status, health and nutritional well-being, risk behaviors and knowledge, and psychological well-being. This report does not contain multivariate analyses that attempt to control for potential confounding variables, such as socioeconomic status. In addition, this study does not analyze the relationship between time varying covariates, such as timing of orphanhood, and measures of well-being such as age at first sex. Further, while the measures of educational status, socioeconomic status, health and nutritional well-being, and risk behaviors and knowledge used in this report have been used extensively in numerous studies and can be considered valid and reliable measures, the psychological well-being measures presented here should be considered exploratory as much work still needs to be done in this area of research.

Chapter 2: Profile of Primary Caregivers, Children Ages 6–19, and Care-Giving Relationships

This chapter provides descriptive information regarding the primary caregivers and children ages 6-19 included in the analyses used for this report. Data regarding the characteristics relating to the primary caregivers (relationship, age) by the three groups of children compared in this report (orphans, children with chronically ill caregiver, and other children) are also presented. The information included in this chapter is intended to provide background for the analyses presented in Chapter 3.

Profile of primary caregiver respondents

Table 1 provides an overview of the profile of primary caregiver characteristics in Zambia and Rwanda. As seen in this table, almost all the primary caregivers in Zambia and Rwanda are female: 98.2 and 96.0 percent, respectively.



18-year-old Musoni and his sister Jaqueline are orphans in Rwanda. (*CARE Rwanda*)

Few of the primary caregivers are youth. Only 8.7 percent of primary caregivers in Zambia and 4.2 percent in Rwanda are in the 15–24 age group. Caregivers aged 50 and over comprise 11.7 percent of the primary caregiver group in Zambia and 19.6 percent of the sample in Rwanda. A substantial proportion of caregivers have no education, 21.7 percent in Zambia and 27.1 percent in Rwanda, whereas the majority of primary caregivers in Zambia and Rwanda have attended primary school: 58.4 percent and 70.3 percent, respectively.

In Zambia 42.4 percent of primary caregivers did not report working outside the home, whereas 97.5 percent of the respondents in the Rwanda primary caregiver sample reported working, mostly as farmers. A large proportion of primary caregivers (42.2%) in the Zambia sample reported working as traders, vendors, artisans, or carpenters. The difference in occupational status by country reflects the variation in geographical context of the two programs whereby CARE Rwanda is working in the rural province of Gitarama. Bwafwano and PCI Zambia are working in peri-urban Lusaka.

Table 1: Characteristics of Primary Caregiver Respondents by Country, Sex, Age, Occupation, and Educational Level, Percent

	Zambia	Rwanda
Sex		
Male	1.8	4.0
Female	98.2	96.0
Total	100.0	100.0
Age		
15–24	8.7	4.2
25–49	79.6	76.1
50+	11.7	19.6
Total	100.0	100.0
Highest level of education attended		
No education	21.7	27.1
Primary	58.4	70.3
Secondary or higher	19.9	2.6
Total	100.0	100.0
Occupation		
Not working	42.4	2.5
Farmer	3.0	95.8
Trader, vendor, artisan, or carpentry	42.2	1.6
Professional	2.2	0.0
Other and no response	10.1	0.2
Total	100.0	100.0
Number of Caregiver Respondents	493	569

Profile of the child respondents ages 6–19

Table 2 provides a brief overview of the demographic characteristics of child and adolescent respondents used in the comparisons of measures of well-being among orphans, children with a chronically ill caregiver, and other children. As seen in Table 2, in Zambia the sample is divided roughly evenly by sex and age. In Rwanda, the sample is also approximately equally divided by sex, but 61.9 percent of the sample includes children aged 6–12 whereas 38.1 percent of the sample includes adolescents aged 13–19.

Table 2: Characteristics of Respondents Ages 6–19 by Country, Sex, and Age, Percent

	Zambia	Rwanda
Sex		
Male	45.5	43.7
Female	54.5	56.3
Total	100.0	100.0
Age		
6–12	47.2	61.9
13–19	52.8	38.1
Total	100.0	100.0
Number of Child and Adolescent Respondents	1,067	1,054

In Figure 1, the composition of the Zambia and Rwanda samples is presented by group of children, orphans, children with a chronically ill caregiver, and other children. The analyses presented in Chapter 3 will be broken out by these three groups of children. In Zambia, 28.1 percent of the sample includes orphans, 11.1 percent includes children with chronically ill caregivers, and 60.8 percent includes other children. With regard to Rwanda, orphans comprise 30.3 percent of the sample, 24.5 percent of the sample includes children with chronically ill caregivers, and 45.2 percent of the sample includes other children.

Figure 1: Groups by Study Sample

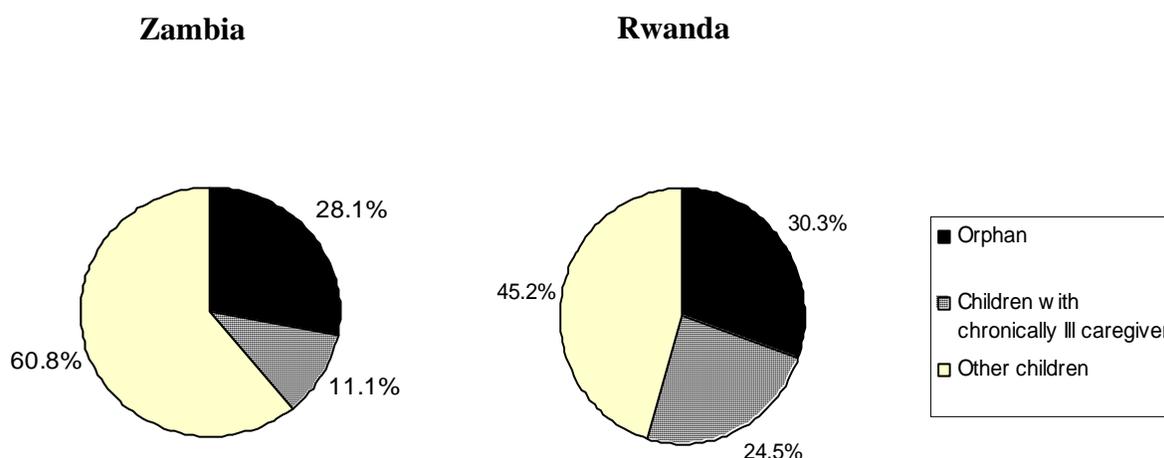
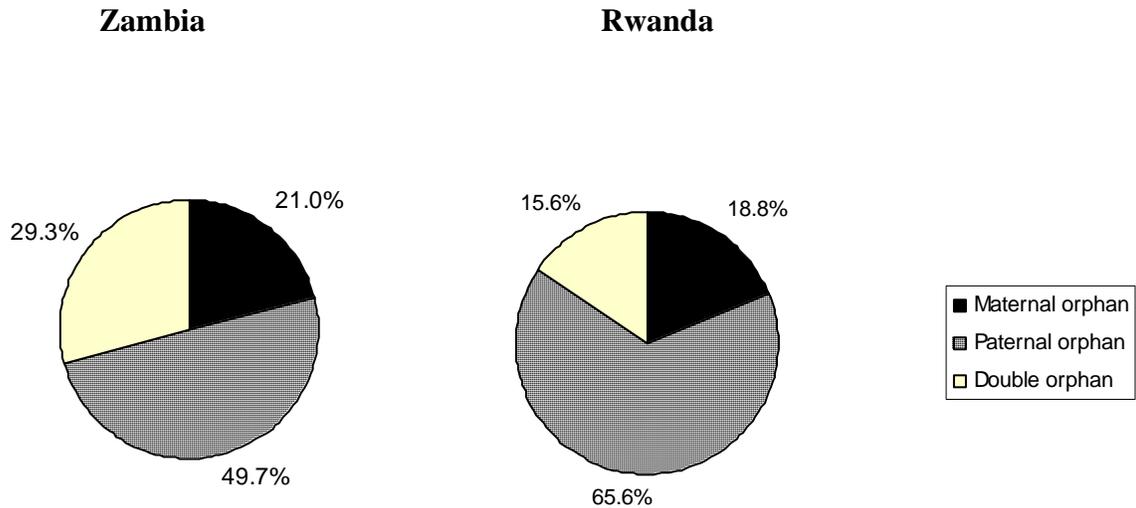


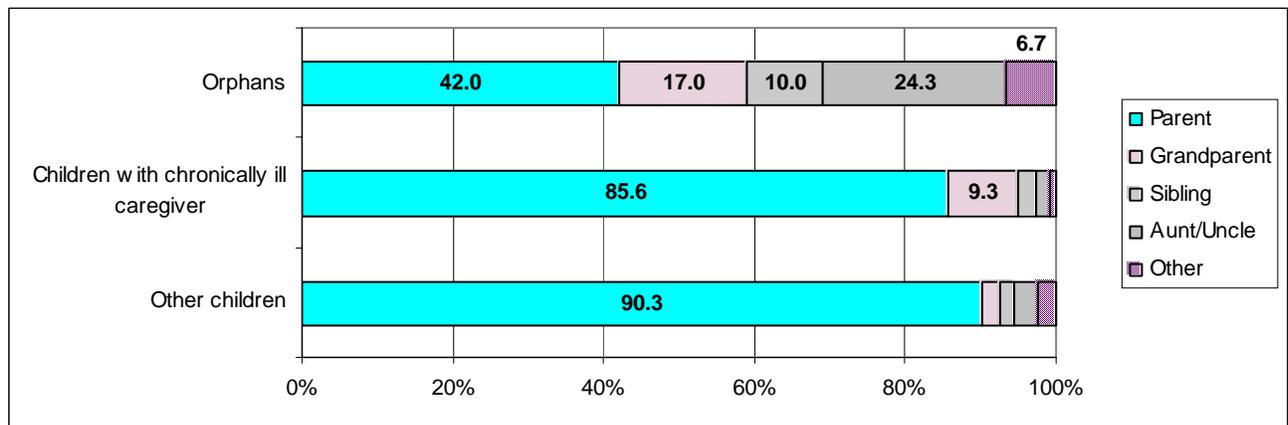
Figure 2 presents the composition of orphan groups in Zambia and Rwanda by type of orphan—double, paternal, or maternal. As shown in Figure 2 in Zambia, 29.3 percent of orphans are double orphans, 49.7 percent are paternal orphans, and 21.0 percent are maternal orphans. In Rwanda the break-down is somewhat similar with a smaller proportion of double orphans and a greater proportion of paternal orphans, as 15.6 percent of the orphan group includes double orphans, 65.6 percent are paternal orphans, and 18.8 percent of the sample is composed of maternal orphans.

Figure 2: Orphan Groups by Type in Rwanda and Zambia (Maternal, Paternal, Double)



As seen in Figure 3, the relationship to primary caregiver is presented by the group of children. A substantial proportion of orphans in Zambia are being cared for by grandparents (17.0 percent) as well as aunts and uncles (24.3 percent). Relatively small numbers of orphans in Zambia are cared for by siblings (10.0 percent). In contrast to the orphans, the majority of children with a chronically ill caregiver (85.6 percent) are cared for by their parents whereas just under 10 percent are cared for by grandparents. Ninety percent of other children are cared for by their parents.

Figure 3: Relationship to Primary Caregiver Among Respondents Ages 6–19 in Zambia



As seen in Figure 4, in Rwanda 67.5 percent of orphans are cared for by a parent. Similar to Zambia, the vast majority (90.7 percent) of children with a chronically ill caregiver are cared for by a parent as are 84.1 percent of other children.

Figure 4: Relationship to Primary Caregiver Among Respondents Ages 6–19 in Rwanda

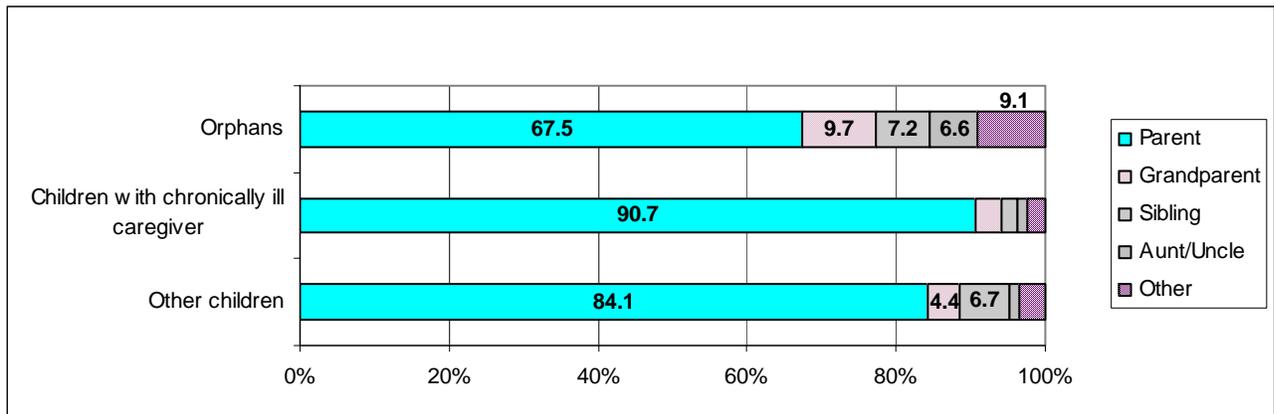
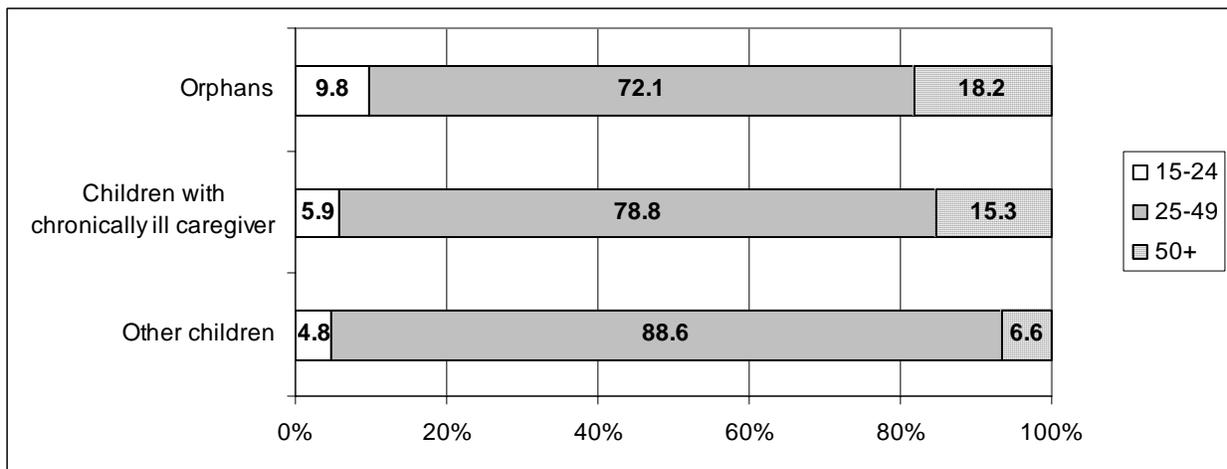


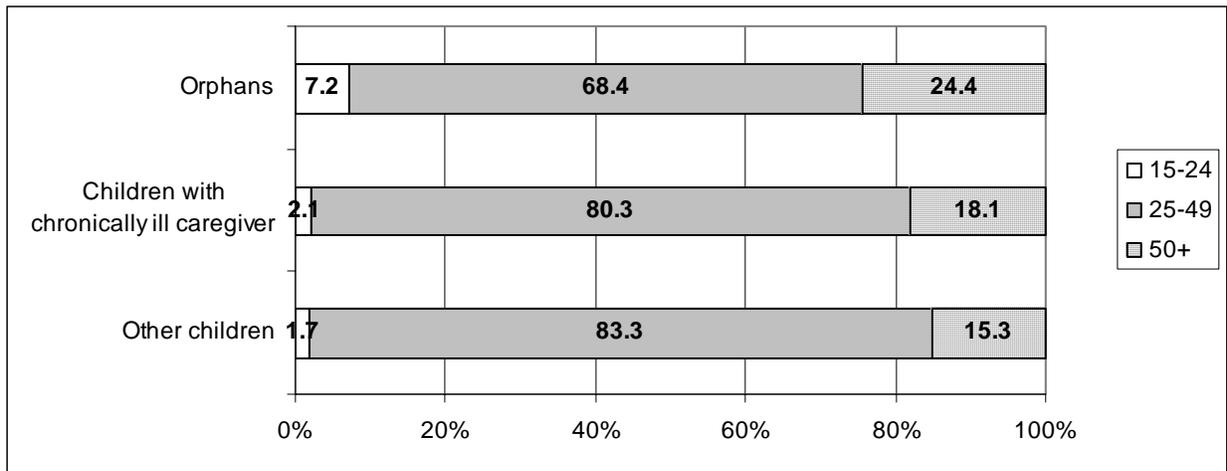
Figure 5 presents the distribution of age of caregiver by group in Zambia. As seen in Figure 5, 9.8 percent of orphans are cared for by youth ages 15–24 and 72.1 percent of orphans have a primary caregiver that is 25–49 years of age. A substantial proportion of orphans in Zambia are cared for by caregivers aged 50 and over (18.2%), as are children with a chronically ill caregiver (15.3%). Only 6.6 percent of other children are cared for by caregivers over age 50.

Figure 5: Age of Caregiver for Respondents Ages 6–19 in Zambia



As seen in Figure 6, in Rwanda, 7.2 percent of orphans are cared for by someone in the 15–24 age group. A substantial proportion of primary caregivers for orphans, children with a chronically ill caregiver, and other children in Rwanda are aged 50 and over (24.4, 18.1, and 15.3, respectively).

Figure 6: Age of Caregiver for Respondents Ages 6–19 in Rwanda



In summary, primary caregivers in both Zambia and Rwanda are overwhelmingly female. In Rwanda, almost all primary caregivers work as farmers, whereas in Zambia approximately 40 percent of primary caregivers are not working outside the home and another 40 percent work as traders, vendors, artisans, or carpenters. The majority of primary caregivers in Zambia and Rwanda have attended some primary school, but approximately 20 percent have no education. The majority of orphans in both countries in this study are paternal orphans, but in Zambia the second largest group of orphans is double orphans whereas in Rwanda the next largest group is composed of maternal orphans. In Rwanda, a larger proportion of orphans are cared for by a parent (67.5 percent) than in Zambia (42.0 percent). In both countries, most children with chronically ill caregivers as well as other children are cared for by a parent. In both countries, 15 to 25 percent of children are cared for by a caregiver aged 50 or over whereas less than ten percent of any group of children is cared for by a youth aged 15–24.

Chapter 3: Comparison of Measures of Well-being Among Orphans, Children with a Chronically Ill Caregiver, and Other Children

This chapter presents results from the analyses of five areas of well-being: 1) education, 2) socioeconomic status, 3) health and nutrition, 4) risk behaviors and knowledge, and 5) psychological well-being among the respondents aged 6–19. The primary focus of these comparisons is between 1) orphans and other children and 2) children with chronically ill caregivers and other children. Thus, other children can be considered the reference group. The discussion of the results has been framed in this manner because the primary objective of this report is to explore whether orphans and children with chronically ill caregivers are worse off than other children.

To interpret the results presented in this chapter, it may be useful for the reader to keep two concepts in mind: statistical and quantitative significance. As mentioned in the Methods section, the analyses in this chapter include measures of statistical significance. This report defines statistical significance as having a p-value less than 0.10.

In this study, however, statistical significance is not the sole criterion for determining whether or not a result is relevant for future programs or policies for children in AIDS-affected communities. Readers are advised to also note quantitative significance of the result as defined by the magnitude of the differences among the groups of children. For example, if a result from an analysis of school enrollment is statistically significant, but the difference between orphans and other children is only 2 percent, the information may not be very relevant for programs and policies relating to children in AIDS-affected communities. For the purpose of this report, quantitative significance is defined as a difference of at least 6-10 percent between 1) orphans and other children, or 2) children with chronically ill caregivers and other children. Differences of approximately 15 percent or more are considered to be large in this study. For a result to be considered programmatically relevant for the purpose of this report, the results must be statistically and quantitatively significant with regard to the criteria discussed here.

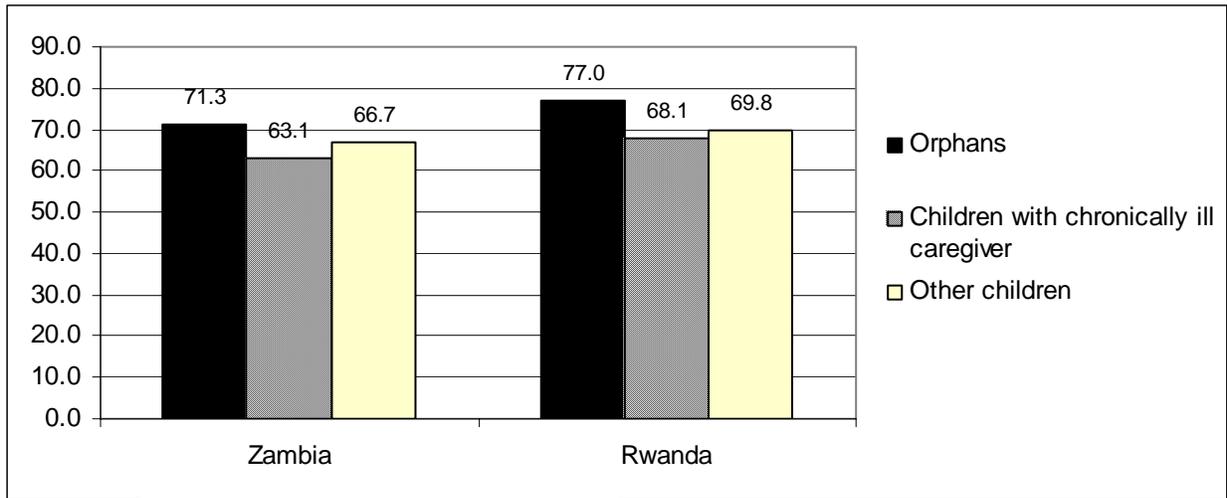
Education

As discussed earlier, findings from existing studies on school enrollment and orphanhood status are inconsistent. While it is hypothesized that orphans are less likely to be in school than non-orphans, studies completed to date do not consistently support this assumption. This section examines differences in in-school status among orphans, children with a chronically ill caregiver, and other children. Because in-school status is closely associated with the age of the individual, two separate analyses for the children ages 6–12 and for adolescents ages 13–19 are presented.

In-school status of children ages 6–12

As seen in Figure 7, in both Zambia and Rwanda, slightly lower proportions of children with a chronically ill caregiver and other children are enrolled in school than orphans. The association between orphanhood status and school enrollment among children ages 6–12 is not statistically significant in either country. The findings suggest that there are minimal differences in school enrollment among orphans, children with chronically ill caregivers, and other children in these locales in Rwanda and Zambia in the 6–12 age group.

Figure 7: Percent of Children Ages 6–12 in School

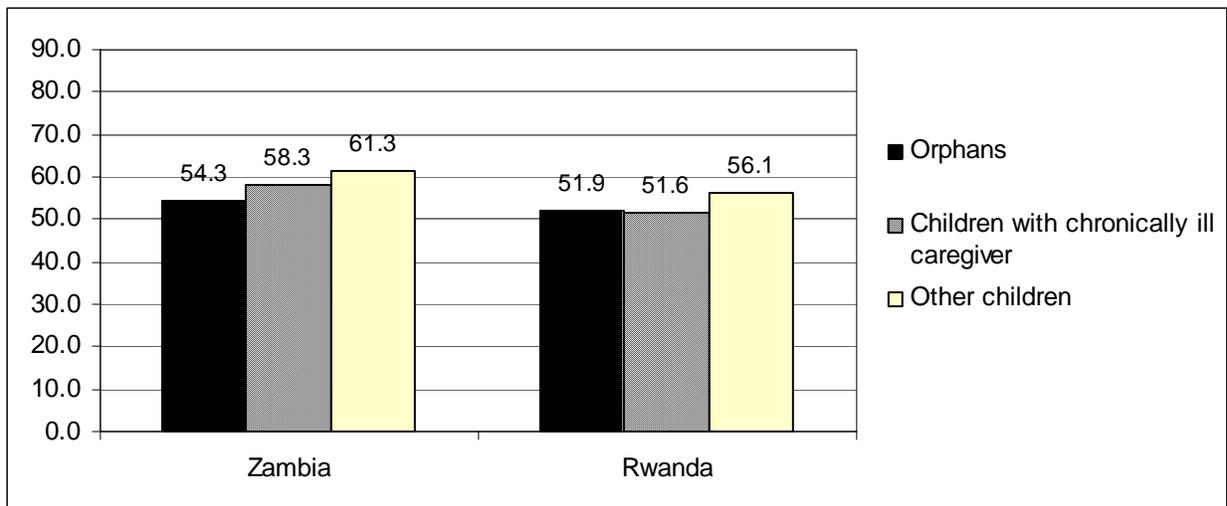


† p<.1 * p<.05 ** p<.01 *** p<.001

In-school status of adolescents ages 13–19

As seen in Figure 8, school enrollment declines for all groups of adolescents ages 13–19 relative to children of ages 6–12, with roughly 60 percent of this age group enrolled in school in Zambia and 50 percent in Rwanda. The differences among school enrollments among orphans, children with a chronically ill caregiver, and other children are minimal in both countries. The association between orphanhood status and school enrollment among adolescents ages 13–19 is not statistically significant in either country. Thus, the findings regarding the 13- to 19-year-old respondents also suggest there is little or no difference in school enrollment among these three groups of children.

Figure 8: Percent of Adolescents Ages 13–19 in School



† p<.1 * p<.05 ** p<.01 *** p<.001

Socioeconomic status

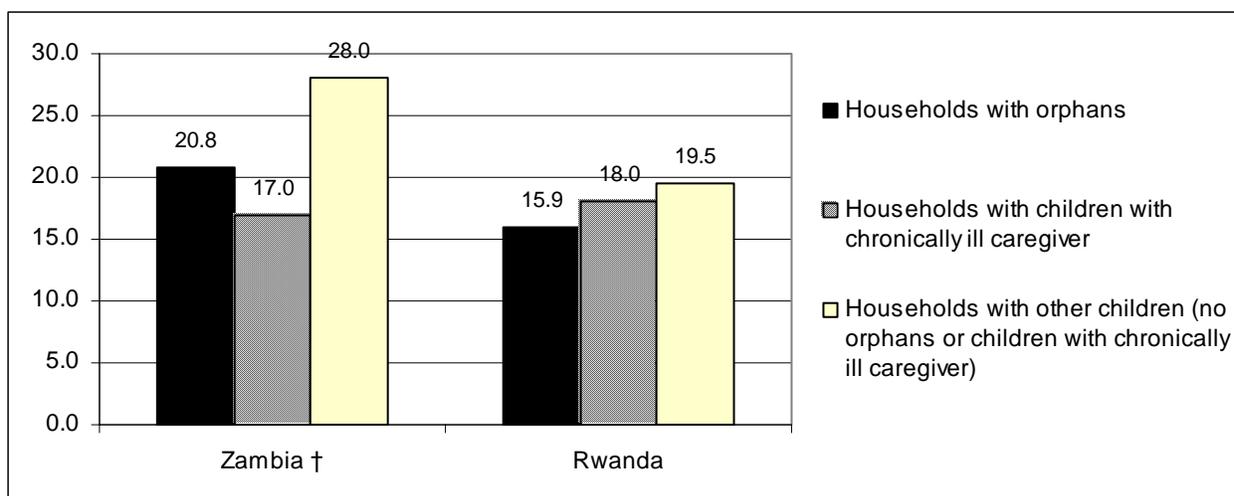
While most policymakers and program implementers assume that orphans and children with chronically ill caregivers are more likely to live in poorer households than other children, studies examining socioeconomic and orphanhood status have had mixed results. Most of these studies have examined household-level measures, such as household consumption. This section examines socioeconomic status with one household-level measure, SLI and two individual level measures, possession of personal items among all children ages 6–19, and school supplies among children in school ages 6–19.

Household-level measures

This report assesses socioeconomic status at the household level with a SLI score. These SLI scores were constructed from the household asset data as described in the Methods section. In order to compare the socioeconomic status of households with orphans, children with a chronically ill caregiver, and other children, this section presents the percentage of households in each of these groups that have SLI scores that are within the top 20 percent of the scores of the entire sample. These three groups are mutually exclusive. All households with an orphan in the 6–19 age range were classified as orphan households. The remaining households with a child with a chronically ill caregiver were categorized as households with children with a chronically ill caregiver. Households that did not have either an orphan or a child with a chronically ill caregiver age 6–19 were classified as other children households. These results cannot be compared across countries, only within Zambia and Rwanda.

As seen in Figure 9, in Zambia 17.0 percent of households containing children with a chronically ill caregiver have SLI scores that are in the top 20 percent of all SLI scores in the sample, whereas 20.8 percent of households that have orphans and 28.0 percent of other households containing only children who are neither orphans nor have a chronically ill caregiver fit in this category. In Rwanda, the differences among the groups are minimal with 15.9 percent orphan households falling into the top 20 percent SLI score group whereas 18 percent of children with a chronically ill caregiver households and 19.5 percent other children households meet this criteria. The association between orphanhood status of household and SLI score is statistically significant in Zambia, but not in Rwanda. The findings from Zambia strongly suggest that households with orphans and with chronically ill caregivers tend to be poorer. In Rwanda, the findings do not suggest that there are any differences in the socioeconomic status of households with orphans and children with chronically ill caregivers versus other children.

Figure 9: Percent of Households in Top Socioeconomic Quintile

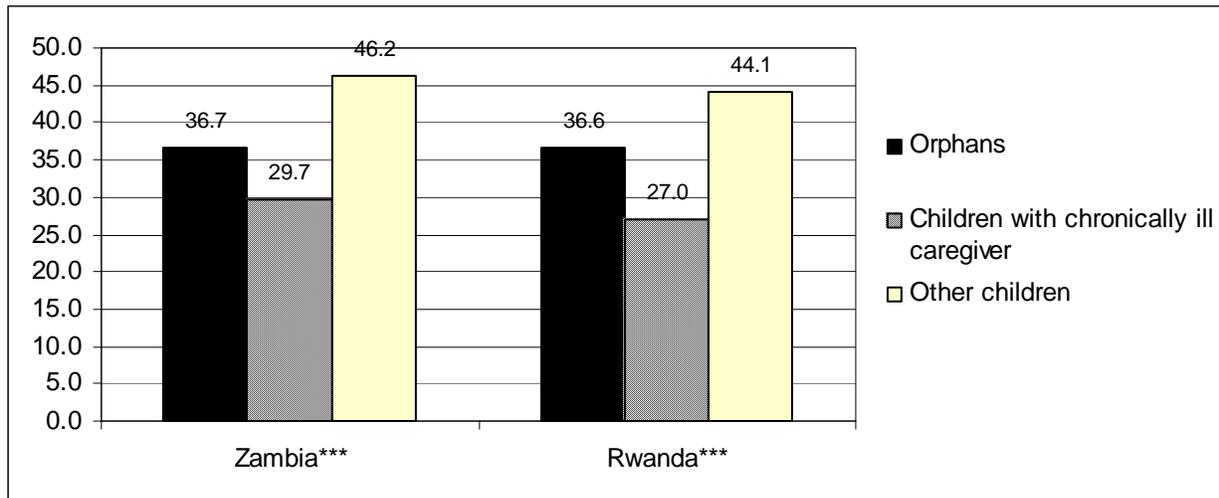


† p<.1 * p<.05 ** p<.01 *** p<.001

Individual-level measures

The first of two individual-level analyses done for this report include examination of the association between orphanhood status and ownership of three essential items: a blanket, a pair of shoes, and an extra (more than one) set of clothes. As seen in Figure 10, lower proportions of orphans and children with a chronically ill caregiver possessed these essential personal possessions compared with other children in both countries. Children with a chronically ill caregiver in both countries appear to fare worse than any other group. The differences among these groups were relatively large. For example, in Zambia, 36.7 percent of orphans and 29.7 percent of children with chronically ill caregivers were reported to have all three items compared with 46.2 percent of other children. Similarly, in Rwanda 36.6 percent and 27.0 percent of children with chronically ill caregivers had all three items compared with 44.1 percent of other children. The association between orphanhood status and possession of a blanket, shoes, and an extra set of clothes is statistically significant in both countries. Thus, results from this individual-level analysis strongly suggest that orphans and children with a chronically ill caregiver in particular have fewer personal possessions than other children in the project catchment areas in Zambia and Rwanda.

Figure 10: Percent of Respondents Ages 6–19 Who Own All Essential Personal Possessions^a

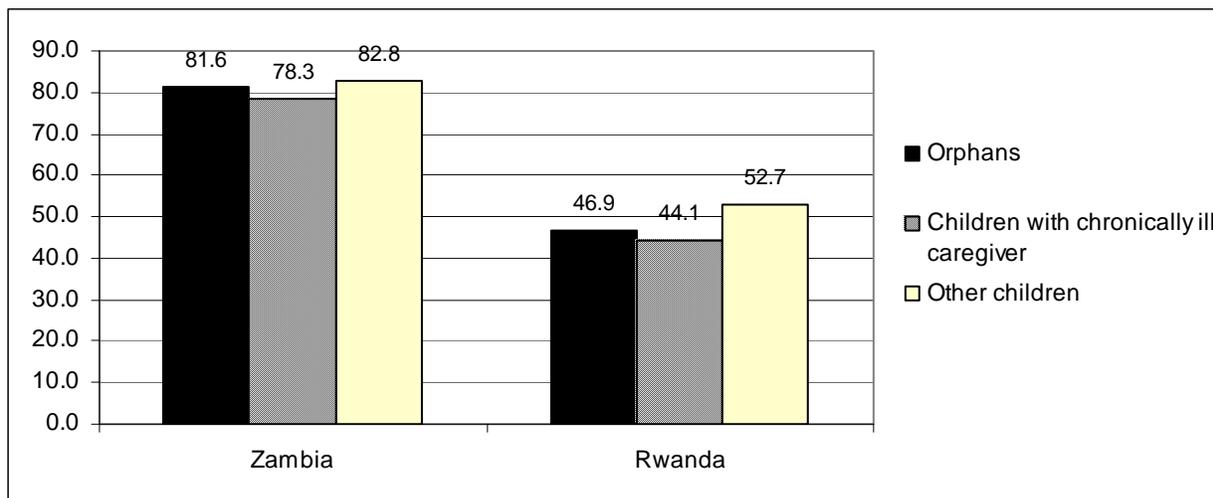


a: Blanket, shoes, and extra set of clothes

† p<.1 * p<.05 ** p<.01 *** p<.001

The second individual-level analysis material well-being is the examination of the association between orphanhood status and possession of two essential school supplies among in-school children ages 6–19: a writing instrument (pen or pencil) and notebook. As seen in Figure 11, in Zambia there was virtually no difference among orphans, children with a chronically ill caregiver, and other children in terms of possession of school supplies. In Rwanda, a lower proportion of orphans (36.6%) and particularly children with a chronically ill caregiver (27.0%) attending school possessed essential school supplies compared to other children (44.1%). All groups in Zambia were more likely than all groups in Rwanda to report having school supplies (approximately 75 percent versus 50 percent, respectively). The association between orphanhood status and possession of essential school supplies among children ages 6-19 enrolled in school is not statistically significant in either country, perhaps due to the smaller sample size since only in-school children were included in these analyses. Thus, the findings from the analysis of the Zambia and Rwanda data do not indicate any differences in possession of school supplies among these three groups of in-school children.

Figure 11: Percent of Respondents Ages 6-19 Who Own Both Essential School Supplies^a



a: Pen/pencils and notebook

† p<.1 * p<.05 ** p<.01 *** p<.001

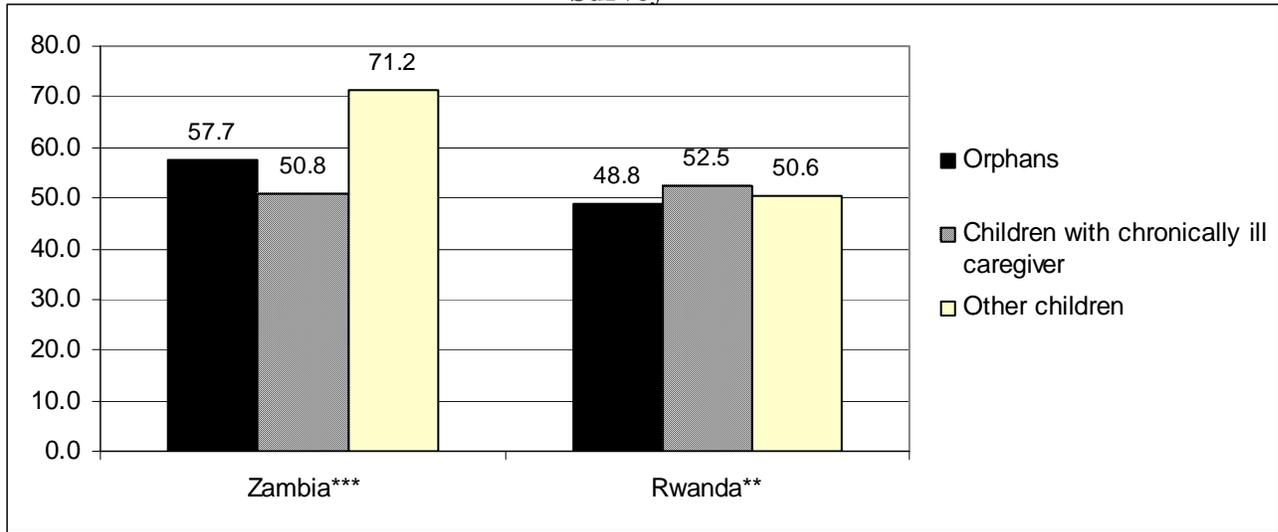
Health and nutrition

This section examines the association between orphanhood status and several measures of health and nutritional status. Food intake among children ages 6-19 is discussed first. After presenting the results of the food intake analyses, health-related measures for respondents ages 6–12 are discussed: possession of an immunization card, ever having an immunization, primary caregiver’s perception of general health of the child, and frequency of illness in the past three months prior to the survey.

Food intake

The literature relating to orphanhood status and nutritional status has focused primarily on children under five, and the results of these studies have been inconsistent. This sub-section of the report examines orphanhood status by food intake among respondents ages 6–19. As seen in Figure 12, the differences in food intake among orphans and children with a chronically ill caregiver and other children were relatively large in Zambia. While more than 70 percent of other children reported eating three meals on the day prior to the survey, only 58 percent of orphans and 51 percent of children with a chronically ill caregiver reported eating three times the day before. In Rwanda, there were virtually no differences in food intake among orphans, children with a chronically ill caregiver, and other children, and approximately 50 percent of children in Rwanda reported eating three meals the day prior to the survey. The association between orphanhood status and food intake was statistically significant in both countries. Thus, the findings from Zambia strongly suggest that orphans and children with chronically ill caregivers have lower food intake than other children. The findings from Rwanda demonstrate that there are not any differences among these three groups of children with regard to food intake. The data also strongly suggest that the overall level of food intake is low in the CARE Rwanda project catchment area among all groups of children.

Figure 12: Percent of Respondents Ages 6-19 Who Had Three Meals the Day Prior to the Survey

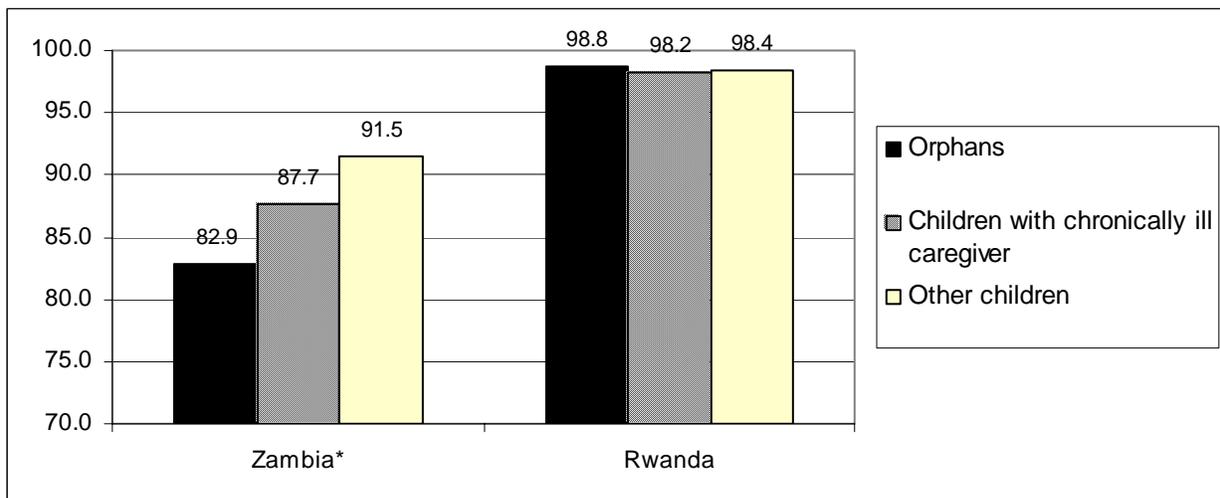


† p<.1 * p<.05 ** p<.01 *** p<.001

Child health

As seen in Figure 13, in Zambia 91.5 percent of other children were reported to have an immunization card compared with 87.7 percent of children with chronically ill caregivers and 82.9 percent of orphans. In Zambia, differences between orphans and other children were quantitatively significant, and the association between orphanhood status and possession of an immunization card is statistically significant. In Rwanda there is no difference among these three groups in terms of possession of an immunization card, and the results are not statistically significant. Thus, the findings from Zambia strongly suggest that orphans ages 6–12 are less likely to have an immunization card than are other children, whereas the findings from Rwanda do not suggest any differences among these groups of children.

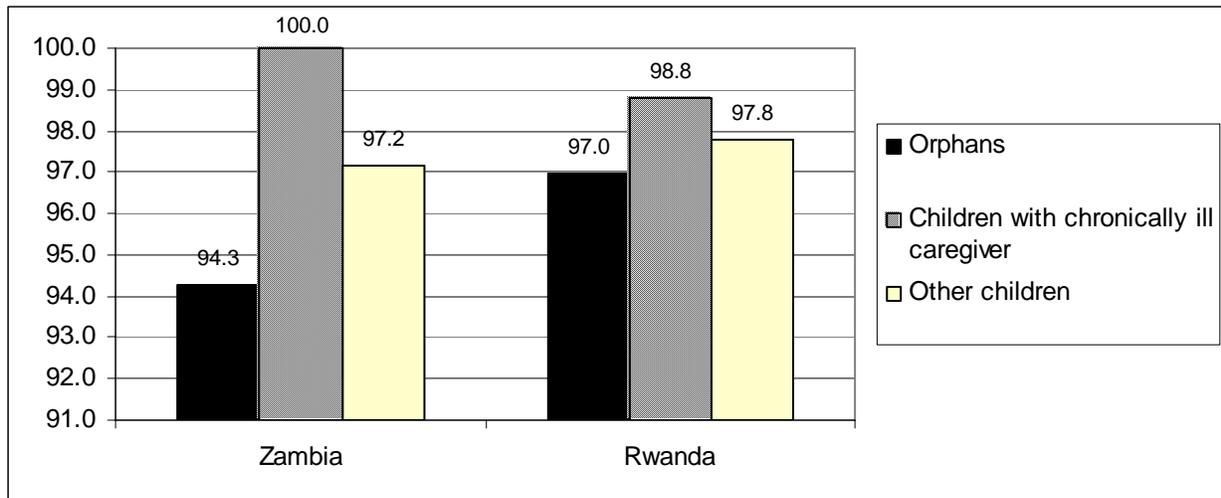
Figure 13: Percent of Children Ages 6–12 Who Have Immunization Card



† p<.1 * p<.05 ** p<.01 *** p<.001

The findings are somewhat different with regard to children who have ever had an immunization as seen in Figure 14. The overall level of children who have ever had an immunization appears to be high in these communities in Rwanda and Zambia. Further, the differences among orphans, children with chronically ill caregivers, and other children are minimal with regard to this measure of child health. The association between orphanhood status and ever having an immunization was not statistically significant. So, the findings from both countries suggest that orphanhood status is unrelated to ever having an immunization among children ages 6–12 in the project catchment areas.

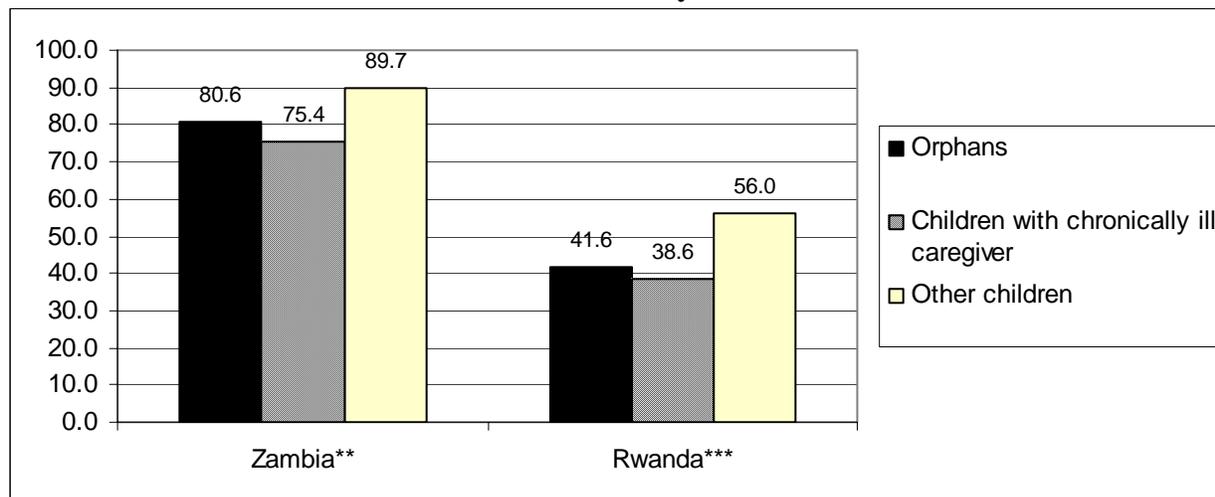
Figure 14: Percent of Children Ages 6–12 Who Are Reported to Have Ever Had an Immunization



† p<.1 * p<.05 ** p<.01 *** p<.001

As shown in Figure 15, lower proportions of orphans and particularly children with chronically ill caregivers are reported to be in good to very good health compared with other children in both countries. The differences between children with chronically ill caregivers and other children is relatively large. For example, in Zambia, 89.7 percent of other children were reported to be in good or very good health compared with 80.6 percent of orphans and 75.4 percent of children with chronically ill caregivers. The same pattern exists in Rwanda with 56.0 percent of other children reported to be in good to very good health in comparison with 41.6 percent of orphans and 38.6 percent of children with chronically ill caregivers. The association between orphanhood status and the primary caregiver’s perception of the child’s health is statistically significant in both countries. The findings strongly suggest that lower proportions of orphans and children with a chronically ill caregiver in particular are considered to be in good health by their primary caregivers compared with other children in both the PCI Zambia and CARE Rwanda catchment areas.

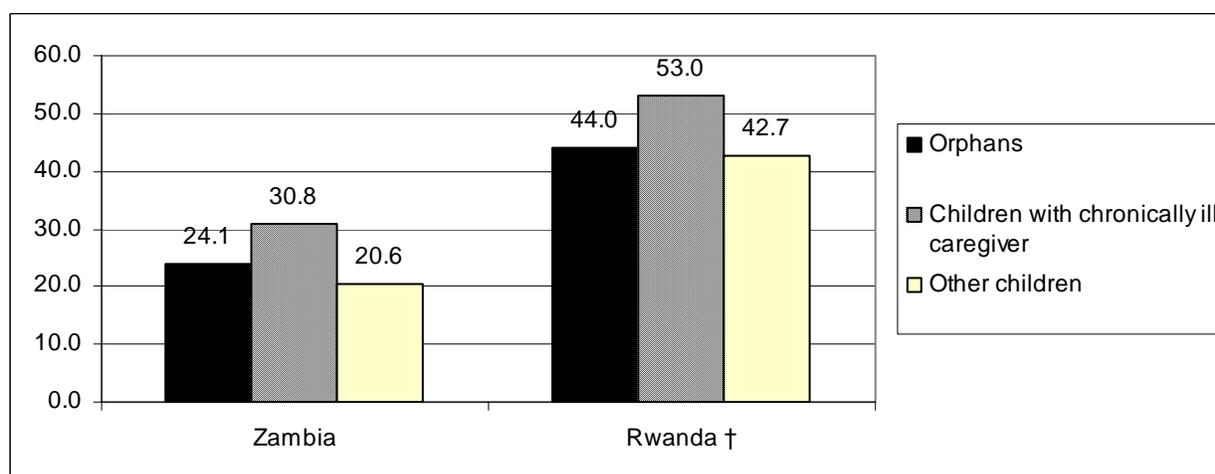
Figure 15: Percent of Children Ages 6–12 Whose Caregiver Reports Their Health Status As Good to Very Good



† p<.1 * p<.05 ** p<.01 *** p<.001

As seen in Figure 16, in both Zambia and Rwanda, higher proportions of children with a chronically ill caregiver, as compared to other children, were reported to have been sick more than three consecutive days in the three months prior to the survey. The differences between orphans and other children, however, were minimal. The findings are statistically significant in Rwanda, but not in Zambia. Thus, the findings in Rwanda strongly suggest that higher proportions of children with chronically ill caregivers get sick often compared with other children.

Figure 16: Percent of Children Ages 6–12 Who Are Reported to Have Been Sick More Than Three Consecutive Days in the Past Three Months



† p<.1 * p<.05 ** p<.01 *** p<.001

Risk behaviors and knowledge

While there have been no empirical studies of adolescent orphans and risk behaviors in sub-Saharan Africa, program documents suggest that orphans are at higher risk for early sex and other risky behaviors.

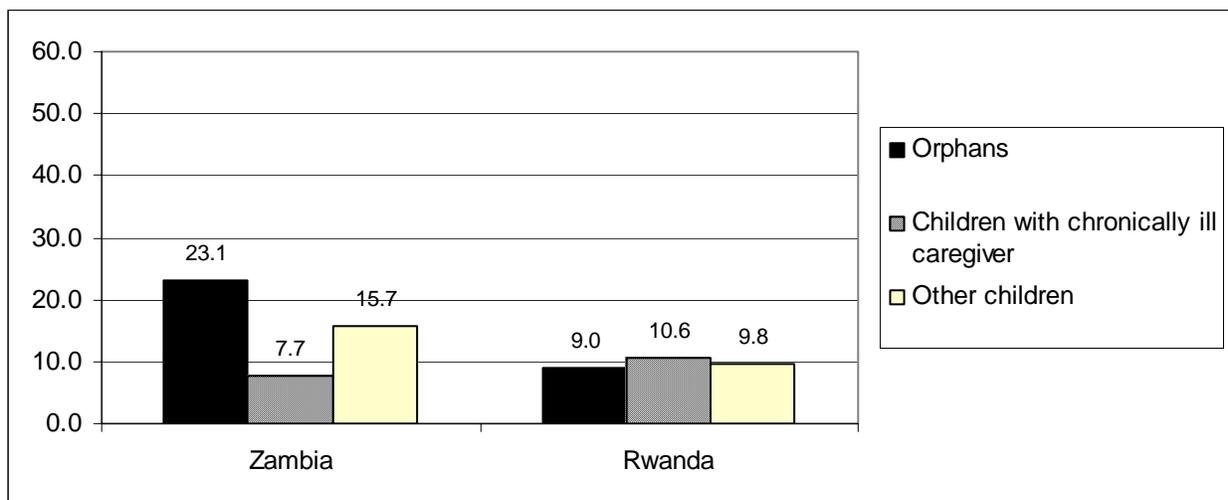
In Zambia, approximately 30 percent of all 13-19 year olds reported ever having sex compared to about 12 percent of respondents in the same age group in Rwanda. The differences between level of sexual activity between Zambian and Rwandan younger adolescents is consistent with the existing data as, according to the Zambia and Rwanda DHS, the median age of sexual debut in these countries is 16.8 and 20.1, respectively (Central Statistical Office [Zambia], 2003; Office National de la Population [ONAPO] Rwanda, 2001).

Proportions of sexually active adolescents reporting first sex at a very early age (defined here as age 12 or younger) and forced sex were computed.⁶ These figures were calculated for the entire sample of sexually active adolescents used in this report rather than by group due to the small sample sizes. In Zambia, 14.5 percent of sexually active adolescents reported first having sex at age 12 or younger, whereas in Rwanda 73.5 percent of sexually active adolescents reported having sex at age 12 or younger. With regard to forced sex, 12.8 percent and 6.1 percent of sexually active adolescents in Zambia and Rwanda respectively reported being forced to have sex. While the absolute numbers of adolescents reporting very early sex and/or forced sex are not large (70 percent of adolescents in Zambia and 88 percent of adolescents in Rwanda have never had sex), the proportions are nevertheless high. The issue of early sex and forced sex in these contexts thus warrants further investigation.

The sample was then broken up into two groups for the sexual debut analyses: 1) respondents ages 13–15 and 2) respondents ages 16–19. As seen in Figure 17, in the analysis of sexual debut among 13–15-year-olds roughly 15 percent of Zambian adolescents ages 13-15 reported ever having sex compared to 10 percent in Rwanda.

In terms of differences among the three groups of adolescents within countries, in Zambia there are 23.1 percent of orphans reporting ever having sex in comparison with 7.7 percent of children with chronically ill caregivers and 15.7 percent of other children. In contrast in Rwanda there are no differences among the different groups of children. The association between orphanhood status and sexual debut is not statistically significant in either country, perhaps due to the reduced sample size. Thus, the findings do not suggest differences in proportion of adolescents ages 13-15 who have ever had sex among these three groups in either country.

Figure 17: Percent of Adolescents Ages 13–15 Who Report Ever Having Sex

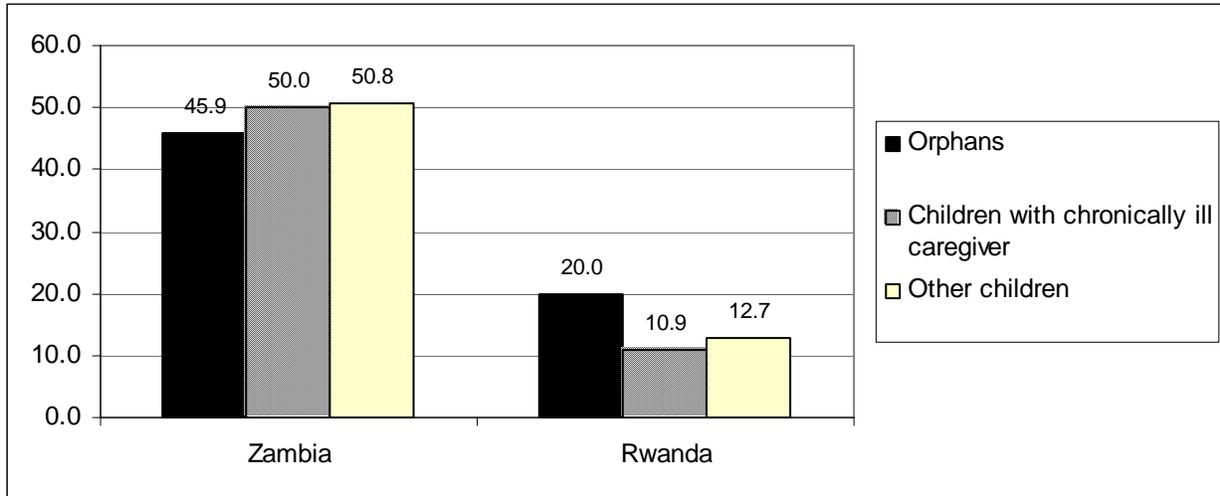


† p<.1 * p<.05 ** p<.01 *** p<.001

⁶ For the purpose of this report, sexually active adolescents are defined as adolescents ages 13–19 who have ever had sex.

The results from the analysis of data from the respondents ages 16-19 suggest a different pattern as seen in Figure 18. There are minimal differences among orphans, children with chronically ill caregivers, and other children in terms of ever having sex in Zambia. In contrast, in Rwanda a larger proportion of orphans report ever having sex (20.0 percent) compared with 10.9 percent of children with chronically ill caregivers and 12.7 percent of other children. However, the association between orphanhood and sexual debut was not statistically significant, so these findings do not demonstrate differences among proportions of adolescents ages 16-19 who have ever had sex in either country.

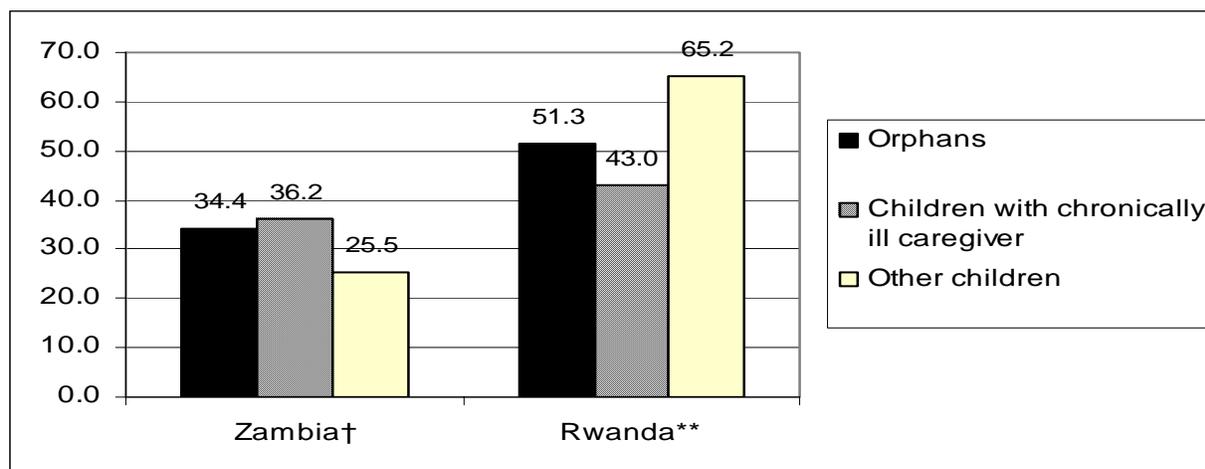
Figure 18: Percent of Adolescents Ages 16–19 Who Report Ever Having Sex



† p<.1 * p<.05 ** p<.01 *** p<.001

This report also examines consumption of alcohol, as this is another common risk behavior among youth. As seen in Figure 19, the differences among groups is quantitatively significant, but the patterns are not the same across both countries. In Zambia, 25.5 percent of other children reported consumption of alcohol compared with approximately 34.4 percent of orphans and 36.2 percent of children with a chronically ill caregiver. The pattern is the reverse with a higher proportion of other children (65.2 percent) reporting consumption of alcohol compared with orphans (51.3 percent) and children with a chronically ill caregiver (43.0 percent) in Rwanda. The association between orphanhood status and consumption of alcohol is statistically significant in both countries. The results from Zambia suggest that orphans and children with chronically ill caregivers are at higher risk of consuming alcohol whereas the findings from Rwanda suggest that other children are more likely to consume alcohol than are orphans or children with chronically ill caregivers.

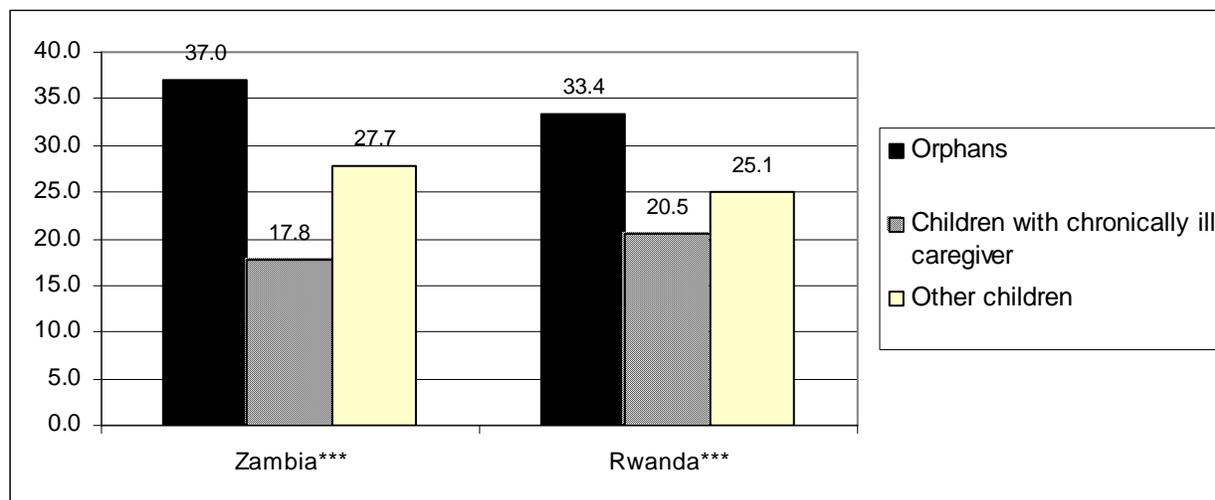
Figure 19: Adolescents Ages 13–19 Who Report Ever Consuming Alcohol



† p<.1 * p<.05 ** p<.01 *** p<.001

There has been no literature to date regarding orphans and their knowledge of HIV/AIDS. In this study, adolescent respondents were asked several questions to test their knowledge of HIV/AIDS. The questions addressed issues relating to transmission and prevention of HIV. Respondents were asked first how people can get HIV/AIDS. Their response was considered correct if they stated that HIV/AIDS could be transmitted through sex. Second, respondents were asked if a healthy looking person could have the AIDS virus. Third, respondents were asked to state some ways to prevent infection. If the respondent answered “abstain from sex,” “use condoms,” “stay faithful to one partner,” “limit sexual partners,” “avoid sex with prostitutes,” or “avoid sex with partners who have many partners,” they were considered to have answered correctly. The percentage of the sample that correctly responded to all three questions is included in Figure 20. Orphans appeared to be more knowledgeable about HIV/AIDS than other children. Conversely, children with chronically ill caregivers were less knowledgeable than other children about HIV/AIDS, particularly in Zambia. For example, 37.0 percent of orphans answered all three AIDS knowledge questions correctly compared with 27.7 percent of other children in Zambia. Among children with chronically ill caregivers, 17.8 percent answered all three questions correctly in Zambia. Similarly, in Rwanda one-third of orphans answered all three questions correctly compared with 21 percent of children with a chronically ill caregiver and 25 percent of other children. The association between orphanhood status and knowledge of HIV/AIDS was statistically significant in both countries. Thus, these findings suggest that orphans are more knowledgeable about AIDS than other children, and children with chronically ill caregivers are less knowledgeable about AIDS in both countries though this difference is only quantitatively significant in Zambia.

Figure 20: Percent of Adolescents Ages 13–19 Who Answered All Three AIDS Knowledge Questions Correctly



† p<.1 * p<.05 ** p<.01 *** p<.001

Psychological well-being

Psychological well-being of children ages 6–12

For children 6–12, two scales representing Worry/Stress and Overburden/Responsibility were created. The Worry/Stress scale consisted of seven items: feeling worried, feeling unhappy, refusing to eat at mealtimes, feeling frustrated, feeling like running away, having no time to play, and having nightmares. The Overburden/Responsibility scale consisted of four items: lack of free time (to play outdoors), too many responsibilities, taking care of family, and concern about the health of family members. Both factors showed acceptable internal consistency in Rwanda and Zambia. (Zambia: Worry/Stress alpha=.55, Burden/Responsibility alpha=.74; Rwanda: Worry/Stress alpha=.63, Burden/Responsibility alpha=.65)

In Zambia, a similar percentage of children (7–8%) reported agreeing with none of the seven questions comprising the worry scale. By contrast, 22.5 percent of orphans versus 18.5 percent of children with chronically ill caregivers and 11.7 percent of other children agreed with five or more of the questions on the worry scale. Responses to worry scale questions in Rwanda were lower overall, but showed a similar pattern. In Rwanda, 13.8 percent of orphans agreed with five or more questions, compared to 15 percent of children with chronically ill caregivers and 7.1 percent of other children, indicating that both orphans and children with chronically ill caregivers reported greater worry than other children. Based on the scale scores (not shown) for these three groups, the results from Rwanda are statistically significant, but not in the case of Zambia. Thus, the findings suggest that in Rwanda, orphans and children with chronically ill caregivers ages 6–12 have higher levels of worry than other children.

Table 3: Children ages 6–12 – Worry Scale, Percent

Response	Zambia			Rwanda**		
	Orphan	Children with Chronically Ill Caregivers	Other Children	Orphan	Children with Chronically Ill Caregivers	Other Children
Agree with none (low worry)	8.1	7.1	7.1	16.9	17.5	21.7
Agree with 1–2 question	28.8	41.5	36.5	31.4	32.6	38.4
Agree with 3–4 questions	40.5	32.9	44.6	38.0	35.0	32.8
Agree with 5–7 questions	22.5	18.5	11.7	13.8	15.0	7.1

alpha=0.55

alpha=0.63

† p<.1 * p<.05 ** p<.01 *** p<.001

In response to the questions on overburden/responsibility, in Zambia, between 37.2 percent and 47.7 percent of children agreed with three or more questions related to feelings of overburden. These proportions are higher than what was seen in Rwanda, where the proportions were 24.8– 33.8 percent. In Zambia, orphans (47.7%) reported the greatest feelings of overburden/ responsibility compared with 37.2 percent of children with chronically ill caregivers and 43.9 percent of other children. In Rwanda, children of chronically ill caregivers reported the highest degree of burden (33.8%) compared with 26.5 percent of orphans and 24.8 percent of other children. Based on the scale scores (not shown) for these three groups, the results from Rwanda are statistically significant, but not in the case of Zambia. Thus, the findings suggest that children ages 6–12 with chronically ill caregivers experience a higher level of burden than other children in Rwanda.

Table 4: Children ages 6–12 – Burden Scale, Percent

Response	Zambia			Rwanda †		
	Orphan	Children with Chronically Ill Caregivers	Other Children	Orphan	Children with Chronically Ill Caregivers	Other Children
Agree with none (low burden)	10.8	12.9	12.7	23.5	19.3	31.9
Agree with 1 question	23.4	22.9	19.2	24.7	21.7	20.1
Agree with 2 questions	18.0	27.1	24.1	25.3	25.3	23.2
Agree with 3–4 questions	47.7	37.2	43.9	26.5	33.8	24.8

alpha=0.74

alpha=0.65

† p<.1 * p<.05 ** p<.01 *** p<.001

Psychological well-being of adolescents ages 13–19

The two factors assessed in adolescents ages 13–19 were locus of control (LOC) and Overburden/Responsibility. The LOC scale consisted of four items: having little control over events, having little to be proud of, feeling helpless, and feeling that little can be done to change things. The Overburden/Responsibility scale consisted of four items: lack of free time, too many responsibilities, feeling burdened by taking care of family, and feeling bothered by concern about the health of family members.

In Zambia, both scales showed acceptable internal consistency (locus of control $\alpha=.57$, burden/responsibility $\alpha=.61$). However, in Rwanda, the level of internal consistency was low for both scales (locus of control $\alpha=.39$, burden/responsibility $\alpha=.43$). Thus, while findings from both countries regarding adolescent psychological well-being are presented here, results regarding adolescent psychological well-being in Rwanda should be interpreted with caution.

Agreement with questions indicating a poor LOC—or self-determination—were common in Zambia, where 49.7–53.4 percent of respondents agreed with three or more questions in the LOC scale. In Rwanda, agreement to three or more questions was significantly less, with 25.2–38.9 percent in agreement. In both countries orphans reported the highest level of agreement, followed by children with chronically ill caregivers, and then other children. However, differences in Zambia were slight. Based on the scale scores (not shown) for these three groups, the results from both countries were not statistically significant. Findings do not suggest differences between groups within each country with regard to locus of control among adolescents.

Table 5: Adolescent ages 13–19 – Locus of Control, Percent

Response	Zambia			Rwanda		
	Orphan	Children with Chronically Ill Caregivers	Other Children	Orphan	Children with Chronically Ill Caregivers	Other Children
Agree with none (low LOC)	3.7	2.1	5.5	2.6	7.5	5.8
Agree with 1 question	11.1	16.7	16.0	21.4	24.7	32.3
Agree with 2 questions	31.7	29.2	28.8	37.0	38.7	36.8
Agree with 3–4 questions	53.4	52.1	49.7	38.9	29.1	25.2

alpha=0.57

alpha=0.39

† $p<.1$ * $p<.05$ ** $p<.01$ *** $p<.001$

In response to the four questions assessing adolescent overburden/responsibility, in Zambia 45.9–59.7 percent agreed with three or more questions, in comparison to 23.9–29.8 percent in Rwanda. In both cases, orphans reported the highest levels of burden. In Zambia, 59.7 percent of orphans agreed with three to four questions compared with 45.9 percent of children with chronically ill caregivers and 47.3 percent of other children. With regard to Rwanda, 29.8 percent of orphans reported the highest level of burden compared with 25.8 percent of children with chronically ill caregivers and 23.9 percent of other children. Based on the scale scores (not shown) for these three groups, the results from Rwanda are statistically significant, but not in the case of Zambia. Due to low level of internal consistency for the Burden scale in Rwanda, no firm conclusions can be made from the results from Rwanda. Thus, findings do not suggest differences between groups within each country with regard to burden among adolescents.

Table 6: Adolescent ages 13–19 – Burden, Percent

Response	Zambia			Rwanda*		
	Orphan	Children with Chronically Ill Caregivers	Other Children	Orphan	Children with Chronically Ill Caregivers	Other Children
Agree with none (low burden)	1.1	2.1	1.8	16.9	17.2	16.1
Agree with 1 question	21.7	39.6	30.4	29.2	39.8	35.5
Agree with 2 questions	17.5	12.5	20.6	24.0	17.2	24.5
Agree with 3–4 questions	59.7	45.9	47.3	29.8	25.8	23.9

alpha=0.61

alpha=0.43

† p<.1 * p<.05 ** p<.01 *** p<.001

Overall, measures of worry (among children), locus of control (among adolescents) and overburden/responsibility (among both) found that orphans reported more negative feelings of psychological well-being compared to non-orphans, with children of chronically ill caregivers generally reporting intermediate scores. Children and adolescents in Zambia reported more negative psychological well-being than children and adolescents in Rwanda.

Chapter 4: Key Findings and Program/Policy Implications

This chapter summarizes the key findings from the study and discusses program and policy implications.

In this baseline report, the research team addressed two questions:

- Do households with orphans and/or children ages 6-19 with a chronically ill caregiver have lower socioeconomic status than households that do not have orphans or vulnerable children in this age group?
- Do orphans and children ages 6-19 with a chronically ill caregiver have lower levels of educational, socioeconomic, health and nutritional, risk behaviors and knowledge, and psychological well-being as compared to other children in the same age group?

Key findings in the five areas of well-being, education, socioeconomic status, health and nutrition, risk behaviors and knowledge, and psychological well-being are discussed below. Some findings are applicable to both countries, whereas other results are country-specific. This section first summarizes findings that are applicable to both countries and then results that are specific to Zambia and Rwanda. These results are also presented in abbreviated form in Table 7.

Table 7: Summary of Results from Community REACH study: Differences Among Orphans, Children with Chronically Ill Caregivers (CWCIC), and Other Children in Zambia and Rwanda

Category	Orphans and/or CWCIC are worse off than other children	No difference between 1) orphans and other children or 2) CWCIC and other children	Orphans and/or CWCIC are better off than other children
Education		<ul style="list-style-type: none"> • No difference in school enrollment in Zambia and Rwanda 	
Socioeconomic status	<ul style="list-style-type: none"> • Households with orphans and CWCIC less well-off in Zambia • Orphans and CWCIC in particular have fewer personal possessions in Zambia and Rwanda 	<ul style="list-style-type: none"> • No difference in household wealth in Rwanda 	
Health and nutrition	<ul style="list-style-type: none"> • Orphans and CWCIC had lower food intake in Zambia. • Orphans and CWCIC in particular were less likely to have indicators of good health in Zambia and Rwanda 	<ul style="list-style-type: none"> • No difference in food intake in Rwanda 	
Risk behaviors and knowledge	<ul style="list-style-type: none"> • Orphans and CWCIC were more likely to have consumed alcohol in Zambia • CWCIC were less knowledgeable about HIV/AIDS in Zambia 	<ul style="list-style-type: none"> • No difference in age at sexual debut in Zambia and Rwanda 	<ul style="list-style-type: none"> • Orphans and CWCIC were less likely to have ever consumed alcohol in Rwanda • Orphans were more knowledgeable about HIV/AIDS in Zambia and Rwanda
Psychological well-being	<ul style="list-style-type: none"> • Orphans and CWCIC ages 6–12 demonstrate slightly higher levels of worry in Rwanda • CWCIC ages 6–12 reported a higher level of burden than other children in Rwanda 	<ul style="list-style-type: none"> • No difference in psychological well-being in Zambia 	

Key Findings and Related Program and Policy Implications Applicable to Both Countries

Education

Approximately 70 percent of 6–12 year olds in both countries was enrolled in school, but only about 50 percent of 13–19 year olds is in school. Findings did not suggest that there are any differences in school enrollment among orphans, children with chronically ill caregivers, and other children ages 6-19 in Zambia and Rwanda.

- Educational programs should target all out-of-school children, not only orphans and children with chronically ill caregivers. Adolescents ages 13-19 in particular need encouragement and support to stay in school.

Socioeconomic status

At the individual level, orphans and children with a chronically ill caregiver in particular are worse off with regard to possession of a blanket, shoes, and extra set of clothes compared to other children in both countries.

- Program implementers need to develop proven and sustainable interventions to help improve the individual material well-being of children. In addition, programs should consider providing assistance with basic needs and include children with chronically ill caregivers.

Health and nutrition

Lower proportions of orphans and children with chronically ill caregivers ages 6–12 in particular have indicators of good health compared with other children in Zambia and Rwanda.

- Policies should ensure that national maternal and child health (MCH) programs give particular attention to orphans and children with chronically ill caregivers. In particular, the primary caregivers of these children, some of which are very young (15–24) or older (50+), need to be targeted by health promotion campaigns that typically reach mothers aged 25–49. Program implementers involved in MCH programs also need to make efforts to include these children and their caregivers in their programs.

Risk behaviors and knowledge

In Zambia, approximately 30 percent of all 13-19 year olds reported ever having sex compared to about 12 percent of respondents in the same age group in Rwanda. Approximately 15 and 75 percent of sexually active adolescents reported first having sex at age 12 or younger in Zambia and Rwanda. With regard to forced sex, 12.8 percent and 6.1 percent of sexually active adolescents in Zambia and Rwanda respectively reported having being forced to have sex. Findings did not suggest any differences in age of sexual debut among orphans, children with chronically ill caregivers, and other children in Zambia and Rwanda.

- The sample sizes for the analyses on sexual behavior were small, so this issue warrants future research and analysis. The prevalence of sex at very early ages and forced sex should also be further investigated in Rwanda and Zambia.

Higher proportions of orphans in both Zambia and Rwanda are knowledgeable about HIV/AIDS than are other children. Yet these children may still be more vulnerable than other children to contracting HIV/AIDS and other STIs.

- Program implementers need to develop programs that help these children translate their increased knowledge into safe behavior. These children should also be encouraged to educate their peers.

Psychological well-being

There were no conclusive findings that applied to both countries.

Key Findings specific to Zambia

- ***Socioeconomic status:*** Households with orphans and children living with chronically ill caregivers have lower socioeconomic status, as measured by the SLI score, compared with households that do not have these groups of children in Zambia.
- ***Health and nutrition:*** Orphans and children with chronically ill caregivers have lower food intake than other children in Zambia.
- ***Risk behaviors and knowledge:*** Higher proportions of orphans and children with chronically ill caregivers have ever consumed alcohol compared with other children in Zambia. Additionally, children with chronically ill caregivers are less knowledgeable about HIV/AIDS than are other children in Zambia.

Key Findings specific to Rwanda

- ***Socioeconomic status:*** There is no difference in household wealth among households with orphans, children living with chronically ill caregivers, and other children in Rwanda.
- ***Health and nutrition:*** There is no difference among the three groups of children in terms of food intake in Rwanda, and the overall level of food intake appears low, with approximately 50 percent of all children reporting consumption of three meals the day prior to the survey.
- ***Risk behaviors and knowledge:*** Lower proportions of orphans and children living with chronically ill caregivers report ever having consumed alcohol compared with other children in Rwanda.
- ***Psychological well-being:*** Orphans and children with chronically ill caregivers ages 6–12 demonstrate slightly higher levels of worry than other children in Rwanda. Additionally, children with chronically ill caregivers ages 6–12 have higher levels of burden than other children in Rwanda.

Conclusion

The results from this report do not present a simple story regarding children affected by AIDS in these areas of Zambia and Rwanda. Although there are some results that are remarkably similar in both Zambia and Rwanda (e.g., lack of personal possessions and relatively poor child health status among orphans and children living with chronically ill caregivers), perhaps what is more notable are the differences between the two countries. In Zambia, the differences among orphans, children with chronically ill caregivers, and other children is more pronounced across multiple dimensions: socioeconomic status at the household and individual levels, food intake, health indicators, alcohol consumption, and knowledge of HIV/AIDS (among children with chronically ill caregivers). While orphans and children with chronically ill caregivers are disadvantaged with regard to some indicators in Rwanda (e.g., individual material well-being and child health indicators), in general it appears that many children in the project catchment area—regardless of orphanhood status—are living in poor households and have limited access to food. Thus,

perhaps one of the most important lessons from this study is that there is no uniform approach to dealing with orphans, children living with chronically ill caregivers, and other children—some of which may be vulnerable—in AIDS-affected communities in sub-Saharan Africa. In some areas, orphans and children with chronically ill caregivers may be generally worse off than other children, whereas in other communities children from all groups may be in need of assistance. Program approaches will need to be tailored to the context, and program implementers will need to use existing data as well as rapid assessments to determine which children in the community should be targeted with what services.

Additionally, even in the case of Zambia, the magnitude of the differences between the orphans and children with chronically ill caregivers and other children was not very large, generally ranging from 7–15 percent except in a few cases. This result suggests that orphanhood status should not be the sole criterion for eligibility for interventions regardless of the context. It is likely that other factors, such as socioeconomic status, sex of the child, and type of orphan (double, paternal, or maternal), together with orphanhood status, should be used to identify needy children. Multivariate analyses were beyond the scope of this report, but are necessary to further investigate this issue. In addition, the relationship between time-varying covariates, such as age at death of parent, and time-varying outcomes, such as age at first sex or age at school leaving, should be analyzed to explore whether becoming an orphan actually puts children and adolescents at risk for experiencing adverse outcomes.

Another important finding from this study is that children with chronically ill caregivers should be examined distinctly from orphans. These children may have different needs and may be more or less disadvantaged depending on the dimension of well-being and the context. Generally speaking, policymakers and program implementers tend to use the term “orphans and vulnerable children” or “OVC” to describe children affected by AIDS, but the vulnerable, non-orphan children in this group are sometimes an afterthought. Home-based care programs that are already serving PLHAs should take special care to make sure the needs of children with chronically ill caregivers are met.

Measurement of psychological well-being of children in sub-Saharan Africa is also an area that should be further investigated and refined. Given the possible adverse psychological consequences of a parent’s illness and death, program implementers desperately need reliable and valid methods to measure the psychological well-being of children and determine their needs. Policymakers also need this information at the national level to make future plans for resource allocation.

Appendix 1: Modules Included in Survey Instruments

Data was collected on a variety of specific topics. The tables below list each module and a brief description of the components included by the questionnaire.

Questionnaire I: Caregivers:

Module	Description
1. Socio-demographic variables	Basic background information, numbers of individuals in the household, ages, sex, ethnic group (Zambia only), religion, education, health status of caregiver, living arrangements
2. Caregiver coping	Attitudes and perceptions of relative burden of OVC, coping mechanisms
3. Exposure to interventions	Types of assistance received and from what sources
4. Household financial security	Current household resources and materials.
5. Community relations	Relationships with neighbors, property grabbing

Questionnaire II: Children heading households (Rwanda only)

Module	Description
1. Psychological well-being and coping	Attitude of child vis-à-vis family, community, and self, including hopes and fears for present and future
2. School attendance	History of recent school attendance for children aged 13–19
3. Exposure to interventions	Types of assistance received and from what sources
4. Food intake	Food consumed in the past week
5. Health and illness	Illness history
6. Living environments	Ownership of shoes, bedding, etc.
7. Risk behaviors and environments	Consumption of alcohol, cigarettes, and drugs. Involvement in violence, sexual coercion, harassment, etc. Knowledge of rights

Questionnaire III: Caregiver's perspective on children ages 6–12

1. Psychological well-being	Caretaker perception of psychological well-being of children aged 6–12
2. School attendance	History of recent school attendance for children aged 6–12
3. Living environment	Material possessions of child: shoes, bedding, etc.
4. Health and illness	Vaccination card availability and illness history
5. Food intake	24-hour recall of meals consumed

Questionnaire IV: Children, 6–12 years

1. Psychological well-being	Self-perception of psychological well-being
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Questionnaire V: Adolescents 13–19 years

Module	Description
1. Psychological well-being and coping	Attitude of child vis-à-vis family, community, and self, including hopes and fears for present and future
2. School attendance	History of recent school attendance for children aged 13–19
3. Exposure to interventions	Types of assistance received and from what sources
4. Food intake	Food consumed in the past week
5. Health and illness	Illness history
6. Living environments	Ownership of shoes, bedding, etc.
7. Risk behaviors and environments	Consumption of alcohol, cigarettes, and drugs. Involvement in violence, sexual coercion, harassment, etc. Knowledge of rights

Appendix 2: Sources for Psychological Well-Being Survey Instrument

Assessment Instruments Consulted:

Beck Depression Inventory (BDI)
Behavior Problem Checklist (BPC)
Brief Symptom Inventory (BSI)
Child Behavior Checklist (CBCL)
Child PTSD – Reaction Index (CPTSD-RI)
Children’s Depression Inventory (CDI)
Conners Parent Rating Scale (CPRS)
Depression Self-Rating Scale (DSRS)
Impact of Event Scale/Impact of Event Scale Revised (IES/IES-R)
Pediatric Emotion Distress Scale (PEDS)
Psycho-Social Well-Being Scale (PSWS)
Rand Mental Health Inventory (RMHI)
Revised Children’s Manifest Anxiety Scale (RCMAS)
State and Trait Anxiety Inventory for Children (STAIC)

Appendix 3: Creation of Standard of Living Indices

The variables used were based on the following questions:

In your dwelling, is there:

- Electricity
- A radio
- A telephone
- A refrigerator
- A bicycle
- A television
- A video
- An electric fan
- A water heater
- A sewing machine
- An auto washer
- Other washer
- A car
- A motorcycle
- Farm/other land (Rwanda only)
- Livestock (Rwanda only)

What is the principal household source of drinking water?

- Piped drinking water in residence
- Well in residence
- Public faucet (piped)
- Traditional public well
- River, canal, or surface water for drinking
- Other source of drinking water

What is the principal type of toilet facility used by members of your household?

- Modern flush toilet
- Traditional flush toilet with a tank flush
- Traditional flush toilet with bucket flush
- Traditional pit toilet
- Bush/field
- Other type of latrine

What is the principal type of flooring in your dwelling?

- Dirt, sand, dung
- Cement
- Parquet or polished wood floors
- Tiles
- Carpeted flooring
- Other type of flooring

In your dwelling, how many members are there per sleeping room? (score is per member)

What type of fuel is used for cooking?

- Electricity
- Natural gas
- Kerosene
- Coal, lignite
- Charcoal
- Firewood, straw
- Dung

Appendix 4: Measures of Psychological Well-Being

For children 6–12 years:

How often have you....? Would you say “often,” “sometimes,” or “never”?

- Felt worried
- Felt happy
- Refused to eat at mealtimes
- Felt frustrated
- Felt like running away from home
- Had free time to play outdoors
- Have nightmares

I am going to ask you some questions about some things that may or may not bother you. I want you to tell me for each of the following things that I read if it bothers you a lot, a little, or if doesn't bother you at all.

- Having too many responsibilities (e.g., chores)
- Taking care of family members
- Not having enough money for things, such as clothing and food
- Worrying about the health of a family member
- Having problems with friends and neighbors
- Having problems getting along with your family
- Feeling unsafe in your neighborhood
- Feeling unsafe in your home

For adolescents 13–19 years:

Please tell me how much you agree or disagree with the following statements about yourself. Would you say...

- You have little control over the things that happen to you
- There is really no way you can solve some of the problems you have
- You feel you have much to be proud of
- You often feel helpless in dealing with problems
- When you make a mistake you take responsibility for it
- You are a good person
- There is little you can do to change many of the important things in your life
- At times you think you are no good at all
- You often find yourself so angry that you get into a fight
- It is important for you to help other people

I am going to ask you some questions about yourself. Please tell me how often you feel this way or how often these things occur. Please tell me if it is often, sometimes, or never.

- You are a good person
- You feel happy
- You feel worried
- You refuse to eat at mealtimes

- You feel frustrated when something does not go your way
- You have difficulty making friends
- You feel like running away from home

How often would you say you spend time playing (including sports), either at your home or somewhere else? Would you say... “a lot,” “a little,” or “never”?

I am going to read you some statements about yourself. Please tell me whether these things bother you often, sometimes, or never.

- Having too many responsibilities
- Taking care of family members
- Not having enough money for things such as clothing and food
- Concerns about the health of a family member
- Problems with friends and neighbors
- Problems getting along with your family
- Feeling unsafe in your neighborhood
- Feeling unsafe in your home

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