Health Impacts amongst Carers of Orphans and Other Children in a High HIV Prevalence Community in South Africa

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ABSTRACT: HEALTH IMPACTS AMONGST CARERS OF ORPHANS AND OTHER CHILDREN IN A HIGH HIV PREVALENCE COMMUNITY IN SOUTH AFRICA

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Fifteen million children have been orphaned by AIDS. A growing body of evidence documents impacts of parental deaths on orphans, but little is known about impacts faced by AIDS-orphan carers. This study set out to: (a) investigate physical and mental health outcomes of adults caring for children in Umlazi, a high HIV prevalence township in South Africa; (b) assess whether AIDS-orphan carers face worse outcomes compared to other carers; and, (c) identify risk and protective factors for health. Using a cross-sectional survey, data was gathered from a representative community sample from August 2008 to March 2009 resulting in the largest known study conducted on AIDS-orphan carers to date (n=1599). The majority of carers looked after non-orphaned children (66.85%) followed by AIDS-orphan (22.45%) and other-orphan children (10.69%). Orphan carers had significantly worse general health and functioning, depression, and post-traumatic stress than non-orphan carers but patterns were less clear when orphan carers were disaggregated into AIDS-orphan and other-orphan carers for comparison. This suggests that health interventions might target orphan carers, rather than singling out AIDS-orphan carers. Differences in age, gender, education, economic assets, and source of household income fully accounted for the association between being an orphan carer and poor health. Social policy grants reduced negative health disparities between orphan carers and non-orphan carers. Social support, education, economic assets, food, access to water, and housing were

also identified as risk and protective co-factors that might reduce orphan carer disparities in health. By highlighting health as a serious issue for orphan carers and identifying risk and protective factors for health, this study offers policy and program insights into how to mitigate negative impacts faced by carers in high HIV prevalence communities facing escalating numbers of orphans.

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PUBLICATIONS AND PRESENTATIONS RESULTING FROM THIS THESIS

The work in this thesis has resulted in the following peer-reviewed articles and publications:

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Operario, D. and C. Kuo (2007). "Transporting Evidence to Policy, With a Particular Focus on HIV Research: Challenges and Opportunities". Paper presented at the May 2007 meeting of the African Cochrane Collaboration Meeting on Evidence-Based Medicine, Cape Town, Republic of South Africa.

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Kuo, C. and M. Wilhelm-Solomon (2007). Dilemmas of Hope: HIV/AIDS and Development. International Development Course, Wadham College, University of Oxford, The U8 International Development Student Partnership

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LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ASSA	Actuarial Society of South Africa
AUDIT	Alcohol Use Disorder Identification Test
CBOs	Community Based Organizations
CES-D	Centre for Epidemiologic Studies Depression Scale
CIDI	Composite International Diagnostic Interview
CRC	Convention on the Rights of a Child
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
DUDIT	Drug Use Disorder Identification Test
DHS	Demographic and Health Surveys
GDP	Gross Domestic Product
HEARD	Health Economics and HIV/AIDS Research Division
HIV	Human Immunodeficiency Virus
HTQ	Harvard Trauma Questionnaire
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10^{th} Revision
K10	Kessler scale
KIDS	KwaZulu-Natal Income Dynamics Study
KZN	KwaZulu-Natal Province
LEC	Life Events Checklist
MICS	Multiple Indicator Cluster Surveys
MINI	Mini-International Neuropsychiatric Interview
MPHIL	Master of Philosophy
MSPSS	Multidimensional Scale of Perceived Social Support

NGOs	Non-Governmental Organizations
PI	Principal Investigator
PTSD	Post-traumatic stress disorder
RSA	Republic of South Africa
SF-36v2	Short Form-26 Version 2
UKZN	University of KwaZulu-Natal
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDP	United Nations Development Program
UNGA	United Nations General Assembly
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VA	Verbal Autopsy
WHO	World Health Organization

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CHAPTER I: INTRODUCTION

1. Global Impact of HIV and AIDS and the Policy Context

Thirty-three million people are living with Human Immunodeficiency Virus (HIV) (UNAIDS 2008). The global community faces the certainty of a world with HIV and with this, the challenges of instituting long-term solutions for those living with and affected by HIV. Particularly concerning are the 15 million children who have lost parents to Acquired Immune Deficiency Syndrome (AIDS) and the individuals caring for these children. These carers are the focus of this dissertation. Undertaking a study on carers – a population directly and substantially affected by AIDS deaths – was made after careful deliberation. Whilst considering the worthiness of any research topic is the ethical imperative of every researcher, such considerations were particularly relevant to this study given the current policy debate around what constitutes appropriate responses to the epidemic.

There has been an unprecedented response to AIDS, with $13.8 billion spent globally in 2008 (Kaiser Family Foundation 2009). With so much at stake – lives, programs, and funding – what constitutes an appropriate response to global epidemics has been the source of a heated policy debate. On one side are those who argue against 'AIDS exceptionalism' or approaches that single out AIDS as a disease necessitating a unique response (Bayer 1991). The main proponents of this argument suggest that unprecedented attention and funding for AIDS is unjustifiable because: AIDS spending is not commensurate to the burden of disease; attention on AIDS, particularly in low- and middle-income countries detracts from other vital development priorities (MacKellar 2005); AIDS spending diminishes spending on other important health

priorities (Garret 2007; Shiffman 2007); and, spending is not only misguided and ineffective, but has been detrimental to public health capacities in the hardest hit countries (England 2008). On the other side of the debate are supporters of 'AIDS exceptionalism'. The main proponents from this group argue that: AIDS is vastly underfunded (Piot 2008) and that funding should be scaled up to the $25.1 billion needed to meet country-defined targets for global AIDS response in low- and middle-income countries in 2010 (UNAIDS 2009); AIDS exceptionalism is particularly justifiable in high prevalence countries because of the extensive impact of AIDS upon multiple sectors of society (Whiteside and Smith 2009). While much of this debate has focused on spending for prevention and treatment, the debate is also relevant to responses in communities where AIDS is endemic and mortality is rising. This study on whether carers of AIDS-orphaned children experience exceptional consequences related to AIDS-related deaths and/or care for orphans informs the policy debate around responses to support carers and families in these communities.

Carers face a myriad of implications from AIDS-related deaths. Many carers are relatives of individuals who have died from AIDS-related causes. Moreover, carers play a substantial and direct role in supporting children orphaned by AIDS. With growing numbers of AIDS-orphaned children, carers are likely to face additional childcare responsibilities and with these, escalating challenges related to care provision (UNAIDS et al. 2004). A review of the literature (***Chapter II***) demonstrates a clear scientific need for further study on carers of AIDS-orphaned children. This review showed that a small empirical base exists on this population, not only in terms of the number of studies, but also topic areas and methodological approaches (Kuo and Operario 2009). Therefore, additional study of carers is scientifically and strategically vital for developing long-term strategies to support carers, children, and families.

There is paucity of existing evidence on carers of AIDS-orphaned children more generally, but specifically in regards to the types of outcomes that AIDS-related deaths and care provision may have on carer wellbeing. Identifying whether carers of AIDS-orphaned children experience unique consequences from AIDS related deaths and/or care provision is particularly relevant to the current policy debate. Studies that can identify types of outcomes and quantify these outcomes are particularly valuable for driving evidence-based policy and practice. Furthermore, additional research on how AIDS-related deaths and/or care for orphans influences carer wellbeing is not only necessary but timely as increasing attention and resources have been directed towards AIDS-orphaned children and their carers based on the premise that these cohorts are uniquely in need of assistance. Further investigation into whether carers of AIDS-orphaned children experience unique consequences informs the AIDS exceptionalism policy debate and helps ensure effective, evidence-based expenditures of limited resources.

While the issue of carer wellbeing covers a wide range of topics, this dissertation focuses specifically on carer physical and mental health. A systematic literature review suggests that we know little about the knock-on effects from AIDS-related deaths and/or care provision on carer health but that this is an important area for further exploration (***Chapter II***) (Kuo and Operario 2009). For example, a number of small scale qualitative studies indicate that carers may experience serious health consequences including higher levels of stress (Hansell et al. 2002; Oburu and Palmerus 2003; Rotheram-Borus et al. 2002), unmet mental health needs (Strug and Burr 2003), and physical and nutritional challenges (Ssengonzi 2007). This suggests that a better understanding of the health of individuals caring for AIDS-orphaned children is intrinsically important for supporting carers. Furthermore, studies suggest

that carer health is linked to family health and wellbeing (Afifi et al. 2003; Brehaut et al. 2009; P. and Golding 2001; Tsai et al. 2006). Thus, studies investigating carer health may also provide information on how to better foster family wellbeing. Studies of risk and protective factors associated with differential health outcomes amongst carers of AIDS-affected children will be critical for formulating effective interventions to bolster resilience and limit potentially negative effects of the epidemic on carers and families.

2. Conceptual Approach

Understanding the challenges carers face can only be achieved by examining these challenges within the specific context in which they occur. A decision to take a holistic approach resulted directly from the candidate's Master of Philosophy (MPhil) in Development Studies at the University of Oxford. The MPhil findings suggested that follow-on studies would require an expansive focus; rather than focusing singularly upon individual risk and protective factors, the DPhil study needed to capture other contextual factors that play an essential role in influencing carer health. Since findings from the MPhil study were detailed previously and submitted for publication, findings will not be described in detail. Instead, select elements of the MPhil thesis will be drawn out to highlight why a holistic approach was central to this dissertation.

2.1 Preliminary Exploratory Study

The MPhil exploratory study sought to (a) identify challenges confronted by carers of AIDS-orphaned children; (b) explore factors contributing to these challenges; and, (c) assess areas in need for further quantitative investigation. Primary data was collected between July and September 2006 from three communities in the vicinity of Durban, South Africa (RSA) from: (i) interviews with 14 key respondents at non-

governmental organizations (NGOs) and community based organizations (CBOs); and (ii) four focus groups with carers providing non-institutional care to AIDS-orphaned children (n=84).

In terms of the types of challenges carers encountered, physical and mental health were identified as leading challenges (***Table 1.1***).

Table 1.1: Challenges Associated with Caring for Children Orphaned by AIDS

Challenges Carers Experience	NGO/CBO Respondents (affirmative responses denoted with an 'x')	Carer Respondents (affirmative responses denoted with an 'x')
Carer's Physical and Mental Health Challenges		
Carer health	x	x
Disappointment about the expectations they had about their lives at this stage	x	
Carer bereavement	x	
Carer's sense of isolation	x	
Stigma	x	x
Tiredness/stress because of the energy involved in caring for children	x	
Stress of combining families	x	
Child's Physical and Mental Health Challenges		
Children bereavement	x	
Sexual abuse of children	x	x
Child health	x	x
Children's affective needs	x	x
Economic Challenges		
Clothing	x	x
Poverty	x	x
Unemployment	x	x
Environmental Challenges		
Food	x	x
Shelter	x	x
Transport, particularly to go to clinics	x	x
Clean water		x (only in rural areas)
Child Care Challenges		
Accessing documents for children to get financial support	x	x
School fees/uniforms	x	x
Disciplining children	x	x

That physical and mental health would figure so prominently as challenges carers experienced was unexpected. Thus, the MPhil study highlighted that health would be an important issue for further study.

In terms of the factors that contributed to carer challenges, the exploratory study identified a diverse range of individual, care related, household, and policy level factors. At the individual level, carers suggested that a number of factors including age, gender, and education, contributed to challenges. Most prominent was the issue of age, with elderly carers facing special difficulties in care provision, which was related to their inability to access resources:

> Elderly women face special challenges . . . they want to care for the children to the best of their ability. However they cannot because they are not getting anything. It is more difficult to extend their help to these children because they do not have anything. (Respondent A, NGO/CBO 3, August 18, 2006)

Similarly, carers said,

> Now, the families are bigger in the grandchildren side because a lot of people are dying and leaving kids behind. These grandchildren are being taken care of by grandparents rather than the parents themselves. This makes it difficult for the family because these grandparents are over 60 and cannot find employment . . . People are older and it is hard to find work. Many older people depend on disability funds or pension funds which is not a lot to take care of a family that is sometimes more than 10 people. (Urban Focus Group, August 16, 2006)

While individual characteristics contributed to challenges, data suggested that focusing only on these individual factors would not adequately capture the diverse range of care related, household, and policy level factors that contribute to care challenges.

For example, providing care to children also generated a number of challenges for carers. For example, a NGO/CBO respondent argued that meeting children's emotional needs was one of the most challenging aspects of caring for children:

> [Carers are] . . . concerned about physical well being. Some are concerned about education. Some of the grandmothers have spoken about their sense of the need to address emotional and social issues, but say that they struggle with this aspect. (Respondent A, NGO/CBO 4, July 25, 2006)

Carers were also "concerned with the most basic needs – primarily food, clothes, shelter which is not large enough for these growing families of children left behind" (Respondent B, NGO/CBO 3, August 22, 2006). Clearly, there are multiple factors related to meeting children's needs which created challenges for carers.

At the household level, a number of pressures contributed to challenges. First, deaths of household members created constraints to providing for children's needs.

> The epidemic seems to be placing a heavy burden on grandmothers who are taking care of many children without support of parents. While this is to some extent traditional, they increasingly have to take care of children without other financial and emotional support. (Respondent A, NGO/CBO 4, June 25, 2006)

Thus, deaths of family members deprived carers of important economic and social support. In turn, these reduced forms of support made it difficult to meet children's needs. A second example of household factors which created challenges was the difficulties experienced in combining new children into an existing household dynamic.

> Maybe you have four children of your own and four more are coming to join your family; it is a huge challenge to combine these children and treat them as your own. (Respondent B, NGO/CBO 4, August 1, 2006)

Third, high levels of unemployment placed a major strain upon carers be increasing dependency burdens and leading to a cycle of impoverishment. The following story, as told by a NGO/CBO respondent, illustrated this cycle:

> This particular mom is an example of how the epidemic has contributed to poverty. This mother cannot go to work because she has to look after . . . a large number of kids who are orphaned as well as her own. The epidemic reinforces this cycle of poverty. If the people in the valley do find work, the eldest children typically look after children. However, this creates problems because they are deprived of proper schooling. (Respondent B, NGO/CBO 3, August 22, 2006)

Clearly, solely focusing on individual factors detracts from an in-depth analysis of household variables which contribute to the difficulties carers experience.

A number of policy factors led to challenges for carers. Whilst all focus groups and NGO/CBO respondents recognized state grants as "a lifeline for caregivers", documentation requirements posed serious barriers to access (Respondent B, NGO/CBO 7, August 25, 2006).

> It is problematic to get birth and death certificates . . . To get documentation, you have to go back and find relatives of the parents, but the father has never been identified. So you have to get the mother's relatives to go swear affidavits at a certain place which you then have to bring into the magistrates office. (NGO/CBO 9, August 14, 2006)

Also, the eligibility requirements for grants failed to address need for grants. One example of this was the child support grant; respondents suggested that the 14 year age limit set for the child support grant (230ZAR or approximately 22USD per month) was a severe constraint given that 55 percentage of all orphans are age 12 or older (UNAIDS et al. 2004: 12). Another example of this was the foster care grant (650ZAR or approximately 62USD per month); respondents suggested that the eligibility process needed to be re-examined given that, "it used to be for children who needed to be removed for safety. It is now being used to accommodate orphans" in kin-headed households (Respondent B, NGO/CBO1, August 2, 2006). Even if carers were related to children, they had to go through a lengthy judicial process to access the grant. Finally, grants functioned as a source of family conflict since they were a valuable source of steady income. Disagreements occurred over ownership of children's documents since these papers were essential for accessing grants.

> When family members die, some family does not care about the children but do care about the certificates because this is a source of income.

> The family members negotiate who gets the certificate. (Respondent A, NGO/CBO 8, August 24, 2006)

These data illustrates how policy related factors create difficulties for carers.

The MPhil evidence presented previously illustrated that care challenges must be understood within a broader context. The previous analyses identified diverse factors that shaped the challenges carers confronted. Approaches that simplistically focus on individual variables will fail to capture the complexity of how the care relationship, household, and policy dynamics impact upon carer outcomes. Based on these data, a holistic approach was implemented in this DPhil study of carer health. In particular, the socio-ecological model of health was chosen as a heuristic model to guide the conceptual approach towards this study.

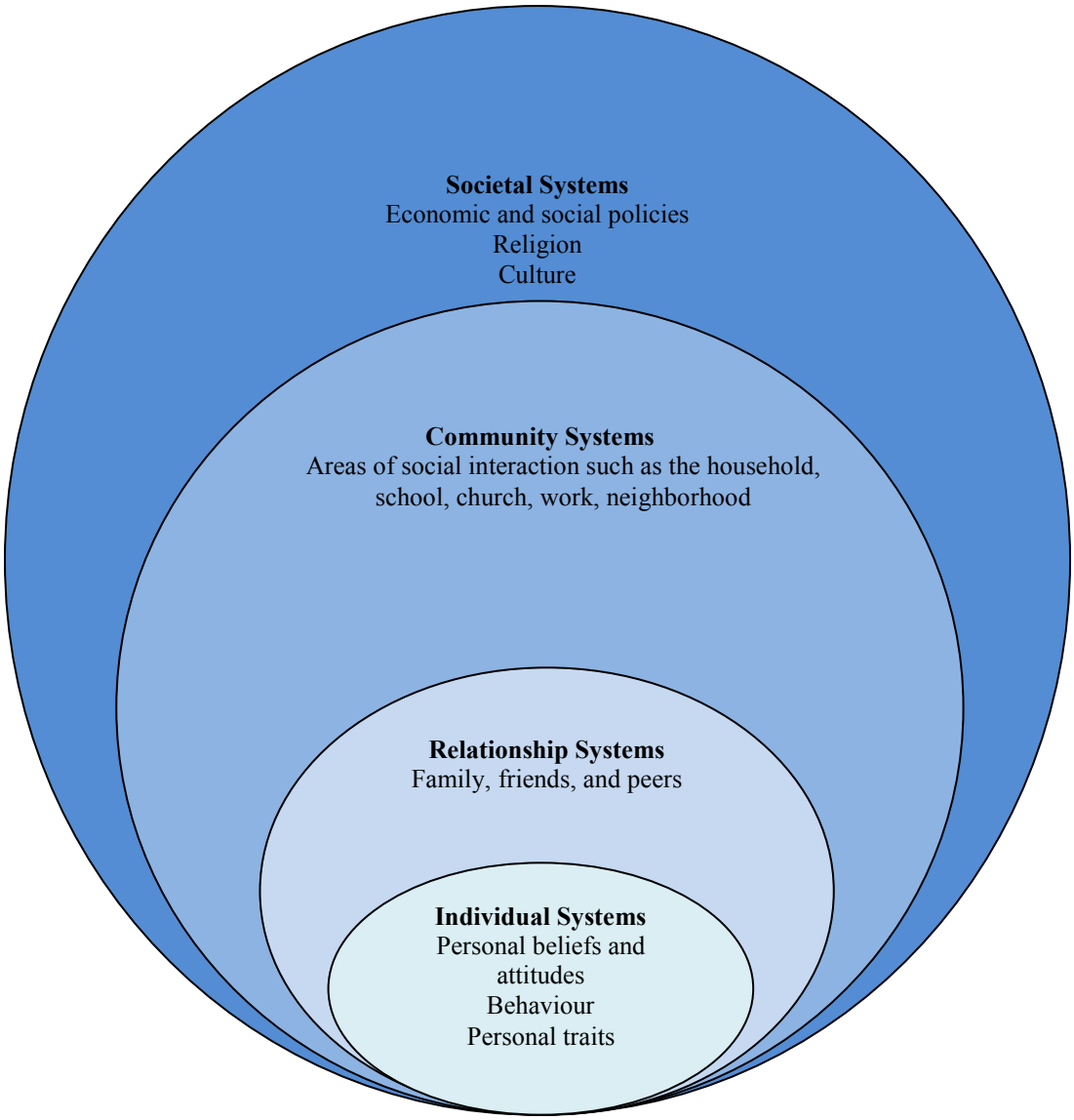
2.2 Conceptual Framework

A number of studies provide further support for an expansive conceptual approach towards studying health. LeClere et al. (1997) study of 346,917 adults in the US showed that while individual factors such as race, income, and education account for disparities in mortality, neighborhood characteristics helped account for a greater percentage of the health disparities that individuals experience. Similarly, Robinson's (2008) review of 12 studies on African American dietary behavior showed that whilst personal factors helped determine nutritional patterns, environmental factors such as culture, traditions, access to food, and interactions with family and friends were equally important in influencing dietary intake. Yen and Kaplan's (1999) study also suggested that environmental factors such as a community's socioeconomic status, access to commercial stores, type of housing, and population characteristics were equally important predictors for mortality as individual variables such as race, income,

education, and health habits. Even though these studies are from the US, and should be applied to South African settings with caution, the evidence supports the need for a broad analytical approach towards the study of carer health.

The socio-ecological model offers a wide conceptual lens for framing possible risk and protective factors influencing carer health outcomes. Choice of this model was based on the premise that health is multi-dimensional in nature and health outcomes can be influenced by a variety of factors. The socio-ecological model posits that individuals are embedded within an environment and the interactions between the individual and a variety of environmental factors determine health outcomes (Morris 1975). A main feature of this model is that individuals exist within a set of embedded systems (***Figure 1.1***).

Figure 1.1: Nested Systems within the Socio-Ecological Model



This conceptual approach offered several crucial insights for approaching the study of carer health. Firstly, variables at multiple system levels influence health outcomes. This conceptual insight provided a guide towards choice of variables for inclusion in the study (see ***Chapter III***). Secondly, variables within multiple nested systems interact to influence health outcomes. This insight led to an approach towards testing the cumulative influence of variables at different systems levels upon health outcomes (see ***Chapter VI***). Thirdly, this conceptual approach suggested that interventions which

address factors at multiple levels will be more effective than interventions which focus only on individual-level risk and protective factors for health (Bauer et al. 2003; McMurray 2007; Stokols 1992). In sum, the model offered a way to test how possible risk and protective factors interact to impact carer health. Since an understanding of the context in which carers are situated is essential to this study, the next two sections describe the community where research took place and burden of illness in more detail.

3. Research Setting: Umlazi Township

Research was conducted in Umlazi Township. Umlazi is located approximately 20 kilometers southwest of Durban and is the largest township in the Durban vicinity (***Figure 1.2***).

Figure 1.2: Map of Umlazi and Surrounding Areas

Established in 1950, Umlazi was one of the largest African townships to be built in a homeland and provided an important source of commuter labour supply to the industrial sector in Durban. Historically, Umlazi has been a site of political unrest between Inkatha and ANC supporters (Wiley et al. 1996). Tensions between these parties remain high in this area today.

The township is comprised of a mix of approximately 65 percent formal (***Figure 1.3***) and 35 percent informal homes (***Figure 1.4***) (2001).

Figure 1.3: Formal Homes in Umlazi Field Site

Figure 1.4: Informal Homes in Umlazi Field Site

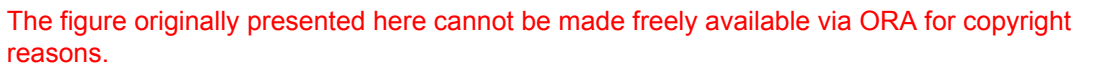
The population is nearly all Black African reflecting divisions from Apartheid; in the municipality Black Africans make up 68 percent of the population followed by 20 percent Indian, 9 percent White, and 3 percent Coloured (Dray et al. 2007).[1] The dominant language is isiZulu, reflecting trends in KwaZulu Natal Province (KZN) where 80.9 percent of the population speaks isiZulu, 73.6 percent speaks English, and 1.5 percent speaks Afrikaans.[2]

Umlazi is located within the Durban-Ilembe health district and is served by Prince Mshiyeni Memorial Hospital and several community clinics. Ward 79, where data collection took place, has one community clinic. Ward 79 is also served by eight schools (***Figure 1.5***).

[1] The terms for racial classification have been historically contested. However, a choice was made in this dissertation to remain consistent with classification categories used in the South African Census (Statistics South Africa, 'Census 2001: Concepts and Definitions', in Statistics South Africa (ed.), (Pretoria: Statistics South Africa, 2004).

[2] The data available at the ward and township level is limited. In these cases, data has been provided at the next most specific geographic unit possible.

Figure 1.5: Ward 79 in Umlazi Township



Educational outcomes in the municipality are poor with fewer than half of the population matriculating from tertiary education or completing higher degrees (***Figure 1.6***).

The figure originally presented here cannot be made freely available via ORA for copyright reasons.

Figure 1.6: Completion of Education in Ethekwini Municipality (Dray et al. 2007: 20)

Although township data is unavailable, broader trends suggest that individuals in this township experience poor educational outcomes; national data indicates that Black Africans consistently rank lowest in terms of educational attainment (Statistics South Africa, 2003b: 49). In addition, rates of unemployment are high with KZN experiencing the second highest provincial rates of unemployment at 31.7 percent (South African Government, 2006) and with Black Africans experiencing the burden of unemployment (Statistics South Africa, 2003b: 53). The township also faces high rates of crime (***Table 1.2***).

Table 1.2: Crime Rates In Umlazi Township, 2007

Type of Crime	Umlazi Township
Murder	98
Attempted murder	145
Rape	185
Assault	1398
Robbery	1238
Car or truck hijacking	106
Burglary	524
Drug-related crime	487
Other theft	455
Culpable homicide	22
Kidnapping	29

Together, these data illustrate a community facing high levels of socioeconomic deprivation. An examination of the burden of disease in the research setting mirrors these themes of deprivation.

4. Epidemiological Burden of Disease in South Africa

This study set out to examine whether carers experienced exceptional consequences from AIDS, particularly in regards to health. Therefore, choice of study sites focused on communities facing a high burden of HIV as well as other health issues (see details regarding site selection in ***Chapter III***). The following overview details a high burden of illness in the research setting.

4.1 Burden of HIV

South Africa has 5.7 million people living with HIV, the largest population of any country globally. AIDS-related deaths have led to substantial demographic and socioeconomic effects and resulted in 1.4 million children orphaned by AIDS (UNAIDS 2008). Within RSA, KZN is the hardest hit province with the highest HIV prevalence and rates of orphanhood at 19.8 percent (Shishana et al. 2005). The majority of orphans are Black African, mirroring dominant demographic characteristics of the epidemic in RSA. Within KZN, Ethekwini Municipality where Umlazi

Township is located is one of the worst affected municipalities with the highest antenatal HIV prevalence at 41.6 percent (Smith 2008). Although data was not available on the number of AIDS-orphaned children at the municipality or ward level, it was expected that the high prevalence of AIDS in this area resulted in corresponding levels of orphanhood.

4.2 Burden of Mental and Physical Illness

Developing countries face a large burden from mental disorders (Desjarlais et al. 1995). Mental and alcohol use disorders account for 15 percent of the total burden of disease in low- and middle- income countries (Patel 2007). In South Africa, the prevalence of mental disorders is high. The first nationally-representative study of common mental disorders in South Africa showed that 30.3 percent of the population experienced a lifetime mental disorder. Twelve-month prevalence estimates for South Africa showed that anxiety disorders (*e.g.,* generalized anxiety disorders, post-traumatic stress, etc.) were the most prevalent at 8.1 percent followed by substance use disorders (*e.g.,* alcohol abuse, alcohol dependence, drug abuse, drug dependence, etc.) at 5.8 percent, and mood disorders (*e.g.,* major depressive disorder, etc.) at 4.9 percent. For KZN, 28.0 percent of the population experienced some sort of lifetime mental disorder (Herman et al. 2009). There are broader health implications to these mental disorders. Mental disorders contribute to and are a consequence of other health issues prevalent in developing countries including poor child nutrition, low birth-weight, and more (Patel 2007).

In South Africa, the prevalence of physical illness is also high. South Africa's first national burden of disease estimates showed that physical illnesses accounted for 17 of the 20 top leading causes of deaths in South Africa. These 17 physical ailments

included: HIV/AIDS, ischaemic heart disease, stroke, tuberculosis, lower respiratory infections, diarrhoeal diseases, hypertensive heart disease, diabetes, chronic obstructive pulmonary disease, low birth weight, nephritis/nephrosis, trachea/bronch/lung cancer, asthma, septioaemia, oesophageal cancer, cirrhosis of liver, and protein-energy malnutrition. Physical illnesses accounted for a large percentage of years of life lost with HIV ranking as the highest cause of all years of life lost (35%) followed by tuberculosis (5.5%), diarrhoeal disease (5.0%), and lower respiratory infections (5.0%) (Norman et al. 2006). Physical illnesses also accounted for a large percentage of years lived with disability. Together, the data presented previously clearly demonstrates that the research setting encountered high burdens of HIV, mental, and physical illness.

5. Definitions

Previous sections presented background information to this study. This section provides definitions for key terms used throughout this dissertation.

5.1 Children

In this study, the term 'child' will be drawn from the Convention on the Rights for a Child (CRC) which defines a 'child' as "every human being below the age of eighteen years" (United Nations Children's Fund 1989: 1). This definition coincides with the definition put forth in RSA's Constitution (Republic of South Africa1996: Section 28). The study applied the CRC definition of the 'child' because this provides a clear method for identifying a 'child'. While such a definition may not always coincide with local understandings of childhood, consistency with policy definitions enabled study findings to have maximum impact upon policy.

5.2 Orphanhood

The term 'orphan' will be used in a manner consistent with the UNAIDS, UNICEF, and USAID definition of an orphan as: a maternal orphan or child under age 18 whose mother has died, a paternal orphan or child under age 18 whose father has died, and a double orphan or child under age 18 whose parents have died (UNICEF 2004). However, it should be noted that this definition is not universally accepted. For example, the Department of Social Development in South Africa defines an orphan as "a child who has no surviving parent caring for him or her" (Department of Social Development2005: 5). Moreover, local understandings of the term 'orphan' are contested. For example, Meintjes and Giese's qualitative study in RSA showed that the term orphan was alternately used to describe somebody that is poor; a child with a sick parent; a child who has lost both parents and was left with no wealth; and, a child who has lost both parents but was left with some wealth (Meinjtes and Giese 2006). Despite these definitional variations, this study utilized the more expansive definition established by UNAIDS et al. (2004) in order to identify the broadest possible range of carers for inclusion in this study. In addition, this definition is consistent with the majority of policy approaches, enabling findings to have a maximum impact.

5.3 Carer

A carer is defined as an individual who takes on primary childcare duties. Using this definition, a carer could be a parent, grandparent, aunt, uncle, sibling, or non-relative. Care provision may involve various responsibilities including meeting the economic, social, and psychological needs of a child. This study focused on home-based childcare (versus institutional care).

5.4 Risk and Protective Factors

A risk or protective factor is "an aspect of personal behavior or lifestyle, an environmental exposure, or an inborn or inherited characteristics which . . . is known to be associated with health-related conditions(s) considered important to prevent" (Last 2001). Some risk and protective factors may be modifiable or "a determinant that can be modified by intervention, thereby reducing the probability of disease" (*e.g.,* education) (Last 2001). However, other risk and protective factors cannot be changed (*e.g.,* age, gender).

6. Organization of Dissertation

The dissertation is structured in the following manner. ***Chapter II*** provides a systematic and comprehensive review of existing studies on carers of AIDS-orphaned children. In addition, because the studies on carers of AIDS-orphaned children are limited, this chapter draws from other relevant literature to provide insight on the physical and mental health of carers.

Chapter III sets out to describe research aims, questions, and hypotheses. This chapter also provides a detailed discussion of study methods including selection of the study site, questionnaire design, and sampling. The chapter also describes the recruitment, training, and management of the research team as well as research challenges. The chapter finishes with a description of handling data, ethical considerations, and study limitations.

Chapters IV, V, and VI present primary data drawn from a large cross-sectional survey of carers in Umlazi Township. ***Chapter IV*** begins by providing characteristics of the carer sample. ***Chapter V*** explores the physical and mental health of carers and

details differences across carer types. It also describes associations between carer health and various demographic and socioeconomic variables. ***Chapter VI*** identifies significant risk and protective factors for physical and mental health.

Chapter VII explores implications of this study. The chapter discusses the contributions of this study to the scientific evidence base. Then, the chapter provides some conclusions regarding what findings may indicate for policy and program planners interested in assisting carers. Finally, the chapter offers suggestions for future research.

CHAPTER II: REVIEW OF THE LITERATURE

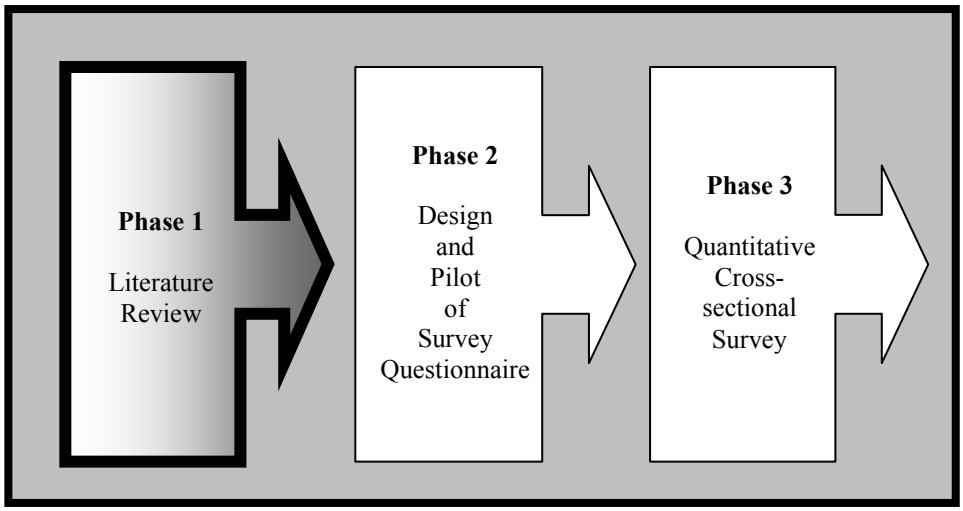


Figure 2.1: Literature Review

1. Introduction

This chapter begins by summarizing existing studies on carers of AIDS-orphaned children. This review illustrates a significant gap in the knowledge base regarding carers of AIDS-orphaned children, particularly in relation to how care provision impacts carer health. Then the chapter explores the broader literature around the health of carers, given that few studies focus on this issue for carers of AIDS-orphaned children.

2. Systematic Review of Studies on Carers of AIDS-Orphaned Children

A systematic review of studies on carers of AIDS-orphaned children was conducted in order to (a) summarize the empirical findings and trends across studies with specific relevance to the types of individuals providing care for children as well as the general needs, care experiences, and care duties amongst orphan carers, and (b) describe and assess the methodological quality of studies of orphan carers.

2.1 Search Methods

2.1.1 Defining Search Terms

In order to capture the full breadth of relevant studies, this review focused on both published and unpublished studies of non-parental carers providing non-institutional care to children who have lost one or both parents to AIDS. A keyword search strategy was devised by: (a) defining the problem of interest – HIV/AIDS – using the following terms and all variations: hiv, aids, hiv infection, hiv-1, hiv-2, hiv1, hiv2, human immunodeficiency virus, human immunedeficiency virus, human immuno-deficiency virus, human immune-deficiency virus, acquired immuno-deficiency syndrome, acquired immune-deficiency syndrome, sexually transmitted disease, and sexually transmitted infection; and (b) defining the population of interest – carers of AIDS orphans – using the following terms and all variations: care giver, family carer, foster, looked after, looked-after, look after, custodial, and orphan. The review aimed to examine any study reporting original primary data or secondary analysis of data related to the experiences of carers of AIDS-orphaned children; the intent of this search was to identify and describe any primary study on this population, rather than restrict the search to specific need domains of this population, such as health or social welfare provision.

2.1.2 Search Parameters

Editorials, commentaries, and theoretical or conceptual reports that did not include empirical quantitative or qualitative data were not included in this review. Sixteen databases were searched for published and unpublished empirical studies: Journals Ovid Full Text, Your Journals Ovid, Biosis Previews (1969-2007); CINAHL (1982-2007), CAB Abstracts (1973-2007), EMBASE (1980-2007), Global Health

(1973-2007), International Bibliography of the Social Sciences, Ovid Medline (1980-2007), PsychInfo (1985-2007), AIDSearch, PubMed, Social Services Abstracts, The Cochrane Library, Applied Social Science Index and Abstracts, and Sociological Abstracts. Although there were no linguistic or geographical search restrictions, articles were excluded if there was insufficient information available in English (*e.g.,* from an English-language abstract) to interpret the study. The search also included eligible non-published 'grey literature' reports on relevant public health and policy websites, including UNAIDS, the World Health Organization, and the U.S. Centers for Disease Control and Prevention; no studies fitting our inclusion criteria were identified. The search was conducted to include all papers published through November 2007. After abstracts were screened for conceptual and methodological relevance, papers were retrieved and the full text was assessed on methodological criteria. For each study, study location, design, and primary aims were identified. In addition, major findings were extracted from each study, and a taxonomy was designed for organizing study findings thematically.

A comprehensive systematic search identified a total of 33 relevant empirical studies (31 published studies and two unpublished dissertations) on carers of AIDS-orphaned children. Of these studies, full text for 29 studies were retrieved and included in this review. Full text for two dissertations and two studies could not be retrieved and were thereby excluded (Mashumba 1994; Mutikani 2003; Ruiz-Casares 2006; Urassa et al. 1997).

2.2 Results

2.2.1 Methodological Characteristics of Studies

Twenty-one studies took place in developing countries including three studies on populations in RSA (Freeman and Nkomo 2006a; Freeman and Nkomo 2006b; Schroeder and Nichola 2006; Townsend and Dawes 2004, 2007)[3]; eight studies took place in the developed world, all which were in the United States (***Table 2.1***).

Table 2.1: Study Locations

Country	Number of Studies In Country	Study Author(s) and Year
Multi-country study of 40 countries in the global South	1	(Monasch and Boerma 2004)
Botswana	2	(Heymann et al. 2007; Miller et al. 2006)
Brazil	1	Doring *et al.* 2005
Dominican Republic	1	(Burgos et al. 2007)
Ethiopia	1	(Abebe and Aase 2007)
Kenya	2	
Malawi	2	(Chirwa 2002; Muula et al. 2003)
South Africa	3	(Freeman and Nkomo 2006a; Freeman and Nkomo 2006b; Schroeder and Nichola 2006; Townsend and Dawes 2004, 2007)[2]
Swaziland	1	(Jones 2006)
Thailand	1	(Safman 2004)
Uganda	4	(Ntozi and Mukiza-Gapere 1995; Oleke et al. 2005; Ssengonzi 2007; Yamano et al. 2006)
United States of America	8	(Boyer and Poindexter 2005; Cook et al. 2003; Hansell et al. 1998; Joslin and Harrison 1998, 2002; Linsk and Mason 2004; Mason and Linsk 2002; Rotheram-Borus et al. 2002; Strug and Burr 2003; Winston 2003)[3]
Zimbabwe	2	(Foster et al. 1995; Howard et al. 2006; Mashumba 1994; Mutikani 2003)

Since studies took place in diverse locations, findings may not be transferable from context to context. Sample size varied widely from study to study, ranging from n=7 to n=1400. Sample sizes tended to reflect the variety of methods employed, which

[3] The Freeman and Nkomo study resulted in two publications. The Townsend and Dawes study resulted in two publications.

encompassed both qualitative and quantitative methodologies. Study size and methods are summarized in ***Table 2.2***.

Table 2.2: Study Size and Methods

Study Author(s) and Year	Study Size (n)		Methods						
		Longitudinal	Cross-Sectional Survey	Secondary Analysis of Survey Data	Semi-Structured or Unstructured Interviews	Focus Groups[1]	Case Studies	Ethnographic Observation	Text Analysis
(Abebe and Aase 2007)	72				x	x (14)		x	x
(Boyer and Poindexter 2005)	7				x				
(Burgos et al. 2007)	52		x						
(Chirwa 2002)	Not provided				x			x	x
(Cook et al. 2003)	45		x						
(Doring et al. 2005)	853		x						
(Foster et al. 1995)	570		x						
(Freeman and Nkomo 2006a; Freeman and Nkomo 2006b)	1400		x						
(Hansell et al. 1998)	70	x							
(Heymann et al. 2007)	1033			x					
(Howard et al. 2006)	371		x						
(Jones 2006)	25				x	x (1)			
(Joslin and Harrison 1998, 2002)	20						x		
(Linsk and Mason 2004); Mason and Linsk 2002	28				x				
(Miller et al. 2006)	1033			x					
(Monasch and Boerma 2004)	Not provided			x					
(Muula et al. 2003)	157				x				
(Ntozi and Mukiza-Gapere 1995)	459					x			
(Nyambedha et al. 2003a, 2003b)	565		x		x	x		x	
(Oburu and Palmerus 2003)	241		x						
(Oleke et al. 2005)	503		x		x	x (5)		x	x
(Rotheram-Borus et al. 2002)	65	x							
(Safman 2004)	8				x	x (3)			
(Schroeder and Nichola 2006)	91		x						
(Ssengonzi 2007)	27				x	x (10)			
(Strug and Burr 2003)	31		x						
(Townsend and Dawes 2004, 2007)	175		x						
(Winston 2003)	10				x				
(Yamano et al. 2006)	940			x					

The majority of studies (13) used cross-sectional survey methods; sample sizes for studies using survey design ranged from n=31 to n=1400. Only two survey studies examined carers in comparison to control groups (Hansell et al. 1998; Linsk and Mason 2004).[4] The remainder of studies used qualitative methods, which included focus groups and in-depth individual interviews (12); consisted of a secondary analysis of existing survey data (4); or utilized a mix of survey and qualitative methods (2).

Strengths of the studies included drawing attention to carers in the developing world where the epidemic has had a disproportionate impact. In addition, six studies explored a subset of potentially vulnerable carers of AIDS-orphaned children. Of these six studies, one study focused on the unique needs of male foster carers and five studies drew attention towards the potentially unique vulnerabilities experienced by elderly carers. Other strengths included 12 qualitative studies which utilized multiple methods to triangulate data. Despite these strengths, studies also exhibited some weaknesses.

A general weakness of the studies was the lack of theoretically framed approaches towards research on carers. Only five studies used some sort of theoretical framework (Abebe and Aase 2007; Chirwa 2002; Joslin and Harrison 2002; Oburu and Palmerus 2003; Townsend and Dawes 2007). The theories utilized included social rupture and resilience theories, the social situational model of stress, and the theory of planned behavior. The remaining studies of AIDS-orphan carers were largely descriptive and did not state the theoretical basis for the research investigation. In addition, the majority of studies used convenience or snowball sampling thus limiting the extent to which conclusions could be extrapolated about the population from a statistically significant representative sample; only four studies utilized random

[4] Linsk and Mason's study resulted in two publications.

sampling, likely due to the lack of data identifying carers in a systematic manner (Foster et al. 1995; Freeman and Nkomo 2006a; Miller et al. 2006; Nyambedha et al. 2003a, 2003b). Finally, the majority of studies were cross-sectional in nature with only two studies collecting longitudinal data (Hansell et al., 1998; Rotheram-Borus et al., 2002).

2.2.2 Content of Studies

Study findings can be organized into six thematic areas (***Table 2.3***).

Table 2.3: Study Themes

Study Author(s) and Year	Themes					
	Who Provides Care	**Capacity of the Extended Family to Provide Care**	**Factors Influencing Decisions to Care**	**Care Challenges**	**Ways of Addressing Care Challenges**	**Carer Wellbeing**
(Abebe and Aase 2007)		x				
(Boyer and Poindexter 2005)			x			x
(Burgos et al. 2007)				x		
(Chirwa 2002)		x				
(Cook et al. 2003)	x		x			
(Doring et al. 2005)	x					
(Foster et al. 1995)	x					
(Freeman and Nkomo 2006a; Freeman and Nkomo 2006b)	x		x			
(Hansell et al. 1998)					x	x
(Heymann et al. 2007)				x		
(Howard et al. 2006)	x		x			
(Jones 2006)	x			x		
(Joslin and Harrison 1998, 2002)						x
(Linsk and Mason 2004); Mason and Linsk 2002				x		
(Miller et al. 2006)				x		
(Monasch and	x					

Study Author(s) and Year	Themes					
	Who Provides Care	Capacity of the Extended Family to Provide Care	Factors Influencing Decisions to Care	Care Challenges	Ways of Addressing Care Challenges	Carer Wellbeing
Boerma 2004)						
(Muula et al. 2003)				x		
(Ntozi and Mukiza-Gapere 1995)	x	x				
(Nyambedha et al. 2003a, 2003b)	x			x		
(Oburu and Palmerus 2003)						x
(Oleke et al. 2005)	x					
(Rotheram-Borus et al. 2002)	x					x
(Safman 2004)				x		
(Schroeder and Nichola 2006)				x		
(Ssengonzi 2007)						x
(Strug and Burr 2003)						x
(Townsend and Dawes 2004, 2007)			x			
(Winston 2003)			x			
(Yamano et al. 2006)	x					

Who Provides Care to Children

Twelve studies documented some of the general trends relating to who provides care (***Table 2.3***). For example, Monasch and Boerma's (2004) secondary analysis of national surveys from 40 sub-Saharan African countries showed that 90 percent of orphans were cared for by extended family members. This trend of familial care was supported in several other studies conducted in South Africa (Freeman and Nkomo 2006), Zimbabwe (Foster et al. 1995), Brazil (Doring et al. 2005), and the United States (Rotheram-Borus et al. 2002). Studies also showed gendered patterns of care with female extended family members more typically taking on care duties (Yamano et al. 2006), particularly older female relatives (Foster et al. 1995; Howard et al. 2006). However, differences arose in terms of whether paternal or maternal kin took on care

duties. For example, cultural norms in some places dictate that children be placed with paternal or maternal kin following death of parents but such cultural norms may be changing in communities where the impact of the epidemic has been more severe (Jones 2006; Oleke et al. 2005). Finally, while child and orphan headed households have been the focus of much discussion within the policy realm, three studies assessing trends in orphan care noted that these households were not prevalent (Foster, 1995; Howard, 2006; Jones, 2006). Foster's (1995) survey of the prevalence of orphans in 570 households in Malawi demonstrated that there were few orphan headed households. Out of the 570 households surveyed, three households were headed by female orphans 17 to 23 years. Similarly, Howard et al.'s (2006) survey of 371 carers in Zimbabwe noted that ten carers were under eighteen years of age; of these ten children, four were orphans caring for their siblings and two were aunts of the orphans). Jones' (2006) qualitative study of orphan care in Swaziland noted that only one household was headed by an orphan over 18 years of age. In addition, Jones noted that in one of her research locations, an informal settlement of over five hundred households, no respondents were able to identify any cases of child headed households. This review of studies on who decides to provide care illustrates that studies have documented general trends in child placement.

Capacity of Extended Family to Provide Care

Three studies examined the capacity of the extended family network to continue caring for children orphaned by AIDS (***Table 2.3***). Ntozi and Mukiza-Gapere's (1995) study in Uganda suggested that extended families are unable to cope with the strain of rising numbers of AIDS-orphaned children. Two additional studies examined the capacity of the extended family using either social rupture theory, which suggests that

the extended family is collapsing under the strain of caring for orphans studies, or social resilience theory, which suggests that the family is able to continue to absorb and care for orphans (Abebe and Aase 2007; Chirwa 2002). Abebe and Aase's (2007) qualitative study in Ethiopia suggested that neither the social rupture or social resilience theories were adequate in explaining how the extended family was coping with rising numbers of AIDS-orphaned children. Rather, the capacity of the extended family to cope with orphans depended on a variety of factors which vary from context to context. In the Ethiopian context, Abebe and Aase (2007) found that the extended family's ability to cope was dependent upon their various social and economic resources as well as the demands of the child under their care. In addition, authors pointed out that capacity may vary in urban versus rural areas since Ethiopia's urban areas experience much higher infection rates than rural areas. Similarly, Chirwa's (2002) qualitative study in Malawi suggested that the social rupture thesis was too simplistic a theory for explaining how families are coping with rising number of orphans. This theory failed to account for the diverse factors which placed pressures upon the extended family. For example, in Malawi factors such as size of the family, age and gender of children, and economic resources all played a role in the capacity of the extended family to care for orphans. Such nuanced findings indicate that the family's capacity to care for AIDS-orphaned children is context dependent and any assessment of the family's capacity must take into the account diverse social, cultural, and economic resources available to the family as well as the particular characteristics of the carer, child, and household.

Factors Influencing Decision to Care

Six studies examined the issue care placement (***Table 2.3***). Two of these studies examined the issue of permanency planning (Boyer and Poindexter 2005; Cook et al. 2003). Cook *et al.*'s (2003) quantitative study examined the permanency planning of mothers with HIV in the United States and the individuals the children are placed with after mothers passed away. Boyer and Poindexter's (2005) qualitative study examined a different issue of permanency, focusing instead on permanency planning of older surrogate parents of AIDS-orphaned children in the United States. Their study showed that carers lack legal knowledge and social support as well as faced emotional barriers and HIV-related stigma when trying to make care plans for children. Three studies examined the factors that impact the willingness of potential surrogate carers to foster children (Freeman and Nkomo 2006a; Howard et al. 2006; Townsend and Dawes 2004, 2007). Freeman and Nkomo's (2006a) qualitative study in South Africa suggested that age and gender played a difference in decisions to care with older male carers less willing to take on younger children. This same study showed that both kin and non-kin carers were more willing to take on care duties if offered direct financial assistance and/or indirect financial assistance (*e.g.*, payment of school fees, etc.). Similarly, Howard et al.'s (2006) study in Zimbabwe suggested that poverty was the main reason that potential carers were unwilling to take on additional children. Townsend and Dawes' (2004, 2007) in South Africa showed that willingness to care for orphans depended on factors such as the child's age, HIV status, and gender as well as the types of financial costs that might be incurred by taking on care duties. Finally, Winston's (2003) study of surrogate African American grandmothers in the United States showed that cultural norms often compel care even if it means care will entail

high personal costs. This review illustrates that studies have only begun to explore the factors influencing the process of deciding who takes on care duties.

Care Experience

Ten studies examined the types of care challenges carers confront as well as how carers address these challenges. Of these studies, nine examined the types of challenges associated with providing care (***Table 2.3***). Several studies in Botswana (Miller et al. 2006), Thailand (Safman 2004), South Africa (Freeman and Nkomo 2006a; Freeman and Nkomo 2006b), Swaziland (Jones 2006), and the United States (Linsk and Mason 2004) highlighted the financial challenges associated with provision of care to additional children. Studies also identified a variety of other child-related care challenges including children's health (Linsk and Mason 2004), children's behavior which varied according to the child's disease status and gender (Burgos et al. 2007), meeting children's educational needs (Freeman and Nkomo 2006a), and decreased food security as a result of taking on additional children into the family (Schroeder and Nichola 2006). Heymann et al.'s (2007) quantitative study in Botswana examined the challenges faced by working carers of AIDS-orphaned children. The study showed that carers experienced more work-care conflicts, decreased levels of work, and spent less time caring for their own children when compared with carers of non-orphans.

Despite the growing amount of data on the challenges associated with care provision, only Hansell et al. (1998) explored how carers overcome these challenges. This quantitative longitudinal control study in the United States showed that an intervention of case management support increased the levels of social support for seronegative carers. However, this intervention had no effect on seropositive carers

who experienced declines in social support regardless of the presence of care management. This suggests that certain carers may be more vulnerable than others and that interventions designed to support carers may need to be tailored towards the variable needs of different types of carers.

Carer Wellbeing

In relation to carer physical and mental wellbeing, one qualitative study in the United States directly examined how care duties impact carer physical and psychosocial wellbeing (Joslin and Harrison 1998, 2002). This study showed that carers experienced high levels of chronic conditions, high stress, poor health, and limited time to address their own health needs due to care duties. While this study was limited in size, consisting of 20 case studies of surrogate carers chosen non-randomly and focused only on older surrogate carers, this findings suggested that care duties impact carer health.

Further support that dynamics of care impact carers in a negative manner can be drawn from six studies which examine the issue of wellbeing tangentially. Oburu and Palmerus (2003) examined discipline strategies used by grandparents fostering their grandchildren in Kenya and in so doing revealed higher levels of stress amongst older, full time grandparents. Higher stress was also associated with caring for older children. Rotherman-Borus et al.'s (2002) longitudinal study in the United States examined carers' living situations and in so doing, revealed that carers report continued stress due to care duties. Studies also suggest that stress may be linked to other adverse health outcomes (Hansell et al. 2002) with older surrogate carers facing higher vulnerability to these poor outcomes due to the additional stress associated with late-life parenting (Boyer and Poindexter 2005: 61 citing Brabant 1994, Hansell et al. 2002). Strug and

Burr's (2003) study, also in the United States, examined male carers needs and revealed that these carers stated that their mental health needs were unmet. Ssengonzi's (2007) study of the challenges faced by elder surrogate carers in Uganda showed that these carers faced economic, emotional, physical and nutritional stresses which impacted their health.

2.2.3 Gaps Identified in the Systematic Literature Review

This systematic review exposed geographical weaknesses. In RSA, there were three known published studies on carers of AIDS-orphaned children. Moreover, the systematic review highlights several methodological weaknesses in existing studies. First, few studies utilize a theoretical framework. However, utilizing a theoretical approach towards studying carers would offer a way to revise existing theory and develop new theories on care for AIDS-orphaned children. Second, few studies used control groups. The use of control groups would aid in isolating the unique challenges that carers of AIDS-orphaned children face. Third, few studies have been based on large, randomly selected, representative samples. While larger sample sizes could provide the basis for generalization, significant obstacles exist in the design of studies drawing from large random samples due to the lack of reliable data identifying carers of AIDS-orphaned children. A fourth methodological issue was the limited number of studies that gathered longitudinal data. This doctoral study tries to address the first three weaknesses identified but was unable to incorporate a longitudinal element into study design due to lack of funds and time.

This comprehensive review of studies also reveals significant gaps in the knowledge base. In terms of care patterns, studies offer strong evidence regarding general patterns of child placement. However, few studies provide detail on what type

of kin (*e.g.*, grandmother, grandfather, aunt, brother, etc.) or the type of relationship these kin have to the child (*e.g.*, maternal versus paternal kin). Similarly, few studies provide details on the type of non-kin relationship carers have with children (*e.g.*, friend, neighbor, etc.). Furthermore, research needs to be conducted on the role of non-family carers since these individuals are likely to play a more significant role in care for AIDS-orphaned children as the pandemic progresses and the numbers of AIDS-orphaned children rises. Finally, studies need to examine how local context influences patterns of care. Situating the carers and the challenges they encounter within context is vital for understanding the broader environment in which challenges arise as well as the types of interventions that may be most appropriate in a resource scarce environment. This dissertation offers one of the most comprehensive assessments of those caring for AIDS-orphaned children to date, drawing information on carer types using a representative sample. The data generated includes information on types of kin and non-kin carers as well as a variety of contextual factors that may influence the types of challenges carers encounter.

In terms of the experience of providing care, studies offer some evidence regarding care challenges. However, little is known about how care challenges vary according to the carer's characteristics including the carer's age, gender, or the relationship to the child. A more nuanced understanding of care challenges would allow policy and program planners to tailor interventions to carer needs. In addition, very little is known about how carers address the challenges associated with provision of care. The health of carers should be a matter of central concern given that global projections suggest that the number of children orphaned from AIDS will increase in the coming decade (UNAIDS et al. 2004); that carers play central role in these children's lives; and because studies suggest the carer health is linked to family health

and wellbeing (Afifi et al. 2003; Brehaut et al. 2009; P. and Golding 2001; Tsai et al. 2006). Evidence from six studies which tangentially examine the issue of carer health suggested that care provision has serious consequences for health and these outcomes need be explored in more depth. Thus this study, which has the overarching aim of examining carer health, contributes significantly to this gap in the evidence base.

3. Review of Literature on Carer Health

One of the main objectives of this study is to better understand how care provision impacts carer health. In the absence of existing studies examining this issue in the target population, the following discussion draws from other relevant literature on carer health.

3.1 Health Outcomes of Other Types of Carers

As noted in the systematic review of studies on carers of AIDS-orphaned children, only one known published study directly examined how care duties impact carer health (Joslin and Harrison 1998, 2002). Due to the paucity of existing studies on the health of those caring for AIDS-orphaned children, the subsequent discussion draws insight from other relevant literature on the health of other carer populations.

3.1.1 Carers of Individuals with Illness

A number of studies in the developed world have examined the health of those caring for individuals with chronic illness. Studies suggest that care provision can influence mental and physical health outcomes, quality of life, depression, stress, general health status (Irving et al. 1995; McMillan 1996; Raveis et al. 1998). Studies on the health of individuals caring for people living with HIV and AIDS suggest that

care provision can negatively impact carer health. In regards to physical health effects, several studies suggest that carers may experience negative physical outcomes. For example, LeBlanc et al.'s (1997) study of 642 carers of AIDS affected gay men showed that carers experienced deteriorating physical health status regardless of whether carers were seropositive or seronegative. Clipp et al.'s (1995) study showed that carers experience physical fatigue due to provision of care. In regards to mental health outcomes, studies suggest that carers of people living with HIV experienced elevated levels of emotional distress (Pearlin et al. 1988; Raveis and Siegal 1991) and depression (LeBlanc et al. 1995; LeBlanc et al. 1997). These studies suggest that carers of those living with HIV experience negative outcomes due to care provision.

3.2 Differential Health Outcomes of Surrogate Parents

The literature on custodial grandparents also suggests that care provision may be associated with poor physical health. This may be linked to stressors specifically related to surrogate parenting such as difficulties controlling grandchildren's behavior, negotiating differences in values, and discipline (Stokes and Greenstone 1981). For example, Solomon and Marx's (2000) secondary analysis of data from the 1995 Health and Retirement Study using a representative sample showed that 45 percent of custodial grandparents (n=123) reported fair to poor physical health as compared to 24.3 percent of noncustodial grandparents (n=1152). Similarly, Minkler et al.'s (1992) study of 72 African American grandparents reported that one third of carers experienced worsening health since the beginning of care provision.

In addition, literature on custodial grandparents suggests that care provision may be associated with poor psychosocial wellbeing. Studies by Halund (2000), Kelley (1993), and Goldberg-Glen et al. (1998) show that custodial grandparent

experience high levels of stress. Several studies suggest that custodial grandparents have higher rates of depression or depressive symptomology (Burton 1992; Fuller-Thomson and Minkler 2000; Goldberg-Glen et al. 1998; Jendrek 1993; Minkler and Roe 1993; Roe et al. 1996; Szinovacz et al. 1999). While these studies were cross-sectional studies or small longitudinal studies, Minkler et al.'s (2000) analysis of longitudinal national data on custodial grandparents (n=144) in the United States using the National Survey of Families and Households provides stronger evidence for the association between care provision and poor psychosocial wellbeing. This study showed elevated levels of depressive symptomology directly associated with care. Similar to studies of custodial grandparents' physical wellbeing, this study suggested that certain cohorts are more at risk for depression including being female, lower income, and being single (Minkler et al. 2000). However, Giarrusso et al.'s (1996) three year longitudinal study comparing self-reported physical wellbeing of co-parenting grandparents with parenting grandparents with grandparents not caring for children found few negative health effects due to care. However, the demographic information from this study – 90 percent of participating grandparents had incomes above the poverty line and 72 percent of grandparents had incomes above the national median income – suggests that socioeconomic status may play some role in health outcomes (Giarrusso et al. 1996).

Particular cohorts within the custodial grandparent group may be more vulnerable to poor health outcomes than others. Three studies suggested that older female custodial grandparents are most likely to report poor physical health (Burton 1992; Minkler et al. 1992; Minkler and Roe 1993). The poor physical outcomes that older female custodial grandparents experience may be due to child care burdens (Roe and Minkler 1995). Other studies suggest that poor outcomes may be due to unequal

prioritization of needs in which grandparents acting as surrogates ignore their health needs in favor of grandchildren's needs (Caliandro and Hughes 1998). Solomon and Marx's (1999) study shows that single custodial grandmothers had poorer health and more restricted daily activities when compared with married custodial grandmothers; these single grandmothers were more likely to have incomes below the poverty line and lacked the social support that a spouse offers (Solomon and Marx 1999). Studies also suggest that grandparent surrogates may be more vulnerable than other types of surrogates. Comparisons on grandparent carers and non-carers show that grandparents have higher levels of depression (Minkler et al. 1997)and fare worse in happiness, health, and activity limitations (Strawbridge et al. 1997).

4. Summary

This study is one of few studies to explore how care challenges impact the wellbeing of adults caring for AIDS-orphaned children in the global South. It is one of the few studies on carers of AIDS-orphaned children that utilize comparison groups and it is one of few studies to examine carers of AIDS-orphaned children in South Africa.

CHAPTER III: STUDY METHODOLOGY

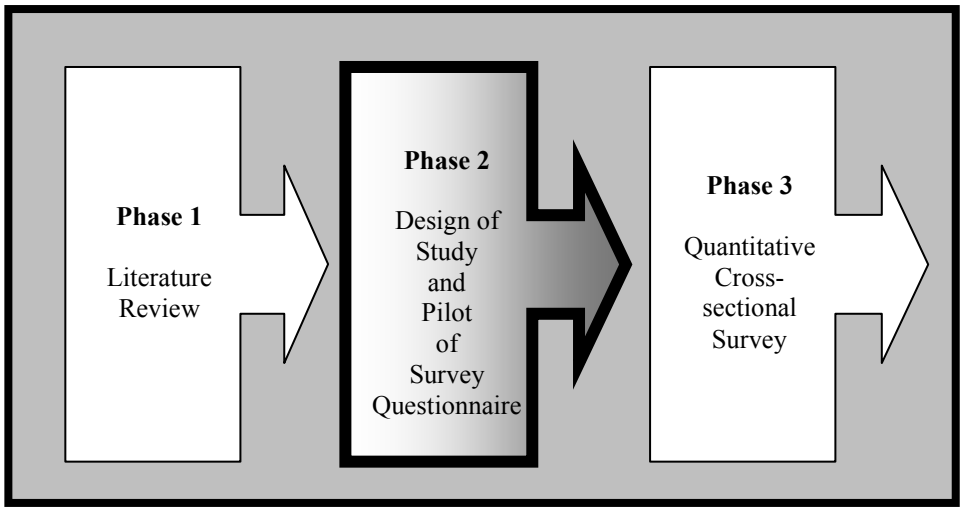


Figure 3.1: Design of Study and Pilot of Survey Questionnaire

1. Introduction

This chapter provides an overview of study methodology. The chapter details the design of a cross-sectional survey representative of adults providing home-based care to children in Ward 79 of Umlazi Township, a high HIV prevalence community in South Africa. Whilst carers of AIDS-orphaned children are of particular interest, the study generates data on carers of all children in order to better contextualize data; subsequent analyses uses carer comparison groups (*i.e.,* carers for other-orphaned and non-orphaned children; carers of AIDS-orphaned, other-orphaned, and non-orphaned children) to elicit distinctions between carer groups. The discussion includes an overview of research aims, questions, and hypotheses. It also describes the design of the questionnaire, sampling strategies, management of the research team, stakeholder consultations, research challenges, handling data, and ethical considerations.

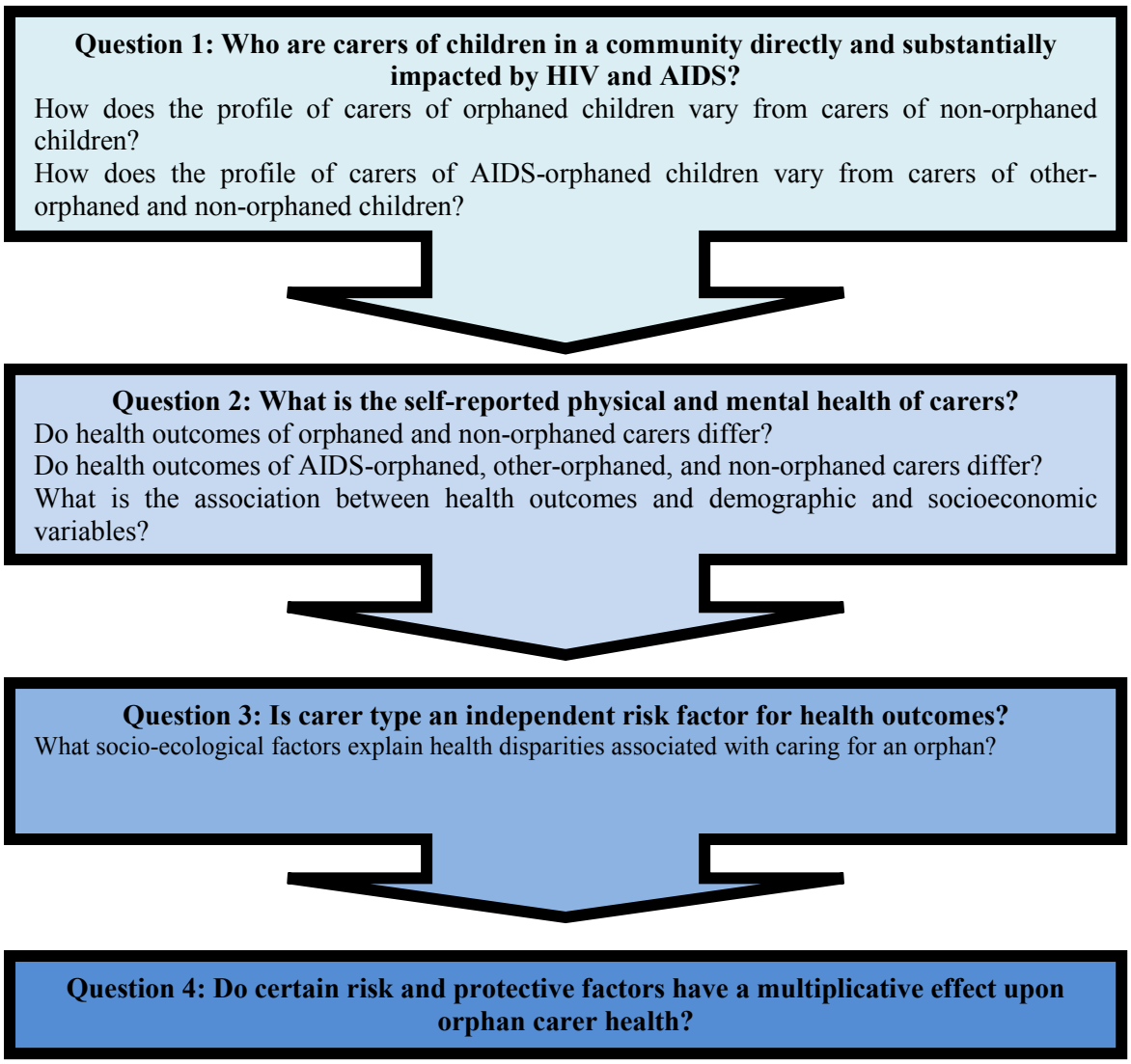
2. Cross-Sectional Survey Aims, Questions, and Hypotheses

The design of the cross-sectional survey was directly influenced by the geographical, content, and methodological gaps identified during the systematic

literature review (see ***Chapter II***). First, the survey was designed to gather descriptive demographic and socioeconomic information on adults providing home-based childcare to children in Umlazi Township, a community directly and substantially impacted by HIV/AIDS. Second, the survey set out to assess the physical and mental health of carers using psychometrically valid instruments. Third, the study assessed whether health outcomes differed by carer type. Finally, the study identified risk and protective factors associated with health outcomes.

The survey was designed to answer four main research questions, each with sub-questions (***Figure 3.2***).

Figure 3.2: Cross-Sectional Survey Research Questions



Based on the literature review and pilot study, the following hypotheses were formed (***Table 3.1***).

Table 3.1: Cross-Sectional Survey Hypotheses

1.1	Orphan carers will exhibit a different demographic and socioeconomic profile than non-orphan carers. Orphan carers are more likely to be female, older, have fewer economic assets, less social support, less education, and have more people in their household than non-orphan carers.
1.2	AIDS-orphan carers will exhibit a different demographic and socioeconomic profile than other-orphan and non-orphan carers. AIDS-orphan carers are more likely to be older, have fewer economic assets, less social support, and less education than other-orphan and non-orphan carers.
2.1	Orphan carers will exhibit different health outcomes than non-orphan carers. Orphan carers will have poorer health outcomes than non-orphaned carers.
2.2	AIDS-orphan carers will exhibit different health outcomes than other-orphan and non-orphan carers. AIDS-orphan carers will have poorer health outcomes than other-orphan and non-orphan carers.
3.1	Carer type is expected to be a primary risk factor for carer health. Carer type will impact health above and beyond all other risk and protective factors.
3.2	Variables related to care provision are expected to buffer upon the relationship between carer type and carer health.
4	Various risk factors are expected to have a multiplicative effect with carer type upon carer health.

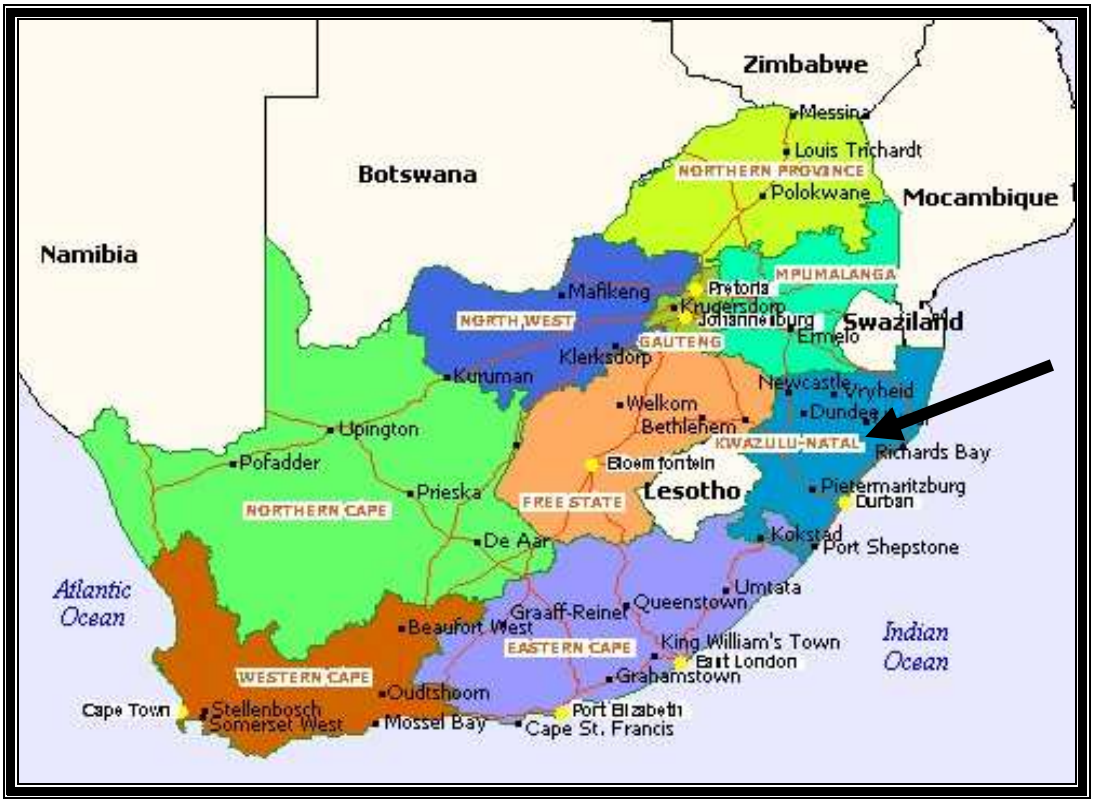
3. Overview of Cross-Sectional Survey Design and Methods

The following discussion details basic components of study design including: (a) site selection; (b) design of a psychometrically valid and culturally appropriate survey questionnaire; (c) sampling; and (d) expert consultations.

3.1 Study Site

Selection of a research site depended upon two sets of scientific criteria. The first consideration included choice of sites with high HIV prevalence. South Africa was chosen because it has the largest epidemic in the world with the fifth highest prevalence globally (UNAIDS and WHO 2008). From there, a site was narrowed to KwaZulu Natal (KZN), the province with highest antenatal HIV prevalence at 37.4 percent (South African National Department of Health 2008) (***Figure 3.3***).

Figure 3.3: Map of Republic of South Africa and KwaZulu Natal Province



Focus then narrowed to Ethekwini, the municipality with the highest antenatal HIV prevalence at 41.6 percent (Smith 2008). Once the site was narrowed to the municipality level, a second set of criteria was used to select a ward, a geographical area determined by electoral voting boundaries.

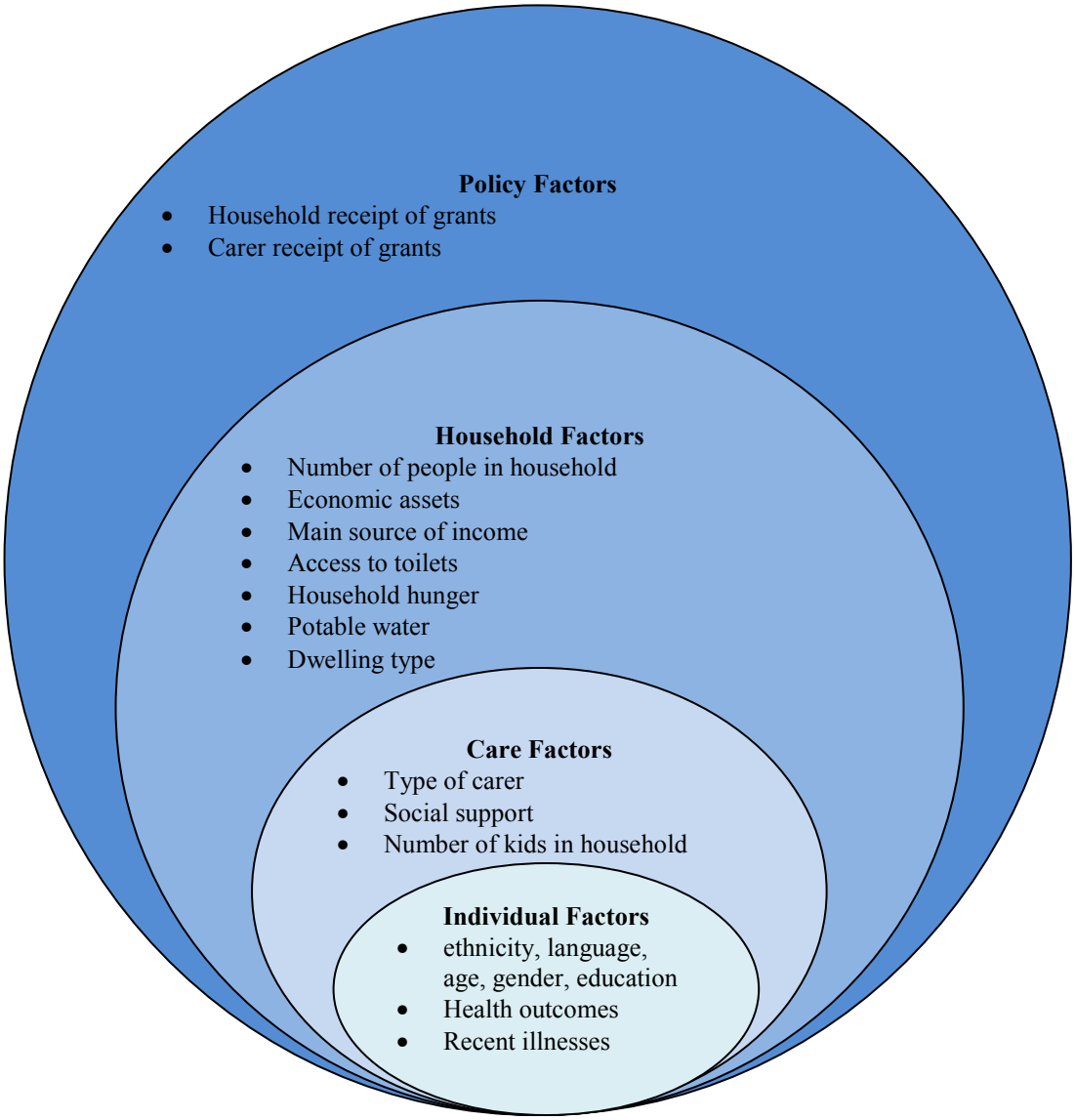
Ward selection focused on sites with similar multiple deprivation scores. This study used previously calculated multiple deprivation scores based on the work of Noble et al. (2006). Noble et al. (2006) based score calculations off of five domains of deprivation using Census 2001 data: income and material, employment, health, education, and living environment. The score for each deprivation domain was standardized to a score of 0 to 100, with higher scores representing more deprivation. The scores were then combined using equal weights to produce a multiple deprivation score. Multiple deprivation scores were ranked for each ward in the province, with a

rank of one representing the most deprived ward. Additional detail regarding Noble et al.'s (2006) work is found at: http://www.casasp.ox.ac.uk/imd.html. Based on their work, the site selection for this study focused on choosing sites with similar deprivation scores in order to minimize sample variation. Attempting to control for vastly differing deprivation during site selection was purposeful, given that such factors could affect central study outcomes. Based on deprivation criteria, sites were narrowed down to geographically clustered wards in Ethekwini Municipality that scored within the 50th to 75th percentile of deprivation within KZN. These included Wards 22, 42, 79, and 80 (Noble et al. 2006). Ultimately, it was unnecessary to sample from multiple wards because the number of participants sampled within Ward 79 in Umlazi Township (the first ward chosen through random selection) met statistical power requirements.

3.2 Design of the Questionnaire

The design of a structured questionnaire was guided first and foremost by study aims and questions, adhering to the most important principle of survey design that central study concepts should "drive your selection of the issues to be covered" in the questionnaire (Buckingham and Saunders 2004: 87). Another consideration included "brevity, simplicity and concreteness" of questions as multiple outcomes were to be measured (Foddy 1999: 50). Finally, selection of variables was guided by the socio-ecological model (see ***Chapter I***). An overview of the conceptual organization of variables using this model is shown in ***Figure 3.4.*** Thus, organization of variables reflects the conceptual approach of this dissertation, which used the socio-ecological model as heuristic guide towards approaching the issue of carer lives and the study of their health.

Figure 3.4: Conceptual Organization of Variables using the Socio-Ecological Model



The English version of the questionnaire is found in ***Appendix 1***.

3.2.1 Health Outcome Measures

Significant study outcomes for carers – general health and functioning, depression, anxiety, post-traumatic stress, alcohol dependence, and drug dependence – were measured using validated scales with strong psychometric properties. All scales included in this study were designed originally for administration via self-report or

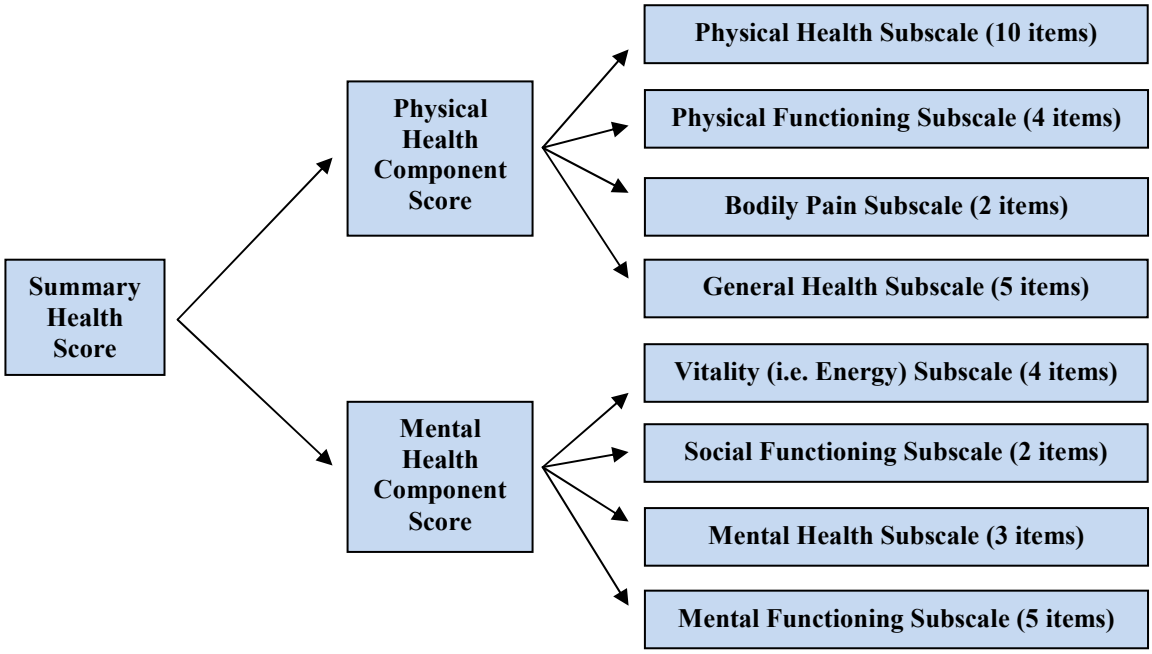
through a non-clinician interviewer. Only three tools (for depression, post-traumatic stress, and alcohol use) were validated for use in South African populations but all tools were used in South African or African settings.

General Health and Functioning

General physical health, mental health, and functioning were measured using the Short Form-36 version two (SF-36v2) scale (Ware 2000, 2004). SF-36v2 is a 36-item generic measure of health status for adults. The choice of a generic measure of health, rather than one specific to age, disease, or treatment group was purposeful. Even though disease-specific measures show better sensitivity and specificity, generic measures better capture total burden of disease, a goal particularly well-suited to this study because knowledge regarding general health of carers of AIDS-orphaned children, much less disease specific conditions, is limited (see ***Chapter II***). SF-36 versions have been used in over 7,000 studies, in varying populations and cultural settings, and have been translated into 60 languages including isiZulu (Ware et al. 2007). The scale has been used in South Africa (Benitha and Tikly 2007; O'Keefe and Wood 1996).

Respondents rate health and functioning on three-, four-, or five-point scales. Using original scoring guidelines, scores are re-scored if necessary so that higher scores correspond with better health. Next, scores are tabulated for each of the eight subscales and transformed to a 0 to 100 scale to enable comparison. Four subscales comprise the physical health component score; the other four subscales comprise the mental health component score. These component scores can be evaluated separately or a total summary score can be used (Ware et al. 2007) (***Figure 3.5***).

Figure 3.5: SF-36v2 Components and Subscales



Original psychometric data was developed for the SF-36v2 using a sample drawn from a general US population (n=7,069). This study showed excellent internal consistency reliability for each of the subscales and physical and mental health component measures (α=0.83 to α=0.95). Internal consistency reliability coefficients remained excellent even when the sample was split by age, gender, and health conditions (α=0.71 to α=0.96). Although studies for test-retest reliability have not been run on the SF-36v2, they have been conducted on the SF-36v1, so reliability estimates can be assumed to be equivalent or better; Pearson r coefficients for test-retest over two and a half weeks ranged from 0.40 to 0.90s and fell within two standard error of measurements from the first administration of the test (Ware et al. 2007). Other studies also showed excellent internal consistency reliability in a general UK population (n=8,889, α=0.80 to α=0.95) (Jenkinson et al. 1999), general Swedish population (n=2,185, α=0.84 to α=0.94) (Taft et al. 2000), older Korean individuals

(n=210, α=0.92 to α=0.94), and in a three week period for test-retest reliability with older Korean individuals (n=52, α=0.71 to α=0.89) (Han et al. 2004).

Depression

Depression was measured using the Centre for Epidemiologic Studies Depression Scale (CES-D). It consists of 20-items designed to measure levels of depressive symptomology in the general population consistent with criteria in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (Radloff 1977). The CES-D is one of the most widely used self-report depression instruments. It has been administered in various settings including South Africa (Hamad et al. 2008; Myer et al. 2008; Pretorius 1991; Smit et al. 2006b), Senegal (Poupard et al. 2007), and Uganda (Kaharuza et al. 2006) and with a wide range of populations including general South African township dwellers (Smit et al. 2006b) and HIV positive individuals (Kaharuza et al. 2006; Poupard et al. 2007).

Respondents are asked to rate symptoms on a four-point scale ranging from "rarely or none of the time" to "most of the time". Scores range from 0 to 60, with higher scores indicating higher levels of depressive symptoms. Radloff (1977) used a cut-off score of 16 to report the prevalence of individuals with probable depression. Other studies demonstrated that this cut-off resulted in a balance between false-positives and false-negatives when compared with research diagnostic criteria, and tended to detect major depression (Myers and Weissman 1980).

Original psychometric data for the CES-D demonstrated high internal consistency reliability in both the general US population (α=0.85) and the psychiatric population (α=0.90) (Radloff, 1977). Other studies have shown good internal

consistency reliability including a study of heterogeneous adults involved in micro-credit financing in South Africa (α=0.88) (Hamad et al. 2008) and in carers of AIDS-sick and cancer-sick individuals (α=0.91) (Stetz and Brown 2004). The cultural validity of the tool was tested in South African populations (Smit et al. 2006a). The validity of the CES-D has been established through comparisons with other tools including the Mini-International Neuropsychiatric Interview (MINI) (Myer et al. 2008), SCL90 Depression Scale, and Hamilton Depression Rating Scale (Stetz and Brown 2004) and through correlations with clinical ratings of depression (Radloff, 1977).

Anxiety

Anxiety was measured using the Kessler scale (K10) which assesses the level of anxiety and depressive symptoms experienced by individuals in the previous four weeks. K10 consists of 10-items developed through a systematic review of 5,000 items, reduced to 45-items for testing in a general US population (n=1401), further reduced to 32-items for testing (n=1574), resulting in 10-items (R. C. Kessler et al. 2002). K10 has been administered in various settings including Burkina Faso (Baggaley et al. 2007).

Respondents rank their symptoms on a five-point scale ranging from "none of the time" to "all of the time". Scores are calculated by summing all items. Scores range from 10 to 50, with higher scores indicating higher levels of psychological distress (R. C. Kessler et al. 2002). Original authors did not publish guidelines on how to interpret scores. However, a series of studies by the Clinical Research Unit for Anxiety and Depression at the University of New South Wales showed that scores in the range of 10 to 15 indicate low or no risk, 16 to 29 indicate moderate risk, 30 to 50 indicate high risk for an anxiety or depressive disorder (2000).

Based on a cut-off score of 16, and compared against Composite International Diagnostic Interview (CIDI) criteria for anxiety or affective disorders, the K10 has a sensitivity of 86 percent and a specificity of 78 percent (Andrews and Slade 2001). A study with mothers after birth shows that the tool has good internal consistency reliability (α =0.87) and item-total correlation (r=0.44 to 0.83) (Baggaley et al. 2007). Comparisons with other tools including the World Health Organization Disability Assessment Schedule demonstrated K10 to be as good of a measure for anxiety as these other tools (Andrews and Slade 2001; R. Kessler et al. 2003).

Post-traumatic Stress Disorder

Post-traumatic stress disorder (PTSD) was assessed using two complementary tools. First, individuals with possible PTSD were identified using the Life Events Checklist (LEC), a list of events defined as traumatic or life threatening by the DSM-IV. Second, individuals who experienced an event on the LEC went on to answer the Harvard Trauma Questionnaire (HTQ), a 30-item questionnaire. The first 16-items of the HTQ are based on DSM-IV criteria and the remaining 24-items assess ability to function in everyday life. HTQ has been developed specifically for use in diverse cultural settings (Mollica et al. 1992). HTQ has been administered in South Africa (Myer et al. 2008; Smit et al. 2006b; Ward et al. 2001) and with diverse populations including individuals from South African townships (Smit et al. 2006b) and women from a general Afghani population (Cardoza et al. 2005)

HTQ can be scored in two ways. First, scores can be summed and a cut-off point used, set by the original researchers at 75, to determine clinically significant symptoms of PTSD. Second, an algorithm method can be used to calculate scores. In the second approach, an algorithm for calculating the presence of PTSD is calculated

based on whether respondents exhibit a minimum threshold of clinically significant PTSD symptoms. This threshold is calculated based on responses to questions that measure three symptom clusters of PTSD: re-experiencing of the event; avoidance or numbing; and hyper-arousal. If respondents have a score of three or four points on: one of the four questions on re-experiencing symptoms; three of the seven questions on avoidance and numbing symptoms; and two of the five questions on hyper-arousal symptoms, they are categorized as having clinically significant levels of PTSD (Mollica et al. 1999). Studies show that caution should be used in applying a pre-determined cut-off score for determination of PTSD if the HTQ has not been normed in the study population (Ichikawa et al. 2006; Mollica et al. 1999). Since HTQ has not been normed in South Africa, the algorithm scoring method was used.

Original psychometric testing showed that HTQ has excellent internal consistency reliability (α=0.89) (Mollica et al. 1999). Another study of the reliability and validity of the HTQ in Sri Lankans experiencing the tsunami disaster (n=127) showed excellent internal consistency reliability (α=0.94) and construct validity (Miyazaki et al. 2006). The cultural validity of the tool was tested in South African populations (Smit et al. 2006a). The validity of the HTQ has been established through comparisons with other tools including the MINI (Myer et al. 2008).

Alcohol Use

Alcohol dependence was assessed using the Alcohol Use Disorder Identification Test (AUDIT), a 10-item instrument designed to identify individuals at risk for, or who are alcohol dependent in various cultural settings (Saunders et al. 1993). It has been administered in South Africa (Kalichman et al. 2007; Myer et al. 2008; Smit et al. 2006b) and with a wide range of populations including individuals with sexually

transmitted infections (Kalichman et al. 2007), clinic patients (Nilssen et al. 2005), unemployed (Claussen and Aasland 1993), individuals from South African townships (Smit et al. 2006b), and urban individuals with low socioeconomic status (Isaacson et al. 1994).

Respondents are asked to rate their use of alcohol on a three- or five-point scale. Possible responses include that they "never" use alcohol to they use alcohol "daily or almost daily". Scores range from 0 to 40, with higher scores indicating higher rates of alcohol use. Scores of 8 to 15 identify individuals with hazardous or harmful alcohol consumption. Scores of 16 to 19 or above indicate higher levels of hazardous drinking. Scores of 20 or above indicate likely alcohol dependence (Babor et al. 2001).

Original psychometric data for the AUDIT was derived from six country studies of primary care populations. A cut-off value of eight yielded sensitivities in the 0.90s range and specificities in the 0.80s range (Saunders et al. 1993). AUDIT has been compared with other tools including the Michigan Alcoholism Screening Test and CAGE Alcohol Test (Hays et al. 1995) and has more sensitivity towards milder levels of problem drinking (MacKenzie et al. 1996). The cultural validity of the tool was tested in South African populations (Smit et al. 2006a). The validity of AUDIT has also been established through a comparison with MINI (Myer et al. 2008), and CIDI (Clements 1998).

Drug Use

Drug dependence was assessed using the Drug Use Disorder Identification Test (DUDIT), an 11-item instrument designed to identify individuals at risk for drug

dependence. Similar to the AUDIT, it was designed to identify individuals at risk for, or who are alcohol dependent in a variety of cultural settings (Berman et al. 2005).

Respondents are asked to rate their use of drugs on a five- or three-point scale. Possible responses include that they "never" use drugs to they use drugs "daily or almost daily". Scores range from 0 to 44, with higher scores indicating higher rates of drug use. Scores of 6 for men and 2 for women can screen for drug-related problems (Berman et al. 2005).

Original psychometric data for the DUDIT was derived from studies of heavy drug users in prison or probations and individuals undergoing inpatient detoxification. For the drug user population, internal consistency reliability was excellent (α=0.80). Compared with the DSM-IV, the tool showed a sensitivity of 90 percent and specificity of 88 percent. Compared with the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10), the tool showed a sensitivity of 90 percent and specificity of 78 percent (Berman et al. 2005).

Reliability of Scales Used in the Study

Reliability coefficients were calculated for each scale used in the questionnaire using the level of α=0.70 for group-level comparisons as an acceptable standard (Nunnally and Bernstein 1994) (***Table 3.2***).

Table 3.2: Reliability of Scales Used for Primary Study Outcomes

Outcome	Scale	Cronbach's Alpha of this study
General health and functioning	Short Form 36 Version 2	0.95
	Physical Health Subscore	0.94
	Physical Functioning Subscale	0.97
	Role Physical Subscale	0.97
	Bodily Pain Subscale	0.90
	General Health Subscale	0.84
	Mental Health Subscore	0.82
	Vitality Subscale	0.57
	Social Functioning Subscale	0.78
	Role Emotional Subscale	0.68
	Mental Health Subscale	0.60
Depression	Center for Epidemiologic Studies Depression Scale	0.92
Anxiety	Kessler 10	0.85
Post Traumatic Stress Disorder	Harvard Trauma Questionnaire	0.97
Alcohol Use	Alcohol Use Disorders Identification Test	0.83
Drug Use	Drug Use Disorders Identification Test	0.60

Overall, scales show excellent internal reliability. Three of the subscales for SF-36v2 had scores below the standard of α=0.70 (Vitality, Role Emotional, and Mental Health subscales) but when these subscales are amalgamated into the Mental Health Subscore, the reliability score is above α=0.70. The drug use scale also exhibited poor reliability, likely due to under-reporting.

3.2.2 Demographic Variables and Potential Risk and Protective Factors

General Approach

In addition to measuring health outcomes, the questionnaire gathered data on demographic, economic, and social variables. In choosing questions for these variables, preference was given to questions previously tested in national or provincial South African surveys. The most recent versions of the following South African surveys were consulted: South Africa National Census (2001), South Africa General

Household Survey, South Africa Demographic and Health Survey, and the KwaZulu-Natal Income Dynamics Study (KIDS) 2004 questionnaire. Selection of previously tested questions maximized chances of including culturally appropriate questions designed for a low literate population. Answer options were chosen in a similar manner in order to limit inappropriate phrasing or biasing responses through inappropriate or restrictive answer choices (Foddy 1999). Two descriptive variables – economic status and social support – were measured using validated and reliable scales.

Economic Status

Choice of a scale to measure economic status was based on a review of existing approaches. Typically, income and expenditure data are used to measure economic status. However, these approaches towards measuring economic data may transfer poorly to the global South context for a number of reasons. For example, income-based measures may be inaccurate given that income fluctuates widely according to savings/dissavings cycles and migratory, sporadic work patterns (Montgomery 2000b). Expenditure-based measures may better account for economic status but fails to account for inequalities; for example, individuals may have similar expenditure patterns but the richer of the two may have savings that remain unaccounted for in this approach. Neither approach takes into account households of varying size (Booysen 2001). Due to these drawbacks, the study used an alternative measure based on economic assets.

Filmer and Pritchett (1998) developed the economic asset index based on factor and principal component analysis of variables relating to ownership of consumer goods and access to services and resources (*e.g.*, electricity and sanitation) from Demographic and Health Surveys (DHS) (Booysen 2001). This method for estimating economic

status has been shown to be as reliable or better than other conventional measures (Deon Filmer and Pritchett 2001; M. Montgomery et al. 2000a). In this approach, factor analysis identifies common asset variables associated with changes in long-term wealth of households. In turn, these assets are weighted for scoring using principal component analysis (M. Montgomery et al. 2000a). Scores for each asset are standardized (*e.g.*, each variable is standardized in relation to the unweighted mean of the particular variable).

Following these steps, scoring can take two routes. In the first option, scores on variables that load heavily (*i.e.*, scores loading larger than 0.50) in a given factor analysis are added up based on the assumption that all variables are equally important in explaining economic status. In the second approach, scores for each variable are weighted with the scoring coefficient of the variable. These values are tabulated to calculate a sum score. Summary scores are typically split into five quintiles in order to enable comparisons across households (Booysen 2001).

Booysen (2001) applied this approach to the South African DHS in order to calculate an economic asset index specific to South Africa. He tested the tool, demonstrating high internal coherency and robustness. In addition, he compared the tool against other methodological approaches for measuring economic status and again, the asset index showed comparable results. Since Booysen (2001) calculated scoring coefficients specific to South Africa, this dissertation takes the second approach towards scoring, weighting each variable with Booysen's scoring coefficients.

Social Support

Social support can be defined as the subjective feeling of belonging, acceptance, love, esteem, and value (Moss 1973). In regards to social support scales, a large number exist and measure various aspects of social support including access, types, and uses of social support, and composition of social networks. Choice of tools focused on establishing perceived access to support since this information would provide a baseline from which to explore types and uses of social support and support networks; exploration of uses of support and networks required more complex methods not suitable to cross-sectional structured survey methods (Van der Gaag and Snijders 2002). Choice of possible social support tools also focused on validated tools and if possible, tools previously used in South Africa.

Social support was evaluated using the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al. 1988; Zimet et al. 1990). This 12-item scale assesses support from three sources: family, friends, and significant others. The significant other category is unique to this tool and advantageous given that a pre-defined category of support may exclude important sources of support in this understudied population of carers. The significant other category is defined by the respondent and can cover a range of individuals including partners, boyfriends/girlfriends, neighbors, etc. MSPSS has been used in various cultural settings including KZN Province (Myint and Mash 2008), elsewhere in South Africa (Bruwer et al. 2008), and in other global South settings such as Turkey (Eker and Arkar 1995). MSPSS has been used in diverse populations including older adults (Kazarian and McCabe 1991; Stanley et al. 1998), individuals with cardiac disease (Frasure-Smith et al. 2000), and individuals with skin disease (Picardo et al. 2005).

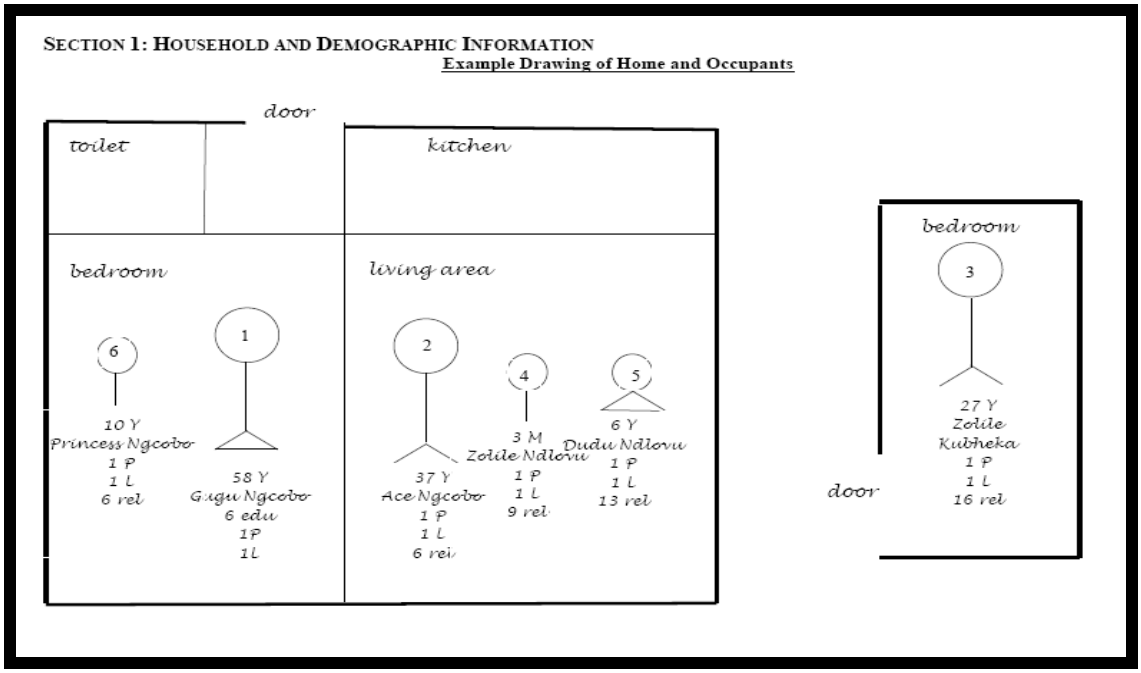
Respondents rank perceived levels of support on a seven-point scale. Possible responses include "very strongly disagree" to "very strongly agree". Scores range from 12 to 84, with higher scores indicating higher levels of perceived social support. Scores can be analyzed using total score or subscale scores.

Validation studies show good internal consistency reliability (α=0.77 to 0.98) in a variety of samples including adolescents in South Africa (Bruwer et al. 2008), individuals with psychiatric illnesses (Cecil et al. 1995; Stanley et al. 1998), developing country populations (Eker and Arkar 1995), university students (Dahlem et al. 1991; Kazarian and McCabe 1991; Zimet et al. 1988), urban adolescents (Canty-Mitchell and Zimet 2000), and adolescents abroad (Zimet et al. 1990). Additional studies using factor analysis have confirmed the rationale behind the three subscales of family, friends, and significant others (Bruwer et al. 2008; Clara et al. 2003). A test and re-test study shows excellent reliability over a two to three month period ranging from 0.72 to 0.85 (Zimet et al. 1988). A study examining the factorial structure, reliability, and construct validity of the MSPSS showed strong internal reliability and construct (Eker and Arkar 1995).

3.2.3 Engaging Respondents and Reducing Fatigue

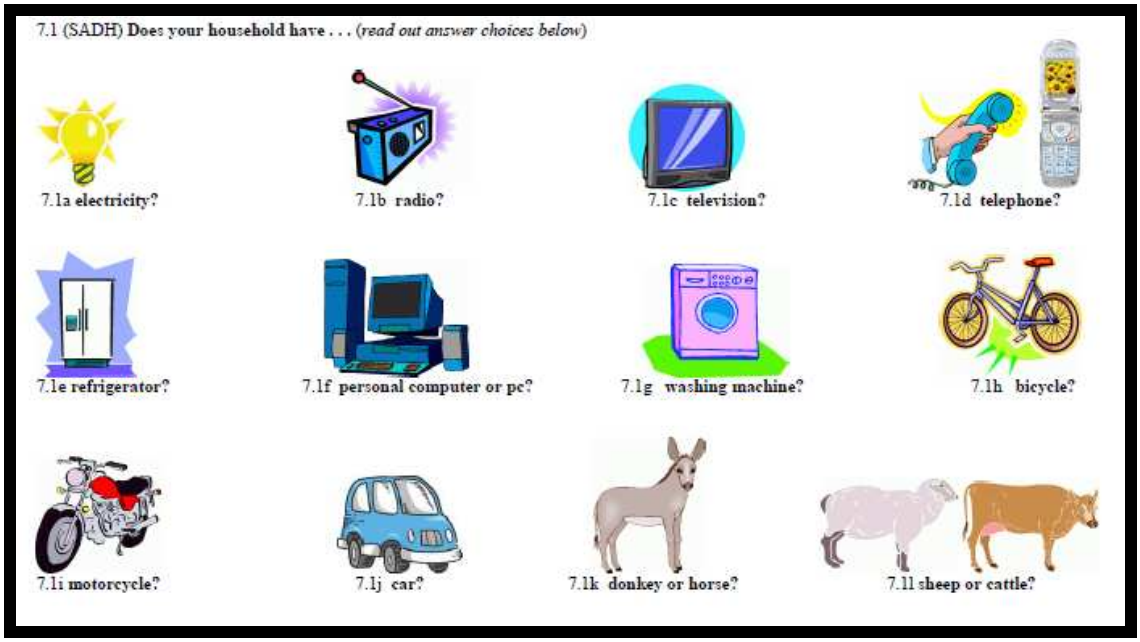
The questionnaire was designed for a low literate population and attentive to issues such as respondent fatigue. For example, the questionnaire utilized visual mapping techniques to ensure questions were engaging. ***Figure 3.6*** displays how this technique was used to map a series of household and demographic variables. In the example, different figures denote adults and children as well as females and males. Shortened abbreviations denote age in years (Y), population group/ethnicity (P), language (L), education (edu), and household member's relationship to the carer (rel).

Figure 3.6: Example of Household and Demographic Information



In addition, visuals were used to accompany questions when possible. ***Figure 3.7*** shows how this technique was used to capture information on household assets.

Figure 3.7: Visuals Used to Capture Household Economic Assets



Most importantly, these strategies increased quality of data by enabling respondents to verify data being captured.

3.2.4 Translation

All survey materials (*e.g.,* consent form, information sheet, questionnaire, project logos, resource sheets, and referral letters) were translated separately by two isiZulu language experts at the University of KwaZulu Natal. These two versions were checked and amalgamated by a third isiZulu language expert. The isiZulu questionnaire was back-translated and checked by two additional isiZulu language experts. Then a group of eight native language speakers checked spelling, grammar, language coherency, and conceptual translation issues.

3.2.5 Piloting of the Cross-Sectional Survey Questionnaire

The questionnaire was reviewed by several researchers at the Health Economics and HIV/AIDS Research Division (HEARD), University of KwaZulu-Natal (UKZN). Then, the questionnaire was piloted with nine adult carers of AIDS-orphaned children from urban townships in the Durban vicinity. Carers were selected from Save the Children KZN's database; carers who lived in Ward 79 were excluded in order to avoid contamination of the study sample. The pilot was hosted at Save the Children, KZN. Carers participating in the pilot received tea, snacks, vouchers for their transport and time, and certificates of appreciation (***Appendix 2***).

The pilot employed three types of techniques: cognitive interviews, behavior coding, and respondent de-briefing. Cognitive interviews and behavior coding occurred in one-on-one sessions between respondent and interviewer. Cognitive interviews involved both concurrent and retrospective think-alouds to identify questions and answers options that were problematic (Presser et al. 2004: 4). Conditional probes were used where respondents seemed to have problems with questions in order to reduce bias associated with conventional probes (Beatty 2004;

Frederisk and Blair 2004). The types of probes used were neutral and included the following types: confirmatory (*e.g.*, asking the respondent to repeat what they said); expansive (*e.g.,* asking the respondent to elaborate); functional (*e.g.*, asking a respondent to clarify or repeat), and cognitive (*e.g.*, asking what the respondent was thinking) (Beatty 2004). Interviewers were also trained to code behavior such as hesitation, laughter, requests for clarification, confused facial expressions, etc. as these may have indicated questions or answers that may be unclear, offensive, etc. Respondent debriefing used a focus group format. This method focuses on exploring the meaning of questions and reactions to questions (Martin 2004). Carers were encouraged to assume the role of the researcher by highlighting misinterpretations of terminology, questions, and instructions (Martin 2004). Debriefing also focused on identifying sequencing and formatting issues which can also impact upon data quality (Buckingham and Saunders 2004; Schwarz 1997). All pilot methods focused on identifying what would actually go wrong in the field or during an interview rather depending on the use of expert reviews which predict what might go wrong (van der Zouwen and Smit 2004).

As a result of pilot findings, the questionnaire was shortened and items re-sequenced. In addition, piloting identified several translation issues which were corrected. Very importantly, carers suggested that given the sensitive nature of verbal autopsy (VA) questions, these items be placed on a separate sheet which respondents had the choice of filling out without the assistance of interviewers. If respondents had low literacy, interviewers would read aloud questions and respondents would fill in answers. When done, VA items were placed in a sealed envelope. A more detailed discussion on the VA is found in ***Section 3.3.3***

3.3 Sampling

Data was collected from August 2008 to March 2009.

3.3.1 Strategy

Gathering information on a representative sample of carers in a high HIV prevalence community was crucial for two reasons. First, a fundamental study aim was to establish statistically significant comparisons between AIDS-orphan carers and other types of carers; a representative sample of carers would allow one to establish baseline information on adult carers of children in a high HIV prevalence area, and then assess whether AIDS-orphan carers differed from other carers. Second, a key study aim was to assess prevalence of carer health issues in the study community, an aim that could achieved only through a representative sample. Based on these specific study goals, a sampling strategy started with a review of available data on carers of AIDS-orphaned children. This review confirmed no existing sampling frame for the target population and was verified through communication with South African experts and researchers familiar with data sources (Dawes and Kuo 2008; May and Kuo 2008).

A strategy for sampling was derived by mapping Ward 79 including enumeration areas (EAs) and land plots falling within ward boundaries using Geographical Information System (GIS) (***Figure 3.8***). A multi-stage cluster sampling design was implemented.

Figure 3.8: GIS Map of Ward 79

The figure originally presented here cannot be made freely available via ORA for copyright reasons.

Ward 79 was stratified into EAs. Fifty-one EAs falling within ward boundaries were assigned double digit ranks ranging from 01 to 51, corresponding to consecutive ordering of EA census numbers (***Figure 3.9 and 3.10***). The order of EA visits were determined through selection of the EA rank numbers from a random number table with a random start. In each EA cluster, all households (median 69.5, range 30-143) were visited with a maximum of three visits at different times on different dates including weekends. A summary of the sampling strategy is shown in ***Figure 3.11***.

Figures 3.9 and 3.10: GIS Maps of Census EA Numbers and Household Plots

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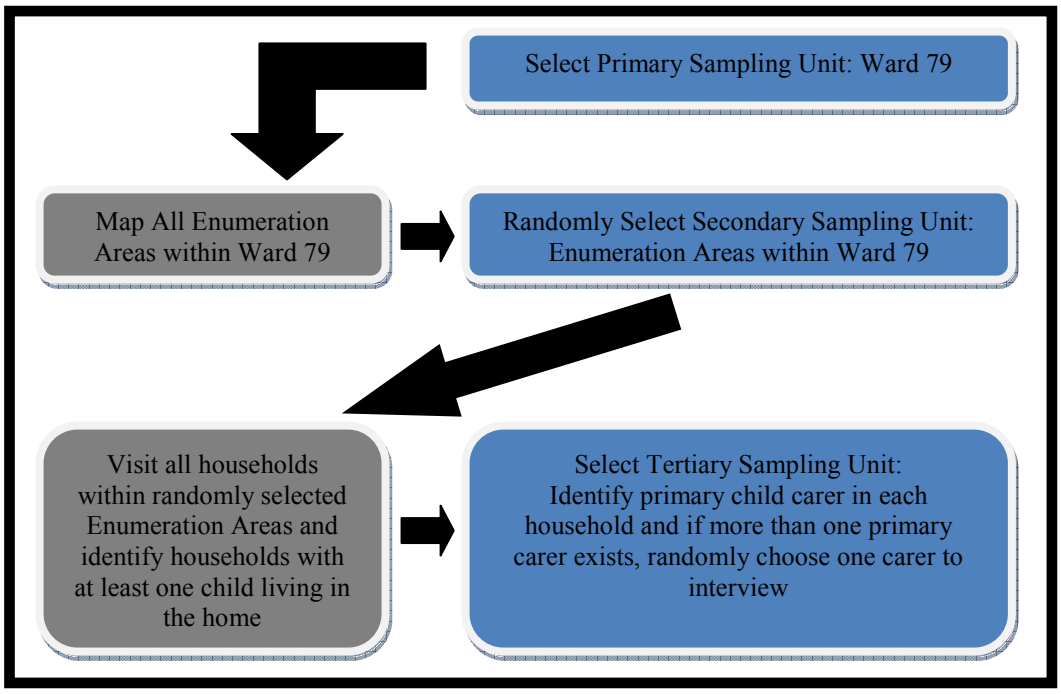
The figure originally presented here cannot be made freely available via ORA for copyright reasons.

Figure 3.11: Sampling Strategy



3.3.2 Recruitment

At each household, the individual answering the door was asked a series of screening questions. These included: 'Are there any children living in the home"; and, 'Can I speak to the primary childcarer in the home?'. If the primary childcarer was

unavailable, revisit dates and times were set. If more than one primary carer existed in the household, one was randomly selected to participate in the study.

Once an individual confirmed their role as primary carer, interviewers would assess whether individuals met inclusion criteria. Carers were identified for inclusion if they were: 1) 18 years or older; 2) provided primary care for at least one child, 17 years of age or younger in the household; and, 3) the child lived in the household at least four nights a week for the past four weeks, adhering to definitions set by the census (Statistics South Africa 2001). The child could be related to the carer in any way (*i.e.*, carers did not have to be the biological parents of the child). Households were excluded from the study if: 1) no child lived in the household and 2) if the primary carer was under 18 years of age. Exclusion of child-headed households was justified based on the grounds that this group is small; 2005 estimates place the number of child-headed households (12-18 years) as 2.6 percent nationally or 180,433 households (Shishana et al. 2005). No child-headed households were found in the study sample.

Just over half of the EAs were visited resulting in coverage of 2,070 households. ***Table 3.3*** provides a summary of response codes.

Table 3.3: Type, Frequencies, and Percentages of Response Codes

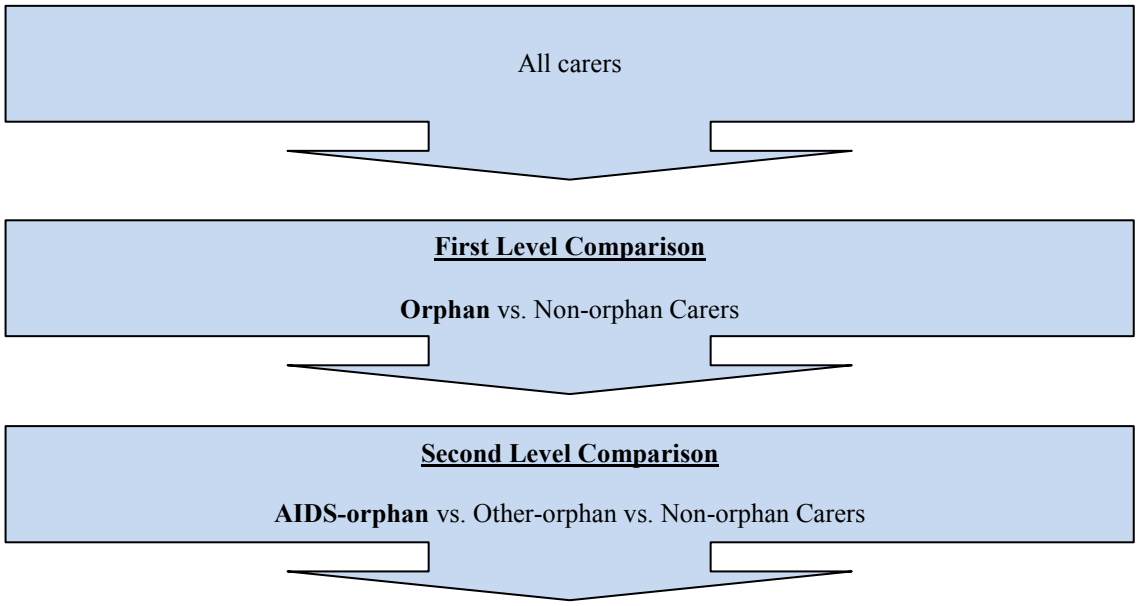
Type of Response	Frequency	Percentage (%)
Carer Survey Fully Completed	1599	77.25
Carer Survey Partially Completed	3	0.14
Household Eligible but Carer Refused to Participate	8	0.39
Ineligible Households	289	13.96
Vacant Dwelling	11	0.53
3 Visits Made but No One Home	160	7.73
Child Headed Household	0	0

Recruiters were unable to make contact with total of n=160 households (a minimum percentage of sampled households at 7.73%). Of the households visited 77.78 percent had at least one child living in the home, and of eligible households, there was a 99.32 percent response rate. Less than one percent of questionnaires were incomplete. No child-headed households (defined as households where the primary childcarer was 17 years or younger) were identified through the sampling process.

3.3.3 Comparison Groups - Determining AIDS Death

Study design sought to gather baseline information on all carers of children, and then determine whether and how carers of AIDS-orphaned children were unique. Thus, the design incorporated comparison groups. ***Figure 3.10*** depicts these groups and the group of interest is highlighted in bold. In the first level of comparison, adults were placed into the "orphan carer" category if *at least one child in the home was defined as orphaned*. All remaining carers, regardless of type of kin or non-kin relationships to the child were placed into the "non-orphan carer" category. In the second level of comparison, adults were placed into the "AIDS-orphan carer" category if *at least one child in the home was defined as being orphaned by AIDS*. This category could include a household where all children were AIDS-orphaned or a mix of the following: at least one AIDS-orphaned child and/or other-orphaned and/or non-orphaned children. Similarly, adults were placed into the "other-orphan carer" category if *at least one child in the household met the definition of being other-orphaned*. Clearly, this group did not include AIDS-orphaned children but could include a mix of other-orphaned and non-orphaned children.

Figure 3.12: Comparison Groups



At the second level comparison, carers might have been aware of, and disclosed cause of parental death as AIDS. In other cases, cause of parental death was unknown or carers did not want to disclose due to stigma. This posed a methodological challenge by leading to a possible underestimation of "AIDS-orphan carers" and an overestimation of "other-orphan carers". Several strategies were considered as methods for verifying cause of parental death. First, a review of medical records was considered. However, this strategy was untenable due to limited access to parental medical records and underuse of the medical system which may have resulted in incomplete records for the study sample. Second, a review of death certificates was considered. However, death records often incorrectly categorize AIDS deaths under AIDS-related illnesses (*i.e.,* pneumonia, flu). A verbal autopsy (VA) method was used to overcome these challenges. The VA method has been used in South Africa (Cluver et al. 2007; Hosegood et al. 2004) and elsewhere in Africa (Lopman et al. 2006; Quigley et al. 2000; Setel et al. 2006).

The study used a validated VA method based on a study of a population-based open cohort in Zimbabwe (Lopman et al. 2006). In this study, Lopman et al. (2006) draws a sample of 381 deceased subjects to determine if deaths were AIDS related. AIDS deaths were determined through a gold standard of a) HIV anti-bodies blood test; b) and exclusion of any deaths resulting from major injury, suicide, accidents, or homicide. Cases were then randomly allocated to two datasets, one which was used to create a VA algorithm, and a second which the algorithm was tested on. In total, 381 individuals who were primary carers, kin, neighbors, or community health workers of a person known to have died from HIV completed VAs. VAs are based on eight signs and symptoms related to HIV including: weight loss, wasting, jaundice, herpes zoster, abscesses or sores, oral candidasis, acute respiratory tract infections, vaginal tumors. The study showed that classifying deaths as AIDS-related when one or more of the eight criteria were present gave a sensitivity of 66 percent and specificity of 76 percent. An eighth and ninth criteria of recent tuberculosis and acute diarrhea were considered but these were found to decrease specificity without an equivalent gain in sensitivity and thus were excluded. The study suggested that sensitivity and specificity did not vary significantly according to gender of respondent, time of death, relationship to respondent, whether the respondent was a primary carer, family member or other relation to the deceased (Lopman et al. 2006).

Identifying carers of AIDS-orphaned children was central to study aims. In order to ensure that Lopman et al.'s (2006) "one or more" classification was stringent enough, an exploratory categorization of AIDS deaths using "two or more" and "three or more" was completed (***Table 3.4***).

Table 3.4: Classification of "Carers of AIDS-orphaned Children" Using One, Two, or Three Criteria from Lopman et al.'s (2006) Verbal Autopsy Method

	One criteria or more on VA (Sample 1)	Two criteria or more on the VA (Sample 2)	% of sample 1 re-categorized
Carers of AIDS-orphans	191	125	66 (34%)

	Two criteria or more on VA (Sample 2)	Three criteria or more on the VA (Sample 3)	% of sample 2 re-categorized
Carers of AIDS-orphans	125	56	69 (55%)

Further analysis using one-way ANOVA and Chi-square tests showed that patterns of significance for AIDS-orphan carers' health outcomes remained consistent regardless of categorization method. Thus, a decision was made to adhere to Lopman's original criteria or "one or more" as this was previously validated.

3.3.4 Minimum Sample Size and Power Estimation

Minimum sample size calculations are important for power estimations, or statistical procedures that enable one to assess whether differences in main study outcomes are statistically significant (Machin et al. 1997). Typically, minimum sample size calculations are based on population mean and standard deviation, or in the absence of population data, mean and standard deviation from studies of similar populations in similar locales. Given the limited number of representative studies on carers of AIDS-orphaned children and no representative studies of this population in South Africa (see ***Chapter II***), power was calculated in the early stages of data collection. It is more advantageous to estimate minimum sample size based on early data from the study sample with the caveat that early data reflects the final distribution of the study sample. Sampling methods used in this study helped ensure that the final study sample was similarly distributed to the preliminary sample; comparisons of the

preliminary sample and final sample confirm similar distributions of carers amongst comparison groups (Cohen 1988).

Power calculations were conducted on the study outcome of depression, which the exploratory study indicated to be a substantial issue in this population. Minimum sample size estimation sought to have enough power to detect significant differences between three comparison groups (*i.e.*, carers of AIDS-orphaned children, other-orphaned, and non-orphaned children) for depression (Buckingham and Saunders 2004). Based on a preliminary sample of carers (n=224), power was estimated using the program NCSS. Analysis showed that a sample size of 300 resulted in a 90.4 percent chance of detecting a statistically significant difference between groups for the main outcome of depression (W=0.21). Sample size was increased by 10 percent for each possible confounding variable, that is, an independent risk factor for the outcome (*i.e.*, depression) that can also be linked to exposure variable (*i.e.*, carer group). The final sample size (n=1599) exceeded minimum sample size requirements.

3.4 Expert Consultations

Consultations were held with various experts. In regards to study design, Dr. Cathy Connolly (Medical Research Council, Biostatistics Unit) advised on sampling strategies. Ms. Tonya Esterhuizen (University of KwaZulu Natal, College of Health Sciences) advised on power estimates. In regards to questionnaire design, Dr. Soraya Seedat (Medical Research Council, Unit for Anxiety and Stress Disorders) contributed extensively to choice of scales to measure mental health outcomes with strong psychometric properties and appropriate for South African populations. Ms. Jane Roberts (University of Oxford, Nuffield College) provided feedback regarding

sequencing of questions and format of the questionnaire, both important for enhancing data quality (Foddy 1999).

4. Research Team

4.1 Recruitment

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Six interviewers (Feziwe Mhlongo, Siyabonga Msomi, Nomvula Mohoto, Silindile Nyawose, Gugu Ndlovu, Thokozani Nzimande) and a fieldwork manager (Reggie Khanyile) were recruited through a review of 45 cvs, interviews, and references (***Figure 3.13***). Interviewers were a mix of genders and ages. All were fluent in isiZulu and familiar with the study area. Each interviewer was hired on a trial basis and offered monthly renewable contracts pending satisfactory written and verbal reviews of performance.

Figure 3.13: Photo of Team Members

4.2 Training and Staff Development

Each team member received extensive preparatory and on-going training. Training was split into several stages. First, preparatory in-office training took place prior to study launch. During this stage, each team member received 60 hours of job-specific and general skills training in group sessions. These sessions covered a range of topics including: research skills, survey design, questionnaire training, interview training including minimizing bias and approaching sensitive topics, basic HIV and mental health training, communication skills, and CV and cover letter development.

Each group session was evaluated using confidential, anonymous evaluation sheets. Based on evaluation feedback, staff members needing extra training received individual training sessions. In preparation for the pilot, team members engaged in mock interviews.

The second training stage was held in-field. During the first week of fieldwork, the two most experienced interviewers were paired with the field coordinator and PI, receiving individual feedback after each interview. During the second week, these interviewers were paired together for interviews. In the third week, an additional two interviewers started work in field. These new interviewers shadowed more experienced interviewers. This process was repeated until the full team was in field. This process of slowly rolling-out the team enabled interviewers to learn from peers and get intensive individual feedback from the fieldwork coordinator and PI. After this in-field training, the fieldwork coordinator and PI rotated with individual team members throughout the remainder of the project to observe and provide feedback.

In the third stage of training, staff development needs were identified on an ongoing basis and addressed. If personal development needs could not be met by the PI, opportunities for seeking training elsewhere were identified and facilitated. The PI also developed written personal development plans with each team member. Periodic meetings were held to discuss progress on development plans. These personal development plans ranged from attaining additional skills training in data programs, securing scholarships for children, to drawing up documents needed to start a business.

Finally, transitional training took place to prepare team members for finding work after the project end. The PI met with each team member on an individual basis in order to discuss transition plans. Furthermore, group training sessions were held in

order to review revised CVs and cover letters and to discuss how to prepare for job interviews. The PI contacted colleagues to discuss and facilitate future hiring possibilities.

4.3 Supervision and Quality Control

During the first two months of fieldwork, team members underwent close daily supervision in field by the PI and fieldwork manager. During the first two weeks of fieldwork, each team member would be briefed individually at the end of day regarding performance. During the first month of fieldwork, each team member received bi-weekly written performance evaluation feedback and monthly evaluation feedback thereafter.

Weekly team meetings were held in the office to discuss fieldwork challenges and issues. Discussions covered a diverse range of topics including study ethics and safety. If necessary, individual meetings were also scheduled to address quality of work or particularly difficult situations experienced by interviewers in field.

After the first two months, the PI scaled back time in field from five days, to four days, and so forth. During this period, random field visits were made. Daily de-briefing meetings occurred with the fieldwork manager and PI prior to fieldwork each day. End of the day de-briefings also occurred by phone. All team members were encouraged to phone the PI to discuss issues.

5. Stakeholder and Community Consultations

Several months were spent preparing for fieldwork through a series of stakeholder and community consultations. Consultations were held with a number of

organizations working with carers and/or orphans in the Durban area including: Treatment Action Campaign, Built Environment Support Group, Children in Distress Network, Children Rights Centre, Nurturing Orphans of Humanity, Save the Children KwaZulu Natal, Sinani, Thousand Hills Community Helpers, Ethekwini Child Welfare, and Durban Rape Crisis Center. Academics were invited to attend two brown bag seminars hosted at HEARD, UKZN and additional briefing updates were sent periodically to forty-five academics working on related issues in South Africa. Key stakeholders in Ward 79 were also consulted including principals and/or assistant principals at each school; Supervisor of G Section Community Clinic, Ms. Lindiwe Made and other clinic staff; Mental Health Clinic and Prince Mysheni Hospital, Assistant Chief of Police of Umlazi Police Station, Mr. Chiliza; and Captain Clifton Parks, in charge of the unit dealing with rape and abuse. Gatekeepers were also consulted including the ward councilor, Mr. Sthenjwa Nyawose and Head of the Community Policing Forum, Ms. Mphume Sithole. Finally, outreach was done within the community with 800 fliers handed to children through ward schools to bring home to carers; 100 fliers posted at intersections within the community, loud hailer announcements over the course of a week, and a community meeting on June 26, 2008 with 75 attendees.

6. Research Challenges and Constraints

Despite extensive site preparation and consultation, several challenges specific to the research site impacted research strategies. First, the team faced unexpected infrastructure challenges including rolling and unexpected electricity cuts (***Figure 3.14***). In windowless township shacks, this made it difficult to accurately record data. Adaptive strategies including enlarging print and re-formatting the questionnaire.

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Figure 3.14: Media Article of Electricity Cuts

Second, the site faced high levels of violent crime. Safety was a primary concern for the research team as well as respondents. Daily safety briefings occurred at the start of each field day. Interviews were conducted in the privacy of homes, and if necessary, team members interviewed in male-female pairs.

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Figure 3.15: Media Article of Stoning

All team members traveled in pairs or groups. A safety escort from the local Community Policing Forum, Sifiso Nzama, was also hired. He provided immediate updates on arising safety issues and used community contacts to troubleshoot issues as they arose in the field. Furthermore, fieldwork and re-visits to homes did not occur in the evenings because rates of violent crime rise during these hours. Plans to tape-record a random sub-set of interviews were canceled due to fears of robbery or worse as a result of carrying equipment in field. In the event of particularly serious events such as shootings and stoning in the community (***Figure 3.15***), team members were debriefed, offered counseling, and if necessary, took time off from field.

Third, ongoing taxi wars resulted in logistical and safety constraints (***Figure 3.16***). In these wars, taxi drivers from competing companies engage in intimidation of opposing taxi company clientele, often through shootings. These shootings made it dangerous for team members to go to work, and when taxi wars occurred in the research location, research was halted in the interest of safety. Finally, local politics disrupted fieldwork. Due to high tensions between Inkatha Freedom Party (IFP) and African National Congress (ANC) followers, political events and protests could escalate into dangerous riots and violence. For this

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Figure 3.16: Media Article of Taxi Wars

reason, fieldwork was halted for local protests regarding the change of the main thoroughfare in the township from the name of an IFP leader to an ANC leader and national election campaigns. These challenges highlight the unpredictable nature of research. However, it was felt that constraints and adaptive strategies used did not impede upon overall research quality.

7. Data

7.1 Data Quality

Interviewers verified questionnaire quality and completion prior to exiting each household and again at the end of the day. The fieldwork manager quality checked questionnaires in field. All questionnaires were turned into the PI within 48 hours of completion. The PI entered data within 48 hours. Incomplete or poor quality questionnaires were sent back into the field with handwritten notes for review. During office hours, the fieldwork manager called a random sub-set of carers (1 in 15). The manager would ask how carers were doing, how interactions with interviewers went, if ethical procedures were adhered to, and verify answers on a sub-set of questions.

7.2 Data Entry and Cleaning

Data was captured in SPSS 17.0. A random sub-set of data was re-checked for accuracy (1 in 10). In cases where missing data was not captured in re-visits, calls were made to fill in missing information. A small number of questionnaires were incomplete. Data was cleaned with guidance from SPSS data cleaning tutorials.

7.3 Data Storage

All data and research materials were stored in locked offices accessible to the PI. Computer databases and files, including scanned surveys were password secured and accessible only by the PI. Respondents were assigned unique identifier numbers to link data sources. Original copies of paper surveys were stored in a doubly secured data archive at HEARD, UKZN and protected by a memorandum of understanding regarding data archival and sharing terms. No individual identities will be used in any reports or publications resulting from the study.

7.4 Overview of Data Analysis Strategies

An overview of data analysis strategies is provided here. Subsequent chapters provide details regarding analysis. Descriptive statistics (*e.g.*, frequencies) for all demographic, social, and economic variables were calculated. Chi-square tests, independent sample t-tests, and one-way ANOVA tests were used to assess: associations between demographic, social, and economic variables and health outcomes; associations between demographic, social, and economic variables and group differences (*e.g.*, orphan vs. non-orphan carers, and different types or orphan carers); associations between carer groups and health outcomes. Regression models were built following principles described by Hosmer and Lemeshow (1989) (*e.g.,* examining bivariate associations and controlling for co-factors significant at $p<0.25$). Multivariate analyses including linear and logistic regressions were calculated for continuous and dichotomized outcome variables, respectively, to determine possible risk and protective factors for health outcomes.

8. Research Ethics

The study was given ethics approval by the Social Science and Humanities Inter-divisional Research Ethics Committee at the University of Oxford. In addition, local ethical clearance was gained through the University of KwaZulu-Natal (***Appendix 3***). All interviewers received extensive training on ethical procedures including informed consent, confidentiality, handling and protecting data, etc. All carers provided informed consent and to ensure that those with low levels of literacy were able to understand the participant information sheet and consent form, all information was explained verbally.

All carers in the study received resource sheets with contacts for local organizations involved in health, carer or child wellbeing, social grants, etc. A number of serious cases concerning carers and other individuals in the community were identified throughout the course of research. Carers who reported concerning levels of health outcomes, as defined by clinical cut-offs for assessment tools, and who provided written consent for referrals to be made, were referred to Community G clinic, resulting in a total of 521 referrals (***Appendix 4***). During the course of the survey, carers also may have identified a need for referrals to schools for school fee waivers, etc. and in these cases, referral letters were provided. Several carers identified themselves or others in the family including children as being raped, physically, or emotionally abused. In these cases, contact was made in writing or by phone with locally assigned adult or child social workers and with the Captain Clifton Parks, Umlazi Police Station's liaison for these issues. In addition, when appropriate, team members provided ad-hoc advice regarding issues of concern including steps to access grants, etc.

9. Methodological Limitations and Strengths

Limitations of the study included use of self-reported data. Furthermore, lack of existing data limited comparisons of self-report data against other sources. There were limited scales validated in South Africa; when it was not possible to use scales validated in South Africa, scales with excellent psychometric properties were used. The verbal autopsy method may have included a margin of error, but attempts to address this were made by increasing the criteria required to diagnose an AIDS-related death and testing whether various classification criteria changed the significance of health outcomes for AIDS-orphan carers. This study also had significant strengths. To date, this is the largest known study to examine carers of AIDS-orphaned and other at-risk children. It adds significantly to geographical gaps in the literature on carers in South Africa. It adds significantly to content gaps around the health of carers and is one of the few studies in the global South to focus specifically on health as a central outcome in this population. It adds methodologically to studies on carers of AIDS-orphaned children with the use of comparison groups.

10. Summary

Chapter III discussed in depth the design and methods used in the large representative cross-sectional survey. The rationale behind sampling, choice of comparison groups, and the process for placing carers into these groups using the VA method is also explained. Strategies for analyzing data were introduced with more detailed discussion to follow in subsequent chapters. Stakeholder outreach, fieldwork challenges, and ethical considerations were also detailed. ***Chapter IV*** provides the first findings from the study, reporting on carer characteristics.

CHAPTER IV RESULTS: CARER CHARACTERISTICS

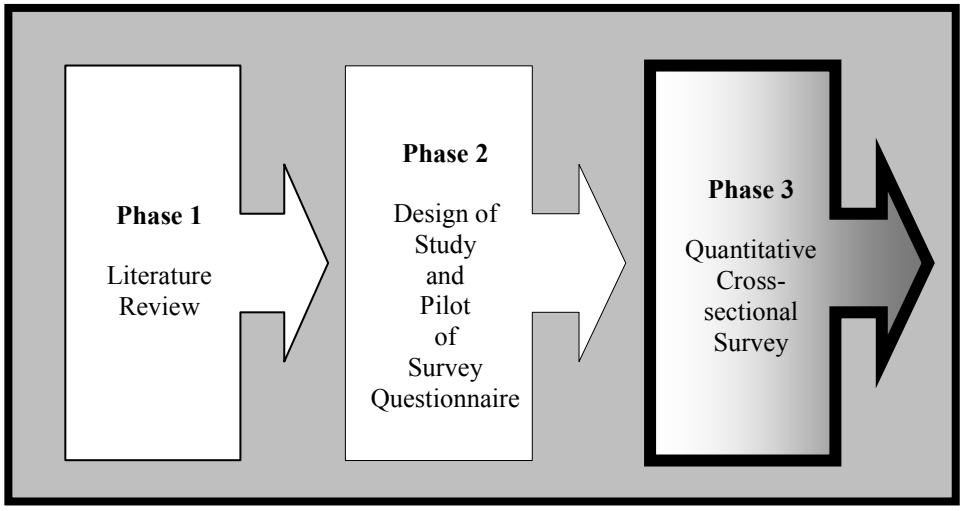


Figure 4.1: Quantitative Cross-sectional Survey

Summary

The primary objective of this chapter is to present a general profile of adults caring for children (n=1599) in a community substantially impacted by HIV and then to assess differences in profiles across carer types. To date, this is the largest known study on carers of AIDS-orphaned children. The analyses showed that the majority of carers in this community were female, Black African, and isiZulu speakers. On average, carers were 40 years of age, challenging prevalent policy notions of elderly carers. Carer profiles reflected high levels of deprivation in the study area. For example, carers only completed some sort of secondary education on average, with many living in informal housing and dependent upon grants as the main source of household income.

The majority of carers looked after non-orphaned children (66.85%) followed by AIDS-orphan (22.45%) and other-orphan children (10.69%). Notable were the high numbers of orphan carers, particularly, AIDS-orphan carers in this community. Carers were predominantly related to children through kinship, mirroring trends within the literature. Although numbers of non-kin carers were too small to draw statistically significant comparisons, patterns suggested that non-kin were more likely to care for AIDS-orphaned children than other-orphaned children. These data may offer support for literature suggesting that the extended family faces strains in care capacity due to AIDS.

There were significant differences in carer profiles. Comparisons of orphan versus non-orphan carers suggested that orphan carers faced a number of demographic, social, and economic disadvantages including being older in age, having lower levels of education, social support, ownership of economic assets, etc. Further comparisons between AIDS-orphan, other-orphan, and non-orphan carers also suggested different profiles. AIDS-orphan carers fared worse than the other two carer groups in a number of indicators including levels of education and social support.

1. Introduction

This chapter addresses the first study question, "Who are carers of children in a community directly and substantially impacted by HIV and AIDS?" The chapter begins by detailing the data analytical approach. Then, in four additional sections it describes characteristics of the sample of 1599 carers who completed the survey and identifies how carers differ. The first of these sections presents characteristics of the overall carer sample with variables organized by the socio-ecological conceptual model. The second section compares orphan and non-orphan carer differences and the third section compares AIDS-orphan, other-orphan, and non-orphan carer differences in characteristics. The fourth section presents information on the children being cared for.

2. Analytical Approach

Question 1: Who are carers of children in a community directly and substantially impacted by HIV and AIDS?

Sub-question 1.1: How does the profile of carers of orphaned children vary from carers of non-orphaned children?
Sub-question 1.2: How does the profile of carers of AIDS-orphaned children vary from carers of other-orphaned and non-orphaned children?

Characteristics of the sample were described using basic frequencies. In addition, shapes of distributions were assessed for continuous variables. All distributions were normal unless otherwise indicated. If distributions were abnormal, additional measures of central tendency (median and mode), size of distribution (range), measures of dispersion (skewness and kurtosis) were reported. When appropriate, abnormally distributed variables were transformed using z-scores. These z-scores were used in all subsequent analyses involving these variables. Distributions

were categorized as normal if skewness and kurtosis values fell within +/-2 standard deviations of the mean.

Differences in characteristics between carer groups were assessed using independent sample T-tests (Levene's Test), Chi-square tests (Pearson's test), and one-way ANOVAs. When ANOVA tests were used, additional post-hoc comparisons using Tukey comparisons were used to identify specific group differences. All tests were two-tailed and statistical significance was set at $p<0.01$ level due to the number of tests conducted. Trends significant at $p<0.05$ level were also noted.

3. Characteristics of the Overall Carer Sample

In total, 1599 adults providing primary childcare were included in the sample.

3.1 Individual Level Variables

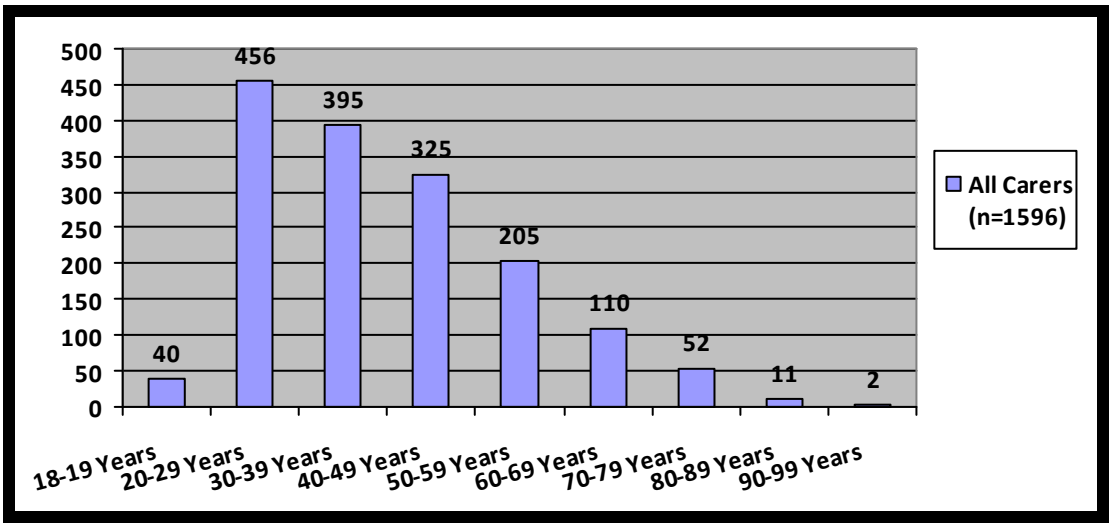
Ethnicity and Language

Carers were predominantly Black African (99.87%) with a small percentage of individuals who were Coloured (0.13%). The majority of carers were isiZulu speakers (98.12%) with the remainder speaking isiXhosa (1.63%), Sedepi (0.13%), and Sesotho (0.13%). In subsequent analysis, ethnicity and language were not analyzed further due to small percentages of Coloured and non-isiZulu speakers.

Age and Gender

On average, carers were 39.39 years old (SD=14.73). The frequency of carers in various age ranges is shown in ***Graph 4.1***.

Graph 4.1: Frequency of Individuals in Various Age Groups

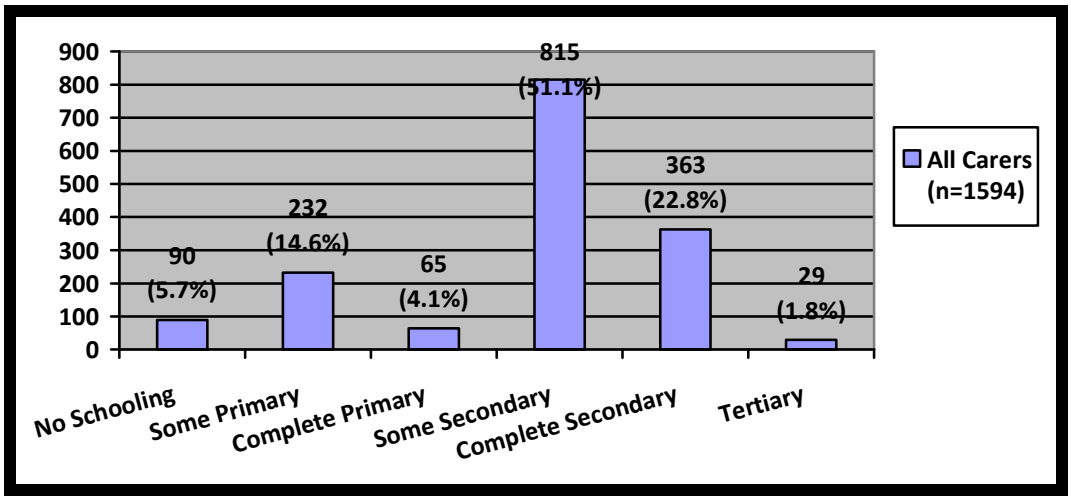


The majority of carers were female (86.40%).

Education

Carers had a mean education level of 10.54 or Grade 8, typically ages 12-13 years (SD=3.85 grade levels). Less than a quarter of carers completed the secondary education standard of Grade 12, typically ages 17-18 years (22.77%), and even fewer completed tertiary education (1.82%). ***Graph 4.2*** displays levels of educational attainment in the overall sample.

Graph 4.2: Carers Overall - Frequencies and Percentages of Educational Attainment



3.2 Care Provision Variables

Types of Carers

Orphan carers were prevalent in the community, comprising nearly a third of the sample (n=530, 33.15%) with the remainder made up of non-orphan carers (n=1069, 66.85%) (see ***Chapter I, Section 4.3.3*** for a details regarding placement of carers into comparison groups). Orphan carers can be further categorized into AIDS-orphan (n=359, 22.45% of total sample) and other-orphan carers (n=171, 10.69% of total sample).

Social Support

Based on an 84-point scale, carers ranked overall social support at a mean score of 63.64 points (SD=13.23), falling within the third quartile of the scale. In terms of who provides support, carers ranked significant others (M=23.36, SD=4.83) as the most important source of support followed by family members (M=22.88, SD=5.24) and friends (M=17.29, SD=8.21).

3.3 Household Variables

Number of Household Members and Dwelling Type

Carers reported a mean of 5.51 individuals living in the household (SD=2.60). The number of individuals living in the household was abnormally distributed (median=5.00, mode=4.00, range=2 to 20, skewness=1.52, kurtosis=3.67) and transformed into z-scores. The majority of carers lived in some type of informal dwelling (53.32%) or formal dwelling (44.31%). Informal dwellings *(i.e.,* buildings made with cardboard, corrugated iron, plastic, etc.) included informal dwellings on their own property or informal dwellings in backyards. Formal dwellings (*i.e.,* buildings made with brick, concrete, etc.) included houses or brick structures on separate stand or yard; townhouses, clusters, or semi-detached houses; rooms in houses in backyards; or rooms in houses. A much smaller percentage of carers lived in traditional dwellings, apartments, or caravan/tents (2.37%).

Potable Water, Toilets, Household Hunger

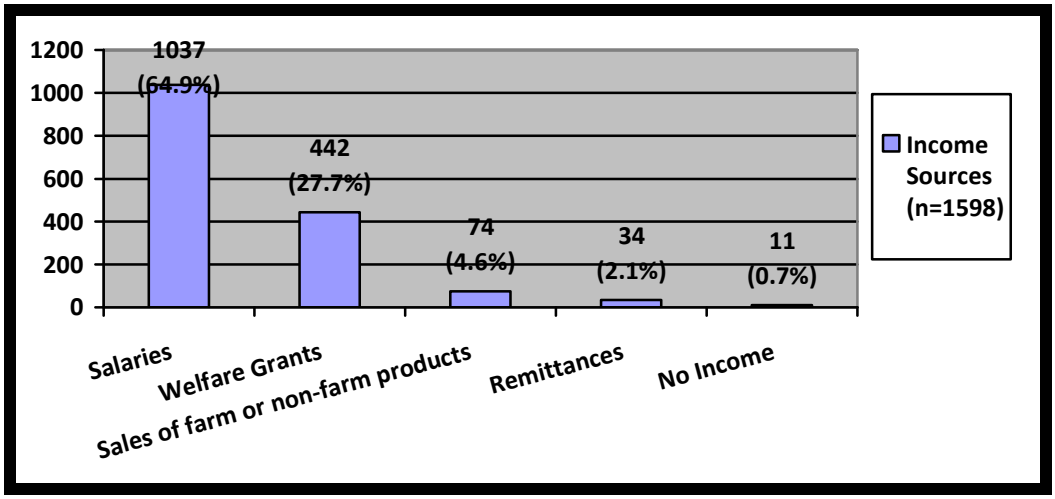
The majority of carers were able to get water from a piped water source (77.52%) and this water was clean (99.44%). Sub-group comparisons on the clean water variable were not conducted. The majority of carers experienced some level of hunger in their household (61.68%), and nearly half (45.02%) had access to a flush toilet.

Figure 4.2: Outside Toilet

Economic Asset Index and Main Source of Household Income

Carers had a mean economic asset index score of 0.05 (SD=0.67) within the range of -4.42 to 1.11. When compared to Booysen's (2001) estimates for national South African economic assets, the mean was similar to the national sample (M=-0.06, SD=1.07) but range was narrower (range of -12.17 to 2.32). That the study sample has a narrower range was expected since the sample had much less economic diversity than the national dataset. The majority of households (99.31%) stated that they had a primary source of income. Primary sources of household income are shown in ***Graph 4.3***.

Graph 4.3: Primary Sources of Household Income



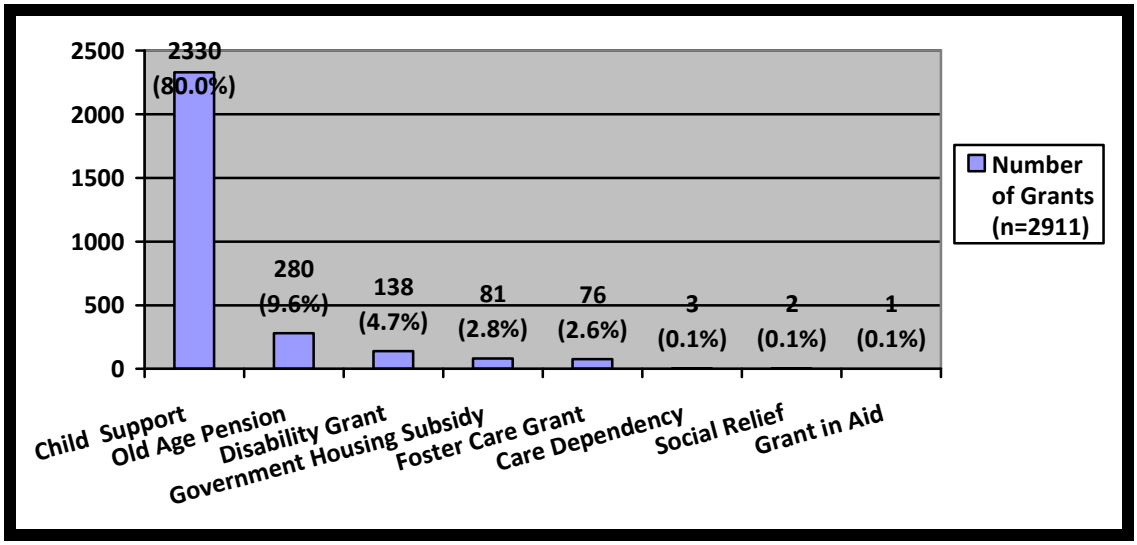
The figure demonstrates that grants were an important source of primary household income. Grant amounts and eligibility requirements can be found in ***Appendix 5***.

3.4 Policy Variables

Household Receipt of Grants

Graph 4.4 displays the frequency of grants received in carer households. Child support grants were the most prevalent type of grant received. Further analysis on the care dependency grant, social relief grant, and grant in aid did not occur due to inadequate sample size.

Graph 4.4: Frequency of Grants by Households



A summary of overall carer sample characteristics is found in ***Table 4.1.***

Table 4.1: Overall Frequencies for Descriptive Variables for All Types of Carers (n=1599)

Descriptive Variables	Number in Sample and Percentage (N, %)	Mean (M), Standard Deviation (D)
Ethnicity		--
African	1594 (99.87%)	
Coloured	2 (0.13%)	
Language		--
isiZulu	1566 (98.12%)	
isiXhosa	26 (1.63%)	
Sepedi/Nothern Sotho	2 (0.13%)	
Sesotho/Southern Sotho/Sotho	2 (0.13%)	
Average age in years (n=1596)	--	39.39 (14.73)
Gender		--
Male	217 (13.60%)	
Female	1379 (86.40%)	
Education level (n=1594)	--	10.54 (Grade 8) (3.85)
Social support (n=1598)	--	63.64 (13.23)
Family support		22.88 (5.24)
Friend support		17.29 (8.21)
Significant others support		23.36 (4.83)
Number of people in household (n=1598)	--	5.51 (2.60)
Dwelling type		--
Informal dwelling in backyard	264 (16.52%)	
Informal dwelling	588 (36.80%)	
Formal dwelling	620 (38.80%)	
Formal dwelling - semi-detached	5 (0.31%)	
Room in formal dwelling	9 (0.56%)	
Room in formal dwelling in backyard	74 (4.63%)	
Traditional dwelling	30 (1.88%)	
Apartment/flat	7 (0.44%)	
Caravan/tent	1 (0.06%)	
Water source		--
Piped	1238 (77.52%)	
Non-piped	359 (22.48%)	
Water safe		--
Yes	1589 (99.44%)	
No	9 (0.56%)	
Toilets		--
Flush	719 (45.02%)	
Non-flush	878 (54.98%)	
Hunger		--
Some level of hunger	985 (61.68%)	
No hunger	612 (38.32%)	
Economic asset index (n=1590)	--	0.05 (0.67)
Main source of income		--
Salaries/wages	1037 (64.89%)	
Pensions/grants	442 (27.66%)	
Other non-farm incomes	67 (4.19%)	
Remittances	34 (2.13%)	
No income	11 (0.69%)	
Sales of farm products	7 (0.44%)	

Descriptive Variables	Number in Sample and Percentage (N, %)	Mean (M), Standard Deviation (D)
Frequency of grants received in household (n=2911)		
Old age pension	280 (9.62%)	0.18 (0.44)
Disability grant	138 (4.74%)	0.09 (0.29)
Care dependency grant	3 (0.10%)	0.002 (0.06)
Grant in aid	1 (0.03%)	0.0006 (0.03)
Social relief	2 (0.07%)	0.001 (0.04)
Government grant	81 (2.78%)	0.05 (0.23)
Child support grant	2330 (80.04%)	1.41 (1.40)
Foster care grant	76 (2.61%)	0.040.27)

Note: Column sums may not add up to n=1599 due to missing values

4. Characteristics of Orphan vs. Non-orphan Carers

Orphan carers faced significant disadvantages in their characteristics as compared to non-orphan carers.

4.1 Individual Level Variables

Age and Gender

Orphan carers were significantly older (M=42.67, SD=15.98) than non-orphan carers (M=37.77, SD=13.80) ($p<0.01$). An observed trend emerged suggesting that orphan carers were moderately more likely to be female (89.02%) than non-orphan carers (85.11% female) ($p<0.03$, $\chi 2=4.58$).

Education

Orphan carers had lower average levels of education (M=9.99 or Grade 7, SD=3.97 grade levels) compared with non-orphan carers (M=10.82 or Grade 8, SD=3.76 grade levels) ($p<0.01$).

4.2 Care Provision Variables

Social Support

Orphan carers reported significantly less social support (M=61.45, SD=13.87) than non-orphan carers (M=64.71, SD=12.78) ($p<0.01$). This pattern of decreased social support held true when comparing levels of support of orphan carers versus non-orphan carers from family (M=22.24 vs. 23.20) ($p<0.01$), friends (M=16.51 vs. 17.82) ($p<0.01$), and significant others (M=22.69 vs. 23.69) ($p<0.01$). Similar to overall sample patterns, and regardless of whether individuals were carers of orphans or non-

orphans, significant others were ranked as the most important source of support followed by family members and friends respectively.

4.3 Household Variables

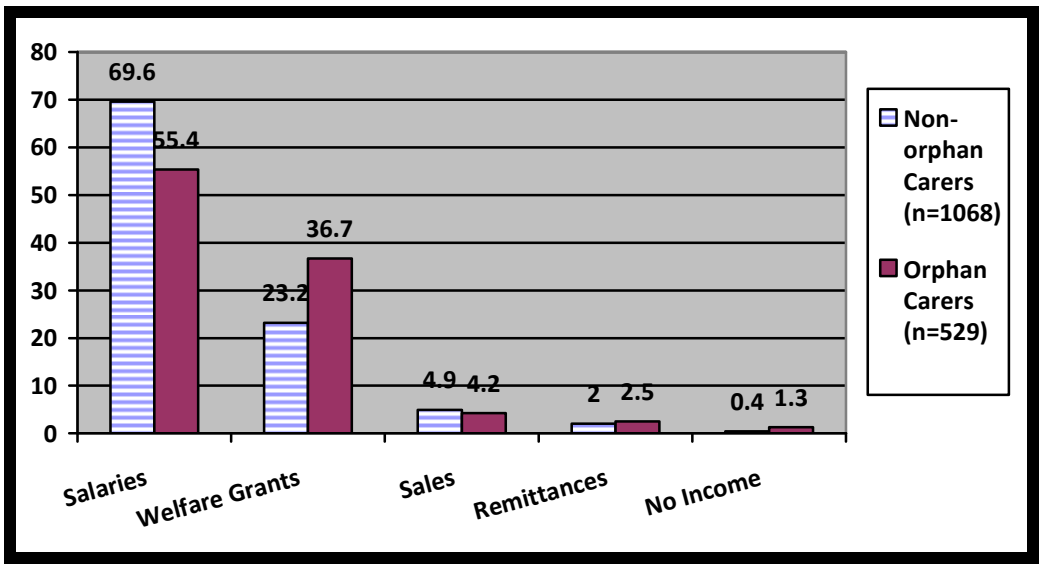
Number of Household Members and Dwelling Type

Orphan carers had significantly more people living in the household (M=0.34, SD=1.12) than non-orphan carers (M=-0.17, SD=0.89) ($p<0.01$). There were no significant differences in dwelling types at $p<0.01$ level.

Economic Asset Index and Main Source of Household Income

Orphan carers did not have significantly different economic asset index scores (M=0.03, SD=0.73) compared to non-orphan carers (M=0.06, SD=0.63). However, orphan and non-orphan carers showed significant differences in main sources of household income sources ($p<0.01$, $\chi 2=40.34$) (***Graph 4.5***).

Graph 4.5: Orphan vs. Non-orphan Carers - Percentages of Main Income Sources



Orphan carers were significantly less likely to depend on salaries/wages as the main source of household income (55.39%) than non-orphan carers (69.57%) ($p<0.01$, $\chi2=31.22$). Orphan carers were also significantly more likely to depend on welfare grants as the main source of household income (36.67%) than non-orphan carers (23.22%) ($p<0.01$, $\chi2=31.98$). An observed trend emerged suggesting that orphan carers were moderately more likely to have no income (1.32%) than non-orphan carers to (0.37%) ($p<0.03$, $\chi2=4.66$).

4.4 Policy Variables

Household Receipt of Grants

In regards to household receipt of grants, orphan carers had significantly higher numbers of old age pensions in their households (M=0.27 grants, SD=0.51) than non-orphan carers (M=0.13 grants, SD=0.39) ($p<0.01$). Similarly, orphan carers had significantly higher numbers of foster care grants in their households (M=0.11 grants, SD=0.45) than non-orphan carers (M=0.02 grants, SD=0.13) ($p<0.01$). Higher frequencies of foster care grants in the orphan carer group is not surprising given that individuals can only qualify for a foster care grant if they care for an orphaned or abandoned child. Trends suggested that orphan carers were likely to receive higher numbers of government housing subsidies in their households (M=0.07 grants, SD=0.25) than non-orphan carers (M=0.04 grants, SD=0.21) ($p<0.04$). Similarly, there were trends suggesting that orphan carers were likely to receive higher numbers of child support grants in their households (M=1.64 grants, SD=1.56) than non-orphan carers (M=1.44 grants, SD=1.30) ($p=0.011$). Orphan (M=0.10 grants, SD=0.30) and non-orphan carers (M=0.08 grants, SD=0.28) were likely to receive equal numbers of disability grants in their households.

Carer Receipt of Grants

In regards to their own status as grant recipients, orphan carers were significantly more likely to receive old age pensions (16.51%) than non-orphan carers (6.28%) ($p<0.01$, $\chi 2=42.29$) but these differences were no longer significant when controlling for age. Trends suggested that orphan carers were moderately more likely to receive disability grants (6.26%) than non-orphan carers (4.03%) ($p<0.049$, $\chi 2=3.87$). Orphan (4.93%) and non-orphan carers (3.75%) were equally likely to receive government housing subsidies.

Table 4.2 summarizes differences in characteristics between orphan and non-orphan carers.

Table 4.2: Differences in Characteristics - Orphan vs. Non-Orphan Carers (n=1599)

Descriptive Variables	Carers of Orphaned Children (n=530)	Carers of Non-Orphaned Children (n=1069)	p^1
Age in years (M, SD)	42.67 (15.98)	37.77 (13.80)	<.01
Gender (n, %)			<.05
Male	58 (10.98%)	159 (14.89%)	
Female	470 (89.02%)	909 (85.11%)	
Average educational level (M, SD)	9.99 or Grade 7 (3.97)	10.82 or Grade 8 (3.76)	<.01
Social support (M, SD)	61.45 (13.87)	64.71 (12.78)	<.01
Family support	22.24 (5.76)	23.20 (4.94)	<.01
Friend support	16.51 (8.47)	17.82 (8.05)	<.01
Significant others support	22.69 (5.44)	23.69 (4.47)	<.01
Number of children in household (M, SD)	0.42 (1.08)	-0.17 (0.88)	<.01
Number of people in household(M, SD)	0.34 (1.12)	-0.17 (0.89)	<.01
Dwelling type (n, %)			
Informal dwelling in backyard	71 (13.42%)	193 (18.05%)	<.05
Informal dwelling	202 (38.19%)	386 (36.11%)	ns
Formal dwelling	214 (40.45%)	406 (37.98%)	ns
Formal dwelling - semi-detached	3 (0.57%)	2 (0.19%)	ns
Room in formal dwelling	1 (0.19%)	8 (0.75%)	ns
Room in formal dwelling in backyard	23 (4.35%)	51 (4.77%)	ns
Traditional dwelling	14 (2.65%)	16 (1.50%)	ns
Apartment/flat	0 (0%)	7 (0.65%)	ns
Caravan/tent	1 (0.19%)	0 (0%)	ns
Economic asset index (M, SD)	0.03 (0.73)	0.06 (0.63)	ns
Main source of income (n, %)			
Salaries/wages	293 (55.39%)	743 (69.57%)	<.01
Pensions/grants	194 (36.67%)	248 (23.22%)	<.01
Other non-farm incomes	21 (3.97%)	46 (4.31%)	ns
Remittances	13 (2.46%)	21 (1.97%)	ns
No income	7 (1.32%)	4 (0.37%)	<.05
Sales of farm products	1 (0.19%)	6 (0.56%)	ns
Frequency of grants received in household (M, SD)			
Old age pension	0.27 (0.51)	0.13 (0.39)	<.01
Disability grant	0.10 (0.30)	0.08 (0.28)	ns
Government housing subsidy	0.07 (0.25)	0.04 (0.21)	<.05

Descriptive Variables	Carers of Orphaned Children (n=530)	Carers of Non-Orphaned Children (n=1069)	p[1]
Child support grant	1.64 (1.56)	1.44 (1.30)	=.011
Foster care grant	0.11 (0.45)	0.02 (0.13)	<.01
Grants received by carer (n, %)			
Old age pension recipient			
Yes	87 (16.51%)	67 (6.28%)	ns
No	440 (83.49%)	1000 (93.72%)	
Disability grant recipient			
Yes	33 (6.26%)	43 (4.03%)	<.05
No	494 (93.74%)	1024 (95.97%)	
Government housing subsidy recipient			
Yes	26 (4.93%)	40 (3.75%)	ns
No	501 (95.07%)	1027 (96.25%)	

Note: Column sums may not add to n=1599 due to missing values

[1] **p-values associated with T-tests for continuous variables and chi-square tests for categorical variables**

5. Characteristics of AIDS-orphan vs. Other-orphan vs. Non-orphan Carers

Analyses showed that carers had significantly different profiles with AIDS-orphan carers facing significant disadvantages in their characteristics as compared to other-orphan carers and non-orphan carers.

5.1 Individual Level Variables

Age and Gender

There were age differences between groups ($p<0.01$, $F=26.62$). AIDS-orphan carers were significantly older ($M=44.24$, $SD=16.36$) than other-orphan carers ($M=39.39$, $SD=14.68$) ($p<0.01$). AIDS-orphan carers were also significantly older ($M=44.24$, $SD=16.36$) than non-orphan carers ($M=37.77$, $SD=13.80$) ($p<0.01$). There were no significant differences in age between other-orphan ($M=39.39$, $SD=14.68$) and non-orphan carers ($M=37.77$, $SD=13.80$). In regards to gender, there were no significant differences between AIDS-orphan (10.08% male, 89.92% female), other-orphan (12.87% male, 87.13% female), and non-orphan carers (14.89% male, 85.11% female).

Education

There were differences in education levels across groups ($p<0.01$, $F=10.96$). On average, AIDS-orphan carers had significantly lower education ($M=9.72$ or Grade 7, $SD=4.11$ grade levels) than non-orphan carers ($M=10.82$ or Grade 8, $SD=3.76$ grade levels) ($p<0.01$). However, there were no significant differences in between AIDS-orphan ($M=9.72$ or Grade 7, $SD=4.11$ grade levels) and other-orphan carers ($M=10.54$ or Grade 8, $SD=3.63$ grade levels). There were no significant differences in mean

levels of education between other-orphan (M=10.54 or Grade 8, SD=3.63 grade levels) and non-orphan carers (M=10.82 or Grade 8, SD=3.76 grade levels).

5.2 Care Provision Variables

Social Support

In terms of overall social support, there were significant differences between groups ($p<0.01$, $F=15.81$). AIDS-orphan carers reported significantly lower levels of social support (M=60.23, SD=13.86) compared with other-orphan carers (M=64.02, SD=13.56) ($p<0.01$) and non-orphan carers (M=64.71, SD=12.78) ($p<0.01$). There were no differences in overall social support between other-orphan (M=64.02, SD=13.56) vs. non-orphan carers (M=64.71, SD=12.78). Analysis of social support sources showed that there were significant differences in support from friends ($p<0.01$, $F=7.19$), family ($p<0.01$, $F=9.90$), and significant others ($p<0.01$, $F=8.80$). AIDS-orphan carers had significantly less support than non-orphan carers from friends (M=15.95 vs. 17.82) ($p<0.01$), family (M=21.81 vs. 23.20) ($p<0.01$), and significant others (M=22.47 vs. 23.69) ($p<0.01$). However, there were no differences when comparing sources of support for AIDS-orphan vs. other-orphan carers and other-orphan vs. non-orphan carers.

5.3 Household Variables

Number of Household Members and Dwelling Type

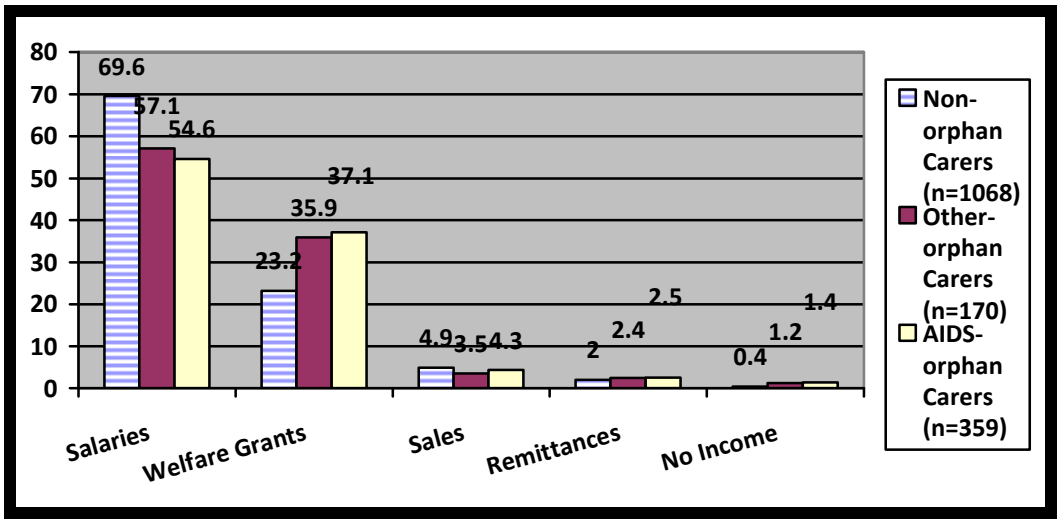
AIDS-orphan carers had significantly more individuals in their household (M=0.38, SD=1.16) than non-orphan carers (M=-0.17, SD=0.89) ($p<0.01$, $F=49.74$). Similarly, other-orphan carers to had significantly more people living in their

household (M=0.26, SD=1.02) than non-orphan carers (M=-0.17, SD=0.89) ($p<0.01$). However, there were no significant differences in household size when comparing AIDS-orphan (M=0.38, SD=1.16) and other-orphan carers (M=0.26, SD=1.02). There were no significant differences in dwelling types at $p<0.01$ level.

Economic Asset Index and Main Source of Household Income

AIDS-orphan, other-orphan, and non-orphan carers did not significantly differ in terms of economic asset index scores. However, carer sub-groups showed significant differences in main sources of household income ($p<0.01$, $\chi 2=40.92$) (***Graph 4.6***).

Figure 4.6: AIDS-orphan vs. Other-orphan vs. Non-orphan Carers - Percentages of Main Income Sources



AIDS-orphan carers were less likely to depend on work salaries as the main source of household income (54.60%) compared with non-orphan carers (69.57%) ($p<0.01$, $\chi 2=26.77$), and were more likely to depend on grants as the main source of income (37.05%) compared with non-orphan carers (23.22%) ($p<0.01$, $\chi 2=26.25$). Similarly, other-orphan carers were less likely to depend on work salaries as the main source of household income (57.06%) compared with non-orphan carers (69.57%) ($p<0.01$,

$\chi 2$=10.52), and were more likely to depend on grants as the main source of household income (35.88%) compared with non-orphan carers (23.22%) ($p<0.01$, $\chi 2$=12.55). There were no differences in main sources of income when comparing AIDS-orphan to other-orphan carers.

5.4 Policy Variables

Household Receipt of Grants

In regards to household receipt of grants, AIDS-orphan carers were compared to other-orphan carers. There were significant differences in the number of foster grants received ($p<0.01$, F=28.74). AIDS-orphan carers were significantly more likely to receive higher numbers of foster care grants in their households (M=0.14 grants, SD=0.51) than other-orphan carers (M=0.05 grants, SD=0.26) ($p<0.01$). AIDS-orphan and other-orphan carers were likely to receive equal numbers of other types of grants in their households. Comparisons were also made between AIDS-orphan and non-orphan carers. There were significant differences the number of old age pensions received ($p<0.01$, F=22.98). AIDS-orphan carers were significantly more likely to receive higher numbers of old age pensions in their households (M=0.31 grants, SD=0.53) than non-orphan carers (M=0.13 grants, SD=0.39) ($p<0.01$). Similarly, there were significant differences in the number of foster grants received ($p<0.01$, F=28.74). AIDS-orphan carers were significantly more likely to receive higher numbers of foster care grants in their households (M=0.14 grants, SD=0.51) than non-orphan carers (M=0.02 grants, SD=0.13) ($p<0.01$). In contrast to these other patterns, AIDS-orphan carers were more likely to have lower numbers of government housing subsidies in their households (M=0.08 grants, SD=0.28) as compared to non-orphan carers (M=0.04 grants, SD=0.21) ($p<0.01$, F=5.04). Trends also suggested that AIDS-orphan carers

were more likely to have higher numbers of child support grants in their households (M=1.64 grants, SD=1.46) than non-orphan carers (M=1.44 grants, SD=1.30) ($p<0.048$, $F=3.62$).

Carer Receipt of Grants

In regards to their own status as grant recipients, AIDS-orphan carers were significantly more likely to receive an old age pension (19.66%) than other-orphan carers (9.94%) ($p<0.01$, $\chi2=54.96$) but these differences were not significant when controlling for age. Similarly, AIDS-orphan carers were significantly more likely to receive the old age pension (19.66%) than non-orphan carers (6.28%) ($p<0.01$, $\chi2=7.92$) but these differences were not significant when controlling for age. Other-orphan (9.94%) and non-orphan (6.28%) carers were equally likely to receive the old age pension. AIDS-orphan (5.62%), other-orphan (7.60%), and non-orphan carers (4.03%) were equally likely to receive disability grants. AIDS-orphan (5.90%), other-orphan (2.92%), and non-orphan carers (3.75%) were equally likely to receive government housing subsidies.

Table 4.3 summarizes differences in characteristics between AIDS-orphan, other-orphan, and non-orphan carers.

Table 4.3: Differences in Characteristics – AIDS-Orphan vs. Other-Orphan vs. Non-Orphan Carers (n=1599)

Descriptive Variables	Carers of AIDS-Orphaned Children (n=359)	Carers of Other-Orphaned Children (n=171)	Carers of Non-Orphaned Children (n=1069)	p^1
Average age in years (M, SD)	44.24 (16.36)	39.39 (14.68)	37.77 (13.80)	<.01 Tukey Test: <.01 AIDS-orphan>Other-orphan carers AIDS-orphan>Non-orphan carers
Gender (n, %)				ns
Male	36 (10.08%)	22 (12.87%)	159 (14.89%)	
Female	321 (89.92%)	149 (87.13%)	909 (85.11%)	
Average education level (M, SD)	9.72 (Grade7) (4.11)	10.54 (Grade 8) (3.63)	10.82 (Grade 8) (3.76)	<.01 Tukey Test: <.01 AIDS-orphan<Non-orphan carers
Social support (M, SD)	60.23 (13.86)	64.02 (13.56)	64.71 (12.78)	<.01 Tukey Test: <.01 AIDS-orphan<Other-orphan carers AIDS-orphan<Non-orphan carers
Family support	21.81 (5.92)	23.16 (5.30)	23.20 (4.94)	<.01 Tukey Test: <.01 AIDS-orphan<Non-orphan carers
Friend support	15.95 (8.37)	17.71 (8.58)	17.82 (8.05)	<.01 Tukey Test: <.01 AIDS-orphan<Non-orphan carers
Significant others support	22.47 (5.52)	23.15 (5.25)	23.69 (4.47)	<.01 Tukey Test: <.01 AIDS-orphan<Non-orphan carers
Number of children in household (M, SD)	0.46 (1.12)	0.32 (0.98)	-0.17 (0.88)	<.01 Tukey Test: <.01 AIDS-orphan>Non-orphan carers Other-orphan>Non-orphan carers
Number of people in household (M, SD)	0.38 (1.16)	0.26 (1.02)	-0.17 (0.89)	<.01 Tukey Test: <.01 AIDS-orphan carers>Non-orphan carers Other-orphan carers>Non-orphan carers

Descriptive Variables	Carers of AIDS-Orphaned Children (n=359)	Carers of Other-Orphaned Children (n=171)	Carers of Non-Orphaned Children (n=1069)	p[1]
Dwelling Type (n, %)				
Informal dwelling in backyard	48 (13.37%)	23 (13.53%)	193 (18.05%)	ns
Informal dwelling	136 (37.88%)	66 (38.82%)	386 (36.11%)	ns
Formal dwelling	141 (39.28%)	73 (42.94%)	406 (37.98%)	ns
Formal dwelling - semi-detached	3 (0.84%)	0 (0%)	2 (0.19%)	ns
Room in formal dwelling	0 (0%)	1 (0.59%)	8 (0.75%)	ns
Room in formal dwelling in backyard	18 (5.01%)	5 (2.94%)	51 (4.77%)	ns
Traditional dwelling	12 (3.34%)	2 (1.17%)	16 (1.50%)	ns
Apartment/flat	0 (0%)	0 (0%)	7 (0.65%)	ns
Caravan/tent	1 (0.29%)	0 (0%)	0 (0%)	ns
Economic asset index (M, SD)	0.001 (0.76)	0.08 (0.67)	0.06 (0.63)	ns
Main source of income (n, %)				
Salaries/wages	196 (54.60%)	97 (57.06%)	743 (69.57%)	<.01
Pensions/grants	133 (37.05%)	61 (35.88%)	248 (23.22%)	<.01
Other non-farm incomes	15 (4.18%)	6 (3.53%)	46 (4.31%)	ns
Remittances	9 (2.51%)	4 (2.35%)	21 (1.97%)	ns
No income	5 (1.39%)	2 (1.18%)	4 (0.37%)	ns
Sales of farm products	1 (0.28%)	0 (0%)	0 (0%)	ns
Frequency of grants received in household (M, SD)				
Old age pension	0.31 (0.53)	0.20 (0.44)	0.13 (0.39)	<.01 Tukey Test: <.01 AIDS-orphan>Non-orphan carers
Disability grant	0.10 (0.31)	0.09 (0.28)	0.08 (0.28)	ns
Government housing subsidy	0.08 (0.28)	0.03 (0.18)	0.04 (0.21)	<.01 Tukey Test: <.01 AIDS-orphan<Non-orphan carers
Child support grant	1.64 (2.60)	1.64 (1.46)	1.44 (1.30)	<.05 Tukey Test: <.05 AIDS-orphan>Non-orphan carers
Foster care grant	0.14 (0.51)	0.05 (0.26)	0.02 (0.13)	<.01 Tukey Test: <.01 AIDS-orphan>Other-orphan carers AIDS-orphan>Non-orphan carers

Descriptive Variables	Carers of AIDS-Orphaned Children (n=359)	Carers of Other-Orphaned Children (n=171)	Carers of Non-Orphaned Children (n=1069)	p[1]
Grants received by carer (n, %)				
Old age pension recipient				ns
Yes	70 (19.66%)	17 (9.94%)	67 (6.28%)	
No	286 (80.34%)	154 (90.06%)	1000 (93.72%)	
Disability grant recipient				ns
Yes	20 (5.62%)	13 (7.60%)	43 (4.03%)	
No	336 (94.38%)	158 (92.40%)	1024 (95.97%)	
Government housing subsidy recipient				ns
Yes	21 (5.90%)	5 (2.92%)	40 (3.75%)	
No	335 (94.10%)	166 (97.07%)	1027 (96.25%)	

Note: Column sums may not add to n=1599 due to missing values

[1] **p-values associated with one-way ANOVA for continuous variables and chi-square tests for categorical variables**

6. Children's Characteristics

The overall sample cared for a total of 4039 children. Over half of the children cared for had one or both parents who were still alive (58.60%, n=2,367), followed by those who had lost one or both parents to AIDS (28.67%, n=1,158), and other causes (12.73%, n=514). Carer households had a range of one to 11 children living in them. On average, carers had 2.49 (SD=1.61) children in their household. The number of children in the household was abnormally distributed (median=2.00, mode=1.00, skewness=1.37, kurtosis=2.77) and transformed into z-scores. Orphan carers had significantly more children in their household (M=3.15, SD=1.73) than non-orphan carers (M=2.21, SD=1.41) ($p<0.01$). There were also differences in mean numbers of children when comparing AIDS-orphan, other-orphan, and non-orphan carers ($p<0.01$, F=69.02). AIDS-orphan carers had significantly more children (M=3.22, SD=1.80) than non-orphan carers (M=2.21, SD=1.41) ($p<0.01$). Likewise, other-orphan carers had significantly more children (M=3.01, SD=1.57) than non-orphan carer households ($p<0.01$). There were no significant differences in number of children in AIDS-orphan and other-orphan carer households.

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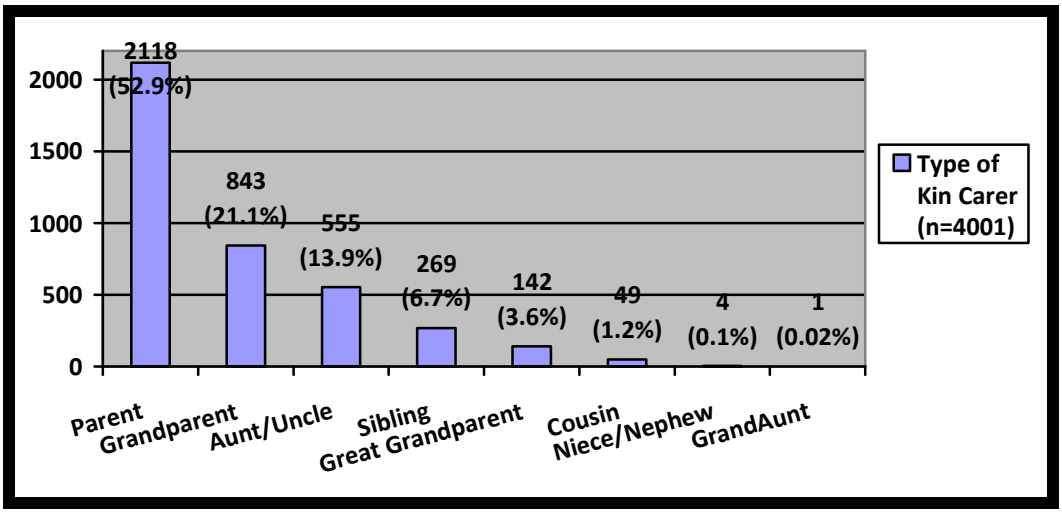
Figure 4.3: Gugu Ndovlu Interviewing a Respondent

6.1 Relationship to Carer

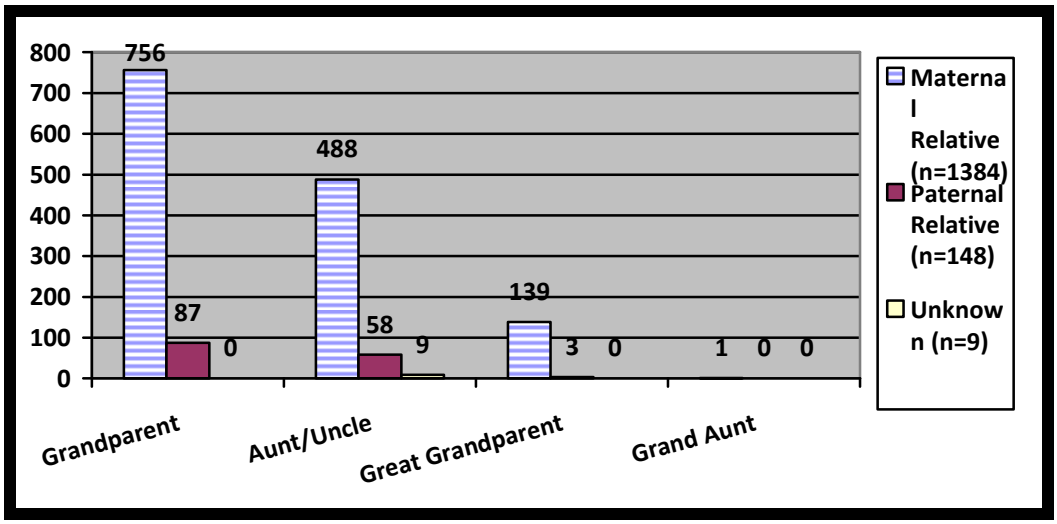
The majority of carers were related to children through kinship (99.06%, n=4001). A much smaller percentage of carers were related to children through non-kin relationships such as neighbors, family friends, foster parents, or tenants (0.84%, n=34). Types of kin carers are shown in ***Graph 4.7***.

Graph 4.7: Relationship of Kin Carers to Children



Further analysis of whether relatives were maternal or paternal is shown in ***Figure 3.9***.

Graph 4.8: Maternal or Paternal Kin Carers



Carers were significantly more likely to be maternal relatives of children than non-maternal relatives ($p<0.01$, $\chi2=10.26$).

Kin and non-kin carers were equally likely to care for orphaned children (n=1,672) and non-orphaned children (n=2,367). Although numbers of non-kin were too small to determine statistical significance, data indicated that there may be differences in whether kin or non-kin cared for AIDS-orphaned (n=1,158), other-orphaned (n=514), and non-orphaned children (n=2,367) ($p<0.04$, $\chi2=6.70$). In high HIV prevalence communities non-kin carers may be more likely to care for AIDS-orphaned children (1.40%) than non-orphaned children (0.60%) ($p<0.03$, $\chi2=4.99$). There were no differences in kin versus non-kin care when AIDS-orphaned children were compared with other-orphaned children and when other-orphaned children were compared with non-orphaned children.

6.2 Reason for Parental Death

Of the 4039 children in the sample, 1111 (27.51%) experienced death of one or both parents.[5] Of these 1111 children, the majority (79.12%, n=879) experienced parental death due to health-related causes. A minority (20.70%, n=230) experienced parental death due to non-health related causes. The cause for parental death was unknown for very few children (0.36%, n=4).

Some of the children whose parents died of health-related causes (n=879) are related. These children can be clustered into 611 unique child or sibling groups that comprise a non-repetitive count of parents who died. Of these 611 child or sibling

[5] The number of children who have lost one or both parents (n=1111) does not add up to the sum of children who have lost one or both parents to AIDS (n=1,158) and children who have lost one or both parents to non-AIDS causes (n=514) because the latter two categories include a double count of children who have lost one parent to AIDS and another to non-AIDS causes.

groups, 84.94 percent (n=519) lost one or both parents to AIDS and 15.06 percent (n=92) lost one or both parents to other health related causes. Of the AIDS-orphaned child or sibling groups, 50.67 percent (n=263) were paternal orphans, 34.87 percent (n=181) were maternal orphans, and 14.45 percent (n=75) were double orphans.

Of the 230 children whose parents died from non-health related causes, over 90 percent of the deaths were from violent crime such as shootings or stabbings and transport accidents. A summary of causes of parental death for these children is shown in ***Graph 4.9***.

Graph 4.9: Non-Health Related Cause of Parental Mortality

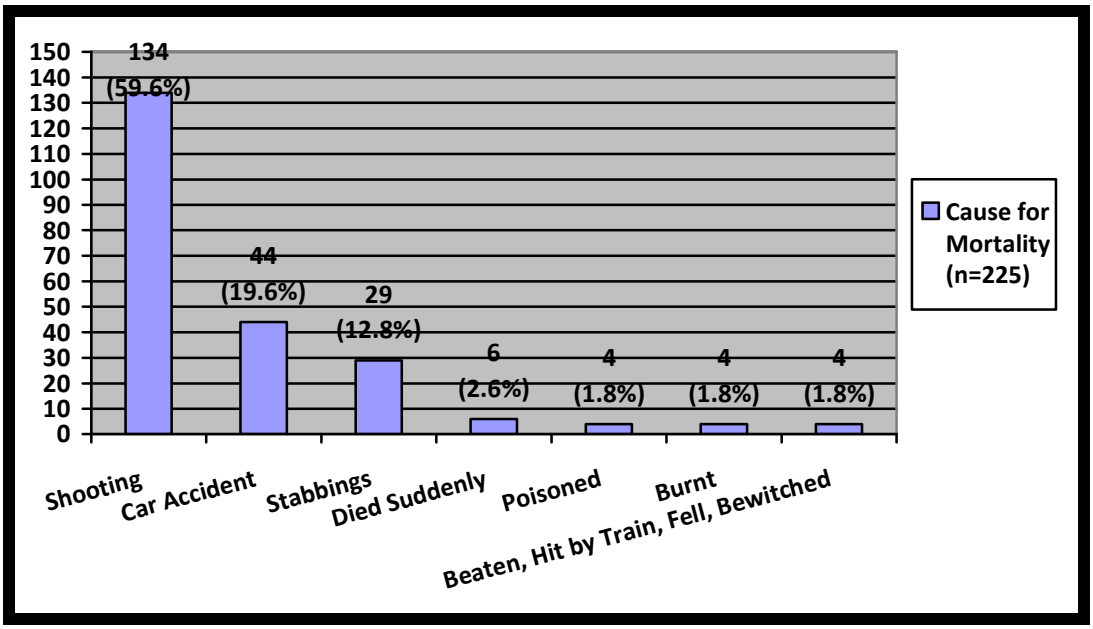


Table 4.4 summarizes the characteristics of the children cared for by the carer sample.

Table 4.4: Descriptive Variables for Children Being Cared For (n=4039)

Descriptive Variables	Number in Sample And Percentage (N, %)	Mean (M), Standard Deviation (D)
Number of children cared for	--	2.49 (1.61)
Children attending school		--
Yes	2639 (65.34%)	
No	1400 (34.66%)	
Reasons not attending		--
Too Old/Young	1143 (94.07%)	
Sick	15 (1.23%)	
Completed education	14 (1.15%)	
No money	11(0.91%)	
Education worthless	9 (0.74%)	
Pregnancy	8 (0.66%)	
Failed exams	8 (0.66%)	
Working/domestic duties	3 (0.25%)	
Denied place	3 (0.25%)	
School not good	1 (0.08%)	
Number of children orphaned by type		--
Non-orphaned	2,367 (58.60%)	
AIDS-orphaned children	1,158 (28.67%)	
Other-orphaned children	514 (12.73%)	
Relationship between carer and orphan		Differences between maternal and paternal kin at $p<.01$
Kin relationship	4001 (99.06%)	
Parent	2119 (52.93%)	
Grandparent	843 (21.07%) – 756 maternal, 87 paternal	
Aunt/Uncle	555 (13.87%) – 488 maternal, 58 paternal, 9 don't know	
Sibling	269 (6.72%)	
Great grandparent	142 (3.55%) – 139 maternal, 3 paternal	
Cousin	49 (1.22%)	
Niece/Nephew	4 (0.09%)	
Grand aunt	1 (0.02%)- 1 maternal	
Non-kin relationship	34 (0.84%)	
Reason for parental death (n=1111)		--
Health	879 (79.12%)	
Non-Health	230 (20.70%)	
Unknown	4 (0.36%)	
Health related deaths (n=879 children in 611 child/sibling groups)		--
One or both parents died of AIDS	519 (84.94%)	
One or both parents died of other causes	92 (15.06%)	
Type of AIDS orphan (n=611 child/sibling groups)		--
Paternal	263 (50.67%)	
Maternal	181 (34.87%)	
Double	75 (14.45%)	
Non-health death (n=225)		--
Shooting	134 (59.56%)	
Car Accident	44 (19.56%)	
Stabbing	29 (12.89%)	
Died suddenly	6 (2.67%)	
Poisoned	4 (1.78%)	
Burnt	4 (1.78%)	
Beaten, hit by train, fell, bewitched	4 (1.78%)	

7. Summary

This chapter provided an overview of sample characteristics. The majority of carers were African, isiZulu speakers. Carers were predominantly female and had a mean age of 40 years. On average, carers completed some secondary schooling but the majority did not complete the secondary school benchmark of Grade 12 or tertiary education. Carers drew primary social support from significant others but family and friends also served as important sources of support. The majority of individuals lived in informal housing and had approximately 5 individuals in the household. Nearly all carers had access to clean water. Most carers had some source of household income with grants functioning as an important source of income.

The chapter also explored differences between orphan and non-orphan carers. Analysis suggested that overall, orphan carers may face some demographic and socioeconomic disadvantages when compared to non-orphan carers. For example, orphan carers tended to be older and less educated than non-orphan carers. Orphan carers were more likely to depend on grants and less likely to depend on work salaries as the primary source of household income, suggesting that orphan households face additional economic strain.

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Figure 4.4: Photo of Community Members

Orphan carers also had less overall social support than non-orphan carers. They also had more individuals in their household and tended to care for more children than non-orphan carers.

Analysis also explored sub-group differences within orphan carers by comparing AIDS-orphan and other-orphan carers, alongside non-orphan carers. Analysis illustrated that while AIDS-orphan and other-orphan carers were similar in some ways (*e.g.*, household size), overall, AIDS-orphan carers had a profile distinct from other-orphan carers and non-orphan carers. AIDS-orphan carers were significantly older and had less education. Also, AIDS-orphan carers had less social support, and were more dependent on grants when compared to other groups. Also, AIDS-orphan carers were more likely to be unrelated to the children through kinship.

Overall, the data presented in this chapter suggested that orphan carers were distinct from non-orphan carers in terms of their characteristics. Furthermore, when different types of orphan carers were compared (*i.e.*, AIDS-orphan vs. other-orphan carers), AIDS-orphan carers tended to have a profile that was significantly different from other-orphan and non-orphan carers. Overall, patterns of distinction suggested that caring for orphans, particularly caring for AIDS-orphaned children was associated with demographic and socioeconomic disadvantage.

This chapter also provided additional details on the characteristics of children being cared for. Most of these children were related to carers through kinship. AIDS-orphaned children were more likely to be cared for by non-kin carers than other-orphaned and non-orphaned children. This may suggest a particular care pattern in communities facing high HIV prevalence. Data on the cause of parental deaths suggested that violence played a key role in the death of parents who died from non-

health causes. Subsequent chapters will explore whether the distinctive profile of orphan carers, and specifically AIDS-orphan carers is associated with certain health outcomes.

CHAPTER V RESULTS: HEALTH OUTCOMES

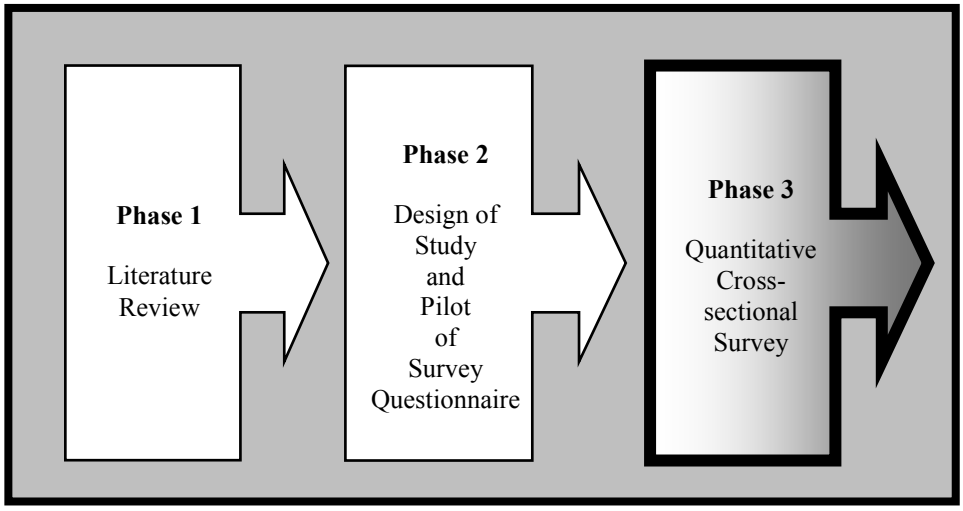

Figure 5.1: Quantitative Cross-sectional Survey

Summary

The primary objective of this chapter is to assess levels of general health and functioning, depression, anxiety, post-traumatic stress disorder, and alcohol use amongst of carers living in a high HIV prevalence community and identify whether health outcomes vary according to carer type. Health was a serious concern in this sample of carers. Overall, these carers had less than optimal health outcomes.

Comparisons of health outcomes showed significant differences amongst carer types. In general, orphan carers had significantly worse health than non-orphan carers. Further comparisons between AIDS-orphan, other-orphan, and non-orphan carers also showed significant differences in health outcomes. AIDS-orphan carers performed the worst in general health and functioning. Other-orphan carers performed the worst in depression and post-traumatic stress outcomes. While patterns were less clear when comparing AIDS-orphan and other-orphan carers, it is clear that as a whole, orphan carers face serious physical and mental health disparities.

The secondary objective of the chapter is to identify relationships between health outcomes and demographic, social, and economic characteristics. Exploring these relationships functions as a key step towards identify possible risk and protective factors for health outcomes. More detailed analyses of the risk and protective factors driving these differences in health outcomes amongst carer types will be explored through multiple regression analyses in subsequent chapters.

1. Introduction

This chapter addresses the second study question, "What is the self-reported physical and mental health of carers?" The chapter begins by detailing the data

analytical approach. Then three sections present data on general health and functioning, depression, anxiety, post-traumatic stress, alcohol and drug use in this overall, representative sample of carers and compares sub-group differences (*i.e.,* orphan vs. non-orphan carers; AIDS-orphan vs. other-orphan vs. non-orphan carers) for each health outcome. A sixth section analyzes bivariate relationships between health outcomes and social, economic, and demographic variables.

2. Analytical Approach

Question 2: What is the self-reported physical and mental health of carers?

Sub-question 2.1: Do health outcomes of other-orphaned and non-orphaned carers differ?
Sub-question 2.2: Do health outcomes of AIDS-orphaned, other-orphaned, and non-orphaned carers differ?
Sub-question 2.3: What is the association between health outcomes and demographic and socioeconomic variables?

All tests were two-tailed and statistical significance was set at $p<0.01$ level due to the number of analyses conducted. Trends at the $p<0.05$ level were also noted. Key study outcomes - general health and functioning (SF-36v2), anxiety (K10), depression (CES-D), post traumatic stress (HTQ), alcohol use (AUDIT), and drug use (DUDIT) - for the overall carer sample were reported using basic frequencies and means tests. SF-36v2 was analyzed as a continuous variable. HTQ was analyzed as a categorical variable. Kessler-10, CES-D, AUDIT, and DUDIT were analyzed both as continuous and categorical variables. CES-D, AUDIT, and DUDIT were analyzed dually as continuous and categorical variables because interpretation of significance using clinical cut-off scores (see ***Chapter III, Section 3.2.1*** for a discussion of clinical cut-off values) necessitated caution given that clinical thresholds had not been validated for

populations in South Africa. In addition, the shape of the distribution was assessed for continuous variables (SF-36v2, CES-D, AUDIT, and DUDIT). All variables were normally distributed unless otherwise indicated. If distributions were abnormal, additional measures of central tendency (median and mode), size of distribution (range), measures of dispersion (skewness and kurtosis) were also reported. If appropriate, abnormally distributed variables were transformed using z-scores. Distributions were categorized as normal if skewness and kurtosis values fell within +/-2.

Bivariate analyses compared differences in health outcomes between carer groups. Tests used for associations and comparisons included independent sample T-tests (Levene's Test), Chi-square tests (Pearson's test), and one-way ANOVAs. When ANOVA tests were used, additional post-hoc comparisons using Tukey comparisons were used to identify specific group differences. Analyses also explored associations between health outcomes and social, economic, and demographic variables. If variables were abnormally distributed (*i.e.,* number of people in the home and number of children in the home), z-transformations were used in analyses. Tests used for associations included independent sample T-tests (Levene's Test), Chi-square tests (Pearson's test), and one-way ANOVAs. Correlations were tested using simple linear regressions (Pearson's r). Multiple regressions, used to model variables that predict health outcomes, are presented in subsequent chapters.

3. Health Outcomes of the Overall Carer Sample

3.1 General Physical and Mental Health and Functioning

Carers had a mean SF-36v2 score of 71.76 (SD=17.66; range=9.38 to 99.00) on a 100-point scale, with higher scores indicating better health and functioning. Carers

had less than optimal general health and functioning, with an average SF-36v2 score falling in the third quartile of the scale. Analysis of SF-36v2 physical and mental health component scores showed that carers had worse mental than physical health. Carers had a mean physical health component score of 73.15 (SD=21.78; range=2.50 to 100.00). Carers had a mean mental health component score of 70.34 (SD=16.09; range=0 to 100.00).

3.2 Depression

Carers had a mean CES-D score of 12.53 (SD=9.75, range=0 to 60), falling below the threshold range for "clinically significant depression" as defined by the threshold of CES-D≥16. When CES-D was analyzed as a categorical variable, one-third of carers (30.33%) were classified as meeting the threshold criteria for clinically significant depression.

3.3 Anxiety

Carers had a mean K10 score of 20.40 (SD=6.68, range=10 to 50), falling within a score range for moderate anxiety as defined by the clinical threshold range of 16≤K10≤29. When analyzed as a categorical variable, over two-thirds of the sample met the threshold classification for

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Figure 5.2: Photo of Respondent during Interview

some level of anxiety; 63.78% were classified as meeting the clinical threshold range for moderate anxiety, defined by scores of 16≤K10≤29 and 8.83% were classified as meeting the threshold range for high anxiety, defined by scores of 30≤K10≤50.

3.4 Post-traumatic Stress Disorder

A number of carers experienced, witnessed, or heard of a potentially traumatic event happening to someone they knew (***Table 5.1***).

Table 5.1: Frequency of Potentially Traumatic Life Events (n=1597)

Type of Life Event	Carer Experienced Event	Carer Witnessed Event	Carer Heard of Event Happening to Someone	Sum Number of Events Experienced	Percentage of Event
Transport accident	103	92	435	630	39.45%
Natural disaster	204	99	228	531	33.25%
Unexpected death of a someone close	24	146	312	482	30.18%
Physical assault	105	136	269	510	31.93%
Assault by a weapon	55	66	353	474	29.68%
Fire or explosion	54	82	246	382	23.92%
Life threatening injury or illness	28	72	205	305	19.10%
Sudden or violent death	21	39	147	207	12.96%
Accident at work	28	25	149	202	12.65%
Sexual assault	24	5	143	172	10.77%
Exposure to war	21	14	57	92	5.76%
Uncomfortable sexual experience	12	5	53	70	4.38%
Another life threatening experience	5	11	42	58	3.63%
Captivity	4	0	47	51	3.19%
Serious injury, harm or death that you caused	2	2	26	30	1.88%

Only a small minority of carers who experienced a potentially traumatic life event were classified as meeting the threshold for post-traumatic stress disorder (PTSD) (2.30%) based on an algorithm of HTQ scores (see ***Chapter III, Section 3.2.1*** for calculation of algorithm).

3.5 Alcohol and Drug Use

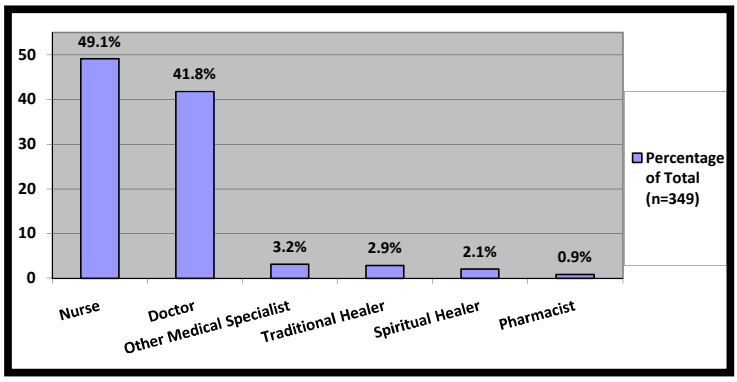
In regards to alcohol use, carers had a mean AUDIT score of 0.78 (SD=3.19, range=0 to 29), falling within the clinical threshold range of "no alcohol problems" as defined by AUDIT≤7. AUDIT scores were abnormally distributed (median=0, mode=0, skewness=5.19, kurtosis=29.49). Abnormal distribution was likely due to small sample size for this scale and variable transformation to z-scores was not conducted. Analysis of AUDIT as a categorical variable was more illustrative. A small percentage of carers met the threshold classification concerning alcohol use; 2.21 percent of carers met the clinical threshold criteria for "hazardous drinking" as defined by 8≤AUDIT≤15; 0.57 percent of carers met the clinical threshold criteria for "high levels of hazardous drinking" as defined by 16≤AUDIT≤19; and 1.01 percent of carers met the clinical threshold criteria for "likely to be alcohol dependent" as defined by 20≤AUDIT.

In regards to drug use, carers had a mean DUDIT score of 0.04 (SD=0.8, range=0 to 22), falling within the clinical threshold range for "no drug problems". DUDIT scores were abnormally distributed (median=0, mode=0, skewness=21.38, kurtosis=516.43) (***Graph 4.2***). Abnormal distribution was due to small sample numbers for this scale and variable transformation to z-scores was not conducted. Analysis of DUDIT as a categorical variable confirmed that a very small percentage of carers (0.04%) who met the clinical threshold criteria for "drug related problems" as defined by DUDIT≤6 for men and DUDIT≤2 for women. Further within group analysis of drug use was not conducted due to the low frequency of reported drug use.

3.6 Recent Illnesses and Access to Health Services

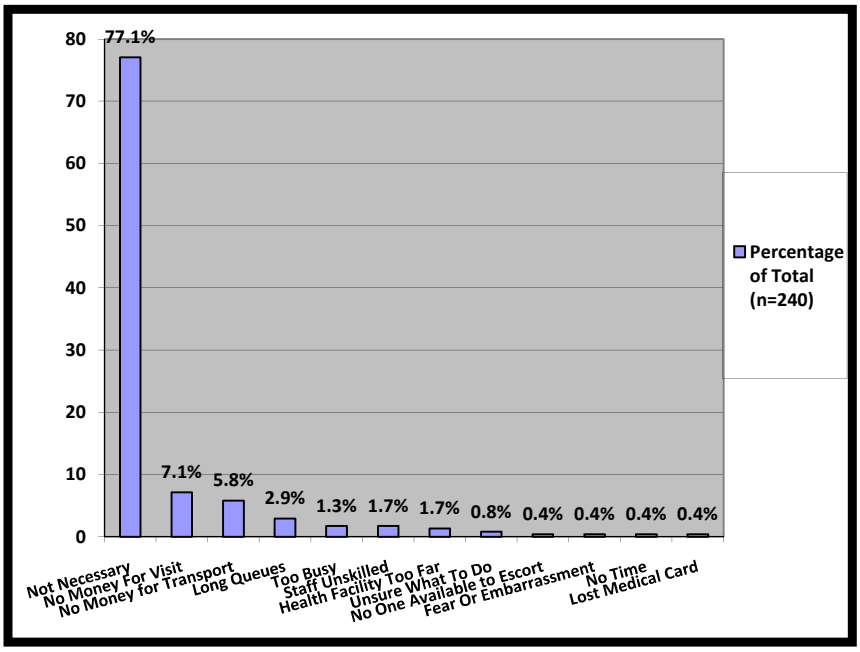
Approximately one-third of carers (36.19%) reported being ill in the month preceding the interview. The most commonly reported illnesses included flu (17.75%), arthritis (14.27%), high blood pressure (13.67%), and diabetes (11.27%). Of the carers who reported being ill in the past month, just over half (59.00%) visited a health practitioner in the past month. There were no significant differences in access patterns amongst carer groups. Carers were most likely to visit nurses and doctors for health needs (***Graph 4.1***).

Graph 5.1: Type of Health Practitioner Visited



Of the carers who did not visit a health practitioner (41.00%), the most common reason given was because a visit was unnecessary. The next most commonly cited reasons were lack of funds for service (7.08%) or transport (5.83%), suggesting that poverty may be a barrier to accessing health services (***Graph 5.2***).

Graph 5.2: Reasons for Not Visiting Health Practitioners



A summary of health outcomes for the overall carer sample is displayed in ***Table 5.2***.

Table 5.2: Frequencies for Health Outcomes for Overall Carer Sample (n=1599)

Health Outcome	Number in Sample and Percentage (N, %)	Mean (M), Standard Deviation (SD)
General health and functioning		
SF-36v2 total (n=1595)	--	71.76 (17.66)
SF-36v2 physical health and functioning (n=1596)	--	73.15 (21.78)
SF-36v2 mental health and functioning (n=1595)	--	70.34 (16.09)
Depression		
CES-D	--	12.53 (9.75)
CES-D Not depressed Clinical levels of depression	 1112 (69.67%) 484 (30.33%)	--
Anxiety		
K10	--	20.15 (6.51)
K10 No anxiety Moderate anxiety High anxiety	 438 (27.43%) 1018 (63.78%) 141 (8.83%)	--
Post traumatic stress disorder		
HTQ[2] No PTSD PTSD	 936 (97.70%) 22 (2.30%)	--
Alcohol use		
AUDIT	--	0.78 (3.19)
AUDIT No alcohol problems Hazardous drinking High hazardous drinking Alcohol dependence	 1526 (96.22%) 35 (2.21%) 9 (0.57%) 16 (1.01%)	--
Drug use		
DUDIT	--	0.04 (0.77)
DUDIT No drug dependence Drug dependence	 1589 (99.62%) 6 (0.38%)	--

Note: Both continuous and categorical summaries are presented for CES-D, K10, and AUDIT Column sums may not add to n=1599 due to missing values

[2] Valid responses for HTS measure is n=958

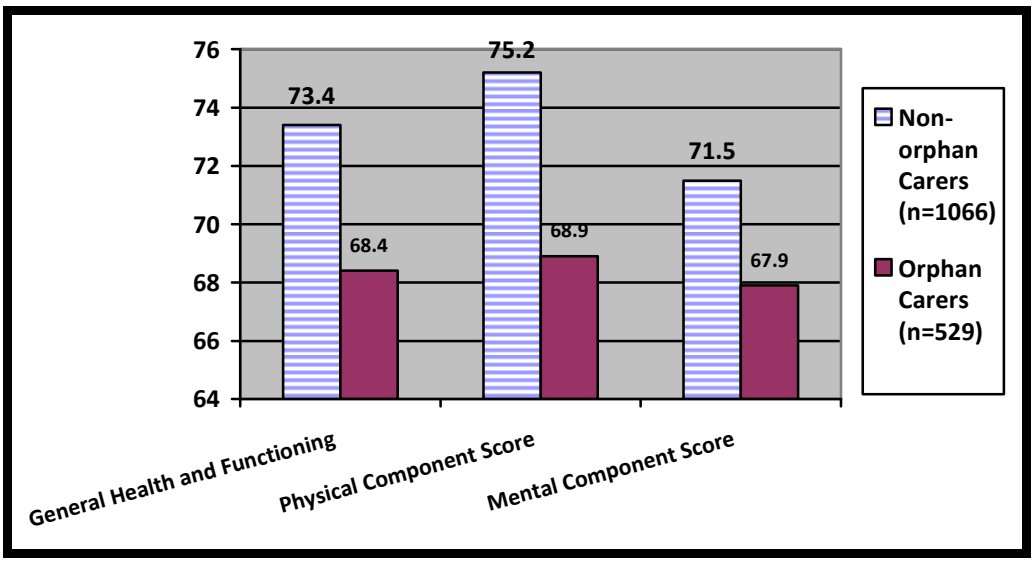
4. Health outcomes of Orphan vs. Non-orphan Carers

Orphan carers had significantly worse general health and functioning than non-orphan carers. Orphan carers were also more likely to experience depression and post-traumatic stress when compared to non-orphan carers.

4.1 General Physical and Mental Health and Functioning

Orphan carers had significantly poorer general health and functioning (SF-36v2 scores) (M=68.41, SD=19.02) than non-orphan carers (M=73.42, SD=16.70) ($p<0.01$). Analyses of SF-36v2 physical and mental health component scores showed similar patterns. Orphan carers had significantly poorer physical health component scores (M=68.90, SD=22.82) than non-orphan carers (M=75.25, SD=20.94) ($p<0.01$). Orphan carers also had significantly poorer mental health component scores (M=67.92, SD=17.40) than non-orphan carers (M=71.53, SD=15.26) ($p<0.01$) (***Graph 5.3***).

Graph 5.3: Orphan vs. Non-orphan Carer Differences in General Health and Functioning (Points on 100 Point Scale)



4.2 Depression

There were no significant differences in depression (CES-D scores) between orphan (M=13.22, SD=10.26) and non-orphan carers (M=12.19, SD=9.47) when analyzed as a continuous variable. However, analysis of CES-D as a categorical variable showed that orphan carers were significantly more likely to be classified as meeting the threshold criteria for clinically significant depression (35.16%) than non-orphan carers (27.93%) ($p<0.01$, $\chi 2=8.75$).

4.3 Anxiety

There were no significant differences in anxiety (K10 scores) between orphan (M=20.40, SD=6.68) and non-orphan carers (M=20.03, SD=6.43) when anxiety was analyzed as a continuous variable. Both groups had mean K10 scores which fell within the clinical threshold range for moderate anxiety. Similarly, when analyzed as a categorical variable, there were no significant differences in K10 scores between groups; 64.27% of orphan carers and 63.48% of non-orphan carers were classified as meeting the clinical threshold criteria for moderate anxiety; 9.83% of orphan carers and 8.33% of non-orphan carers were classified as meeting the clinical threshold criteria for high levels of anxiety.

4.4 Post-traumatic Stress Disorder

The post-traumatic stress tool (HTQ scores) showed that orphan carers were significantly more likely to be classified as meeting the clinical threshold criteria for PSTD (4.51%) than non-orphan carers (1.00%) ($p<0.01$, $\chi 2=12.28$).

4.5 Alcohol Use

There were no significant differences in alcohol use (AUDIT scores) between orphan (M=0.80 SD=3.13) and non-orphan carers (M=0.78, SD=3.24) when analyzed as a continuous variable. Similarly, when analyzed as a categorical variable, there were no significant differences between orphan and non-orphan carers; 2.67% of orphan and 2.99% of non-orphan carers met the clinical threshold criteria for "hazardous drinking"; 0.76% of orphan and 0.47% of non-orphan carers met the clinical threshold criteria for "high levels of hazardous drinking"; 0.57% of orphan and 1.23% of non-orphan carers met the clinical threshold criteria for "alcohol dependence".

A summary of orphan and non-orphan carer differences in health outcomes is found in ***Table 5.3***.

Table 5.3: Differences in Health Outcomes for Orphan versus Non-orphan Carers (n=1599)

Health Outcome	Carers of Orphaned Children (n=530)	Carers of Non-Orphaned Children (n=1069)	p[1]
General health and functioning			
SF-36v2 total (M, SD)	68.41 (19.02)	73.42 (16.70)	<.01
SF-36v2 physical health and functioning (M, SD)	68.90 (22.82)	75.25 (20.94)	<.01
SF-36v2 mental health and functioning(M, SD)	67.92 (17.40)	71.53 (15.26)	<.01
Depression			
CES-D (M, SD)	13.22 (10.259)	12.19 (9.473)	ns
CES-D (n, %)			<.01
Not depressed	343 (64.84%)	769 (72.07%)	
Clinical levels of depression	186 (35.16%)	298 (27.93%)	
Anxiety			
K10 (M, SD)	20.40 (6.68)	20.03 (6.43)	ns
K10 (n, %)			ns
No anxiety	137 (25.90%)	301 (28.18%)	
Moderate anxiety	340 (64.27%)	678 (63.48%)	
High anxiety	52 (9.83%)	89 (8.33%)	
Post traumatic stress disorder			
HTQ (n, %)			<.01
No PTSD	339 (95.49%)	597 (99.00%)	
PTSD	16 (4.51%)	6 (1.00%)	
Alcohol use			
AUDIT (M, SD)	0.80 (3.13)	0.78 (3.24)	ns
AUDIT (n, %)			ns
No alcohol problems	504 (96.00%)	1014 (96.30%)	
Hazardous drinking	14 (2.67%)	21 (1.99%)	
High hazardous drinking	4 (0.76%)	5 (0.47%)	
Alcohol dependence	3 (0.57%)	13 (1.23%)	

Note: Both continuous and categorical summaries are presented for CES-D, K10, and AUDIT. Column sums may not add to n=1599 due to missing values

[1] p-values associated with T-tests for continuous variables and chi-square tests for categorical variables

[2] Valid responses for HTS measure is n=958

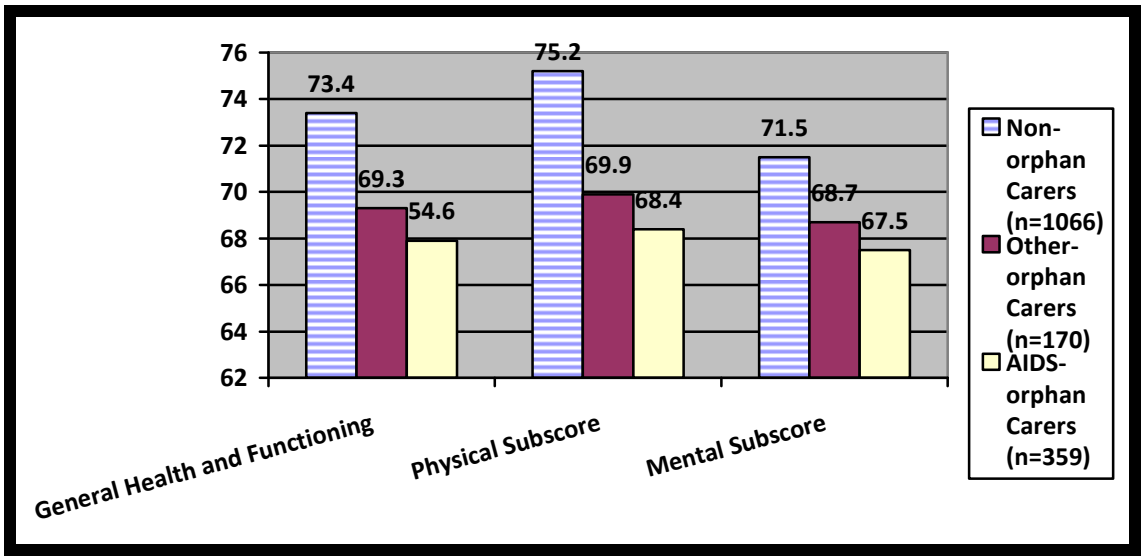
5. Health Outcomes of AIDS-orphan vs. Other-orphan vs. Non-orphan Carers

There were significant differences in health across groups. AIDS-orphan carers were more likely to experience worse general health and functioning than other groups. Other-orphan carers were significantly more likely to experience depression and post-traumatic stress than other groups.

5.1 General Physical and Mental Health and Functioning

There were significant differences in SF-36v2 scores across groups ($p<0.01$, $F=14.81$). AIDS-orphan carers had significantly poorer SF-36v2 scores ($M=67.98$, $SD=19.18$) than non-orphan carers ($M=73.42$, $SD=16.70$) ($p<0.01$). Analyses of SF-36v2 physical and mental health component scores showed similar patterns of difference across groups ($p<0.01$, $F=15.60$; $p<0.01$, $F=9.30$ respectively). AIDS-orphan carers had significantly poorer SF-36v2 physical health component scores ($M=68.40$, $SD=22.92$) than non-orphaned carers ($M=75.25$, $SD=20.94$) ($p<0.01$). Other-orphan carers had significantly poorer SF-36v2 physical health component scores ($M=69.96$, $SD=22.64$) than non-orphan carers ($M=75.25$, $SD=20.94$). AIDS-orphan carers had significantly poorer SF-36v2 mental health component scores ($M=67.55$, $SD=17.53$) than non-orphaned carers ($M=71.53$, $SD=14.26$) ($p<0.01$). In terms of overall SF-36v2 scores, there were no significant differences between other-orphan ($M=69.33$, $SD=18.72$) and non-orphan carers ($M=73.42$, $SD=16.70$). Similarly, in terms of SF-36v2 mental health component scores, there were no significant differences between other-orphan ($M=68.72$, $SD=17.17$) and non-orphaned carers ($M=71.53$, $SD=15.26$) (***Graph 5.4***).

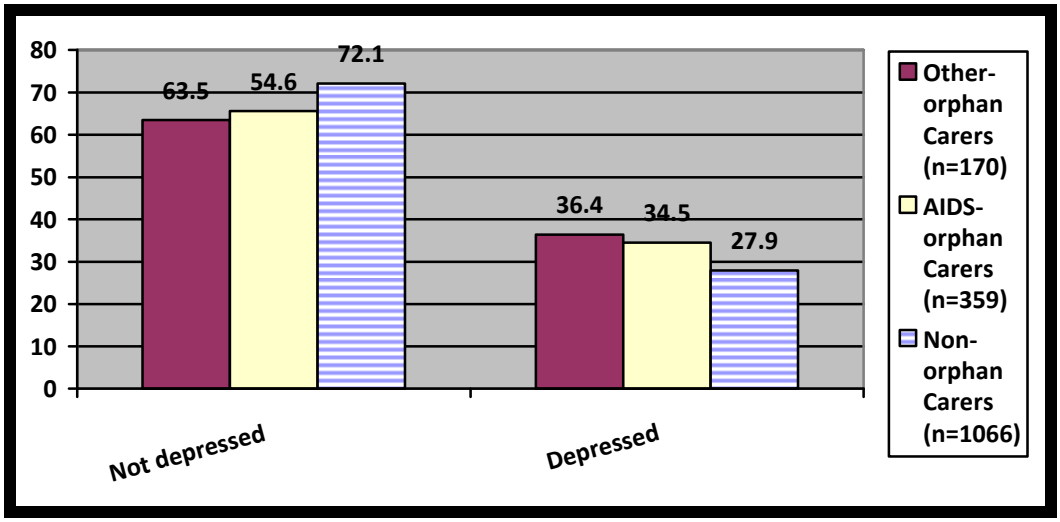
Graph 5.4: AIDS-orphan vs. Other-orphan vs. Non-orphan Carer Differences in General Health and Functioning (Points on 100 Point Scale)



5.2 Depression

There were no significant differences in mean CES-D scores between AIDS-orphan (M=12.83, SD=10.07), other-orphan (M=14.04, SD=10.63), and non-orphan carers (M=12.19, SD=9.47) when analyzed as a continuous variable. When treated as a categorical variable, trends suggested that higher percentages of other-orphan carers were classified as meeting the threshold criteria for "clinically significant levels of depression" (36.54%) followed by AIDS-orphan (34.54%) and non-orphan carers (27.93%) ($p=0.011$, $\chi 2=8.96$) (***Graph 5.5***).

Graph 5.5: AIDS-orphan vs. Other-orphan vs. Non-orphan Carer Differences in Depression (%)



5.3 Anxiety

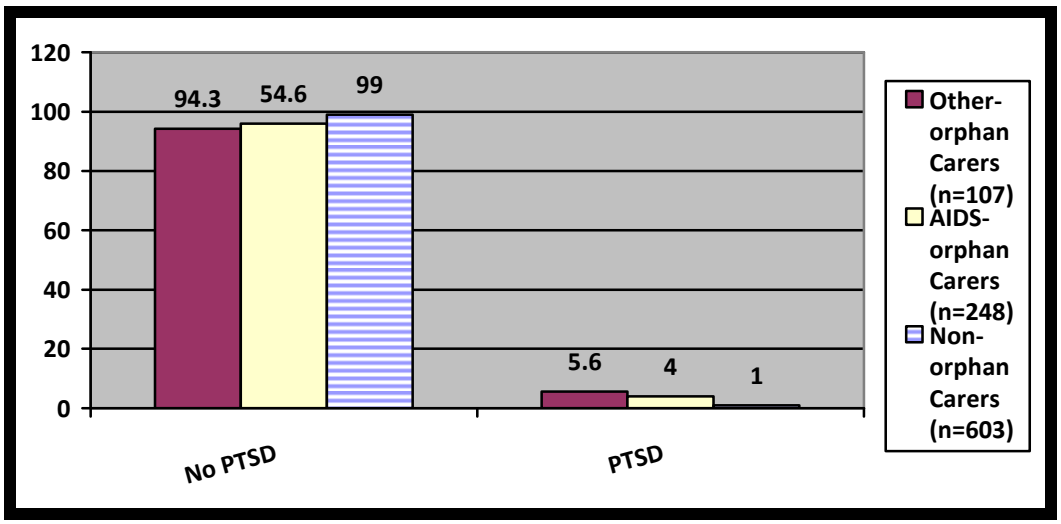
There were no significant differences in K10 scores between AIDS-orphan (M=20.24, SD=6.32), other-orphan (M=20.75, SD=7.40), and non-orphan carers (M=20.03, SD=6.43) when analyzed as a continuous variable. All three types of carers had mean K10 scores which fell in the clinical threshold criteria range of for moderate anxiety. Similarly, when analyzed as a categorical variable, there were no significant differences in K10 scores between groups; 64.35% of AIDS-orphan carers, 64.12% of non-orphan carers, and 63.48% of non-orphan carers were classified as meeting the clinical threshold criteria for moderate anxiety; 8.91% of AIDS-orphan carers, 11.76% of other-orphan carers, and 8.33% of non-orphan carers were classified as meeting the clinical threshold criteria for high levels of anxiety.

5.4 Post-traumatic Stress Disorder

There were significant differences in HTQ scores between AIDS-orphan, other-orphan, and non-orphan carers ($p<0.01$, $\chi 2=13.11$). Other-orphan carers had higher

proportions of carers classified as meeting the clinical threshold criteria for PTSD (5.61%) followed by AIDS-orphan (4.03%), and non-orphan carers (1.00%) (***Graph 5.6***).

Graph 5.6: AIDS-orphan vs. Other-orphan vs. Non-orphan Carer Differences in Post-traumatic Stress (%)



5.5 Alcohol Use

There were no significant differences in AUDIT scores between AIDS-orphan (M=0.87, SD=3.20), other-orphan (M=0.64, SD=2.98), and non-orphan carers (M=0.78, SD=3.24) when analyzed as a continuous variable. Similarly, when analyzed as a categorical variable, there were no significant differences between groups; 3.37% of AIDS-orphan, 1.18% of other-orphan, and 1.99% of non-orphan carers met the clinical threshold criteria for "hazardous drinking"; 0.84% of AIDS-orphan, 0.59% of other-orphan, and 0.47% of non-orphan carers met the clinical threshold criteria for "high levels of hazardous drinking"; 0.56% of AIDS-orphan, 0.59% of other-orphan, and 1.23% of non-orphan carers met the clinical threshold criteria for "alcohol dependence".

A summary of AIDS-orphan, other-orphan, and non-orphan carer differences in health outcomes are found in ***Table 5.4***.

Table 5.4: Differences in Health Outcomes amongst Carer Types (n=1599)

Health Outcome	Carers of AIDS-Orphaned Children (n=359)	Carers of Other-Orphaned Children (n=171)	Carers of Non-Orphaned Children (n=1069)	p[1]
General health and functioning				
SF-36v2 total (M, SD)	67.98 (19.18)	69.33 (18.72)	73.42 (16.70)	<.01
SF-36v2 physical health and functioning (M, SD)	68.40 (22.92)	69.96 (22.64)	75.25 (20.94)	<.01
SF-36v2 mental health and functioning (M, SD)	67.55 (17.53)	68.72 (17.17)	71.53 (15.26)	<.01
Depression				
CES-D (M, SD)	12.83 (10.07)	14.04 (10.63)	12.19 (9.47)	ns
CES-D (n, %)				<.01
Not depressed	235 (65.56%)	108 (63.53%)	759 (72.17%)	
Clinical levels of depression	124 (34.54%)	62 (36.47%)	298 (27.93%)	
Anxiety				
K10 (M, SD)	20.24 (6.32)	20.75 (7.40)	20.03 (6.43)	ns
K10 (n, %)				ns
No anxiety	96 (26.74%)	41 (24.12%)	301 (28.18%)	
Moderate anxiety	231 (64.35%)	109 (64.12%)	678 (63.48%)	
High anxiety	32 (8.91%)	20 (11.76%)	89 (8.33%)	
Post traumatic stress disorder				
HTS[2] (n, %)				<.01
No PTSD	238 (96.07%)	101 (94.39%)	597 (99.00%)	
PTSD	10 (4.03%)	6 (5.61%)	6 (1.00%)	
Alcohol use				
AUDIT (M, SD)	0.87 (3.20)	0.64 (2.98)	0.78 (3.24)	ns
AUDIT (n, %)				ns
No alcohol problems	339 (95.22%)	165 (97.63%)	1014 (96.30%)	
Hazardous drinking	12 (3.37%)	2 (1.18%)	21 (1.99%)	
High hazardous drinking	3 (0.84%)	1 (0.59%)	5 (0.47%)	
Alcohol dependence	2 (0.56%)	1 (0.59%)	13 (1.23%)	

Note: Both continuous and categorical summaries are presented for CES-D, K10, and AUDIT. Column sums may not add to 100% due to missing values

[1] p-values associated with one-way ANOVA for continuous variables and chi-square tests for categorical variables

[2] Valid responses for HTS measure is n=958

6. Bivariate Associations Between Demographic, Social, and Economic Variables and Health Outcomes

The following analyses identify potential risk and protective factors for health outcomes. Whether these factors function as risk and protective factors needs to be confirmed in further multivariate regression analyses (***see Chapter VI***).

6.1 General Physical and Mental Health and Functioning

Age

Age was inversely correlated with general health and functioning (SF-36v2 scores) ($r= -0.48$; $p<0.01$). As age increased, general health and functioning decreased. Further analyses of SF-36v2 physical and mental health component scores showed similar patterns. Age was inversely correlated with SF-36v2 physical health and functioning component scores ($r= -0.47$, $p<0.01$) and mental health and functioning component scores ($r= -0.41$, $p<0.01$).

Gender

Gender was significantly associated with SF-36v2 scores with females reporting worse general health and functioning ($M=71.00$, $SD=17.93$) than males ($M=76.77$, $SD=14.91$) ($p<0.01$). Additional analyses of SF-36v2 physical and mental health component scores showed similar patterns. Females reported worse physical health component scores ($M=72.14$, $SD=22.07$) than males ($M=79.67$, $SD=18.67$) ($p<0.01$). Females reported worse mental health component scores ($M=69.83$, $SD=16.29$) than males ($M=73.87$, $SD=14.03$) ($p<0.01$).

Education

Education was positively correlated with SF-36v2 ($r=0.40$; $p<0.01$). As education increased, general health and functioning improved. Additional analyses of SF36-v2 physical and mental health component scores showed similar patterns of significance ($r=0.39$, $p<0.01$ and $r=0.35$, $p<0.01$ respectively).

Social Support

Overall social support was positively correlated with SF-36v2 ($r=0.09$, $p<0.01$). As overall social support increased, general health and functioning improved. Additional analysis showed similar patterns of significance between overall social support and SF-36v2 physical health component scores ($r=0.12$, $p<0.01$). Overall social support and SF-36v2 mental health component scores were not correlated at $p<0.01$ level but showed trend associations ($r=0.05$, $p=0.05$).

Analyses suggest that certain support sources were more important for general health and functioning than others. Support from significant others was positively correlated with SF-36v2 ($r=0.08$, $p<0.01$). As support from significant others increased, general health and functioning improved. Social support from family and friends was not correlated with SF-36v2 at the $p<0.01$ level but showed trend associations ($r=0.06$, $p<0.013$; $r=0.06$, $p<0.016$ respectively). Analyses of support sources for physical and mental health showed additional patterns of significance. Support from family and significant others was positively correlated with SF-36v2 physical health component scores ($r=0.10$, $p<0.01$; $r=0.10$, $p<0.01$ respectively). Support from friends was not correlated with SF-36v2 physical health component scores at $p<0.01$ but showed trend associations ($r=0.06$, $p<0.017$). For SF-36v3 mental

health component scores, support from friends was not correlated with SF-36v2 mental health component scores at $p<0.01$ but showed trend associations ($r=0.06$, $p<0.03$). Interestingly, and in contrast to SF-36v2 physical health component scores, support from family and significant others was not significantly associated with SF-36v2 mental health component scores.

Number of Children in Household

The number of children per household was inversely correlated with SF-36v2 ($r= -0.08$, $p<0.01$). As the number of children in the household increased, general health and functioning worsened. Analysis of SF-36v2 physical health component scores showed similar patterns of inverse correlation ($r= -0.09$, $p<0.01$). The number of children in the household was not correlated with SF-36v2 mental health component scores at $p<0.01$ but showed trend associations ($r= -0.05$, $p<0.05$).

Number of Persons in Household

The number of persons per household, was inversely correlated with SF-36v2 ($r= -0.09$, $p<0.01$). As the number of individuals increased in the household, SF-36v2 scores worsened. Analysis of SF-36v2 physical health component scores showed similar patterns of inverse correlation ($r= -0.10$, $p<0.01$). Number of persons in the household and SF-36v2 mental health component scores were not correlated at $p<0.01$ level but showed trend associations ($r= -0.06$, $p<0.02$).

Dwelling Type

Dwelling type was not significantly associated with SF-36v2 scores or SF-36v2 physical health component scores. Trends suggested that dwelling type was associated

with SF-36v2 mental health component scores; carers living in informal dwellings had worse SF-36v2 mental component scores (M=69.58, SD=16.84) than carers living in formal dwellings (M=71.20, SD=15.14) ($p<0.04$).

Economic Asset Index and Main Source of Household Income

Economic asset index scores were positively correlated with SF-36v2 ($r=0.15$, $p<0.01$). As economic index scores increased – indicative of higher economic status – general health and functioning improved. Analyses of SF-36v2 physical and mental health component scores showed similar patterns of significance ($r=0.16$, $p<0.01$; $r=0.11$, $p<0.01$ respectively).

Analyses of primary sources of income suggested that carers dependent on salaries/wages as the main source of income had significantly better SF-36v2 scores (M=75.68, SD=14.57) than carers not dependent on salaries/wages (M=64.53, SD=20.38) ($p<0.01$). In contrast, carers dependent on pensions/grants as the main source of income had significantly worse SF-36v2 scores (M=63.04, SD=20.75) than carers not dependent on pensions/wages (M=75.10, SD=15.04) ($p<0.01$). Trends suggested that carers with no income had worse SF-36v2 scores (M=60.55, SD=16.79) than other carers (M=71.84, SD=17.64) ($p<0.04$). Analysis of SF-36v2 physical health component scores showed similar patterns of significance. Carers dependent on salaries/wages as the main source of income had significantly better SF-36v2 physical health component scores (M=77.87, SD=18.53) than carers not dependent on salaries/wages (M=64.44, SD=24.49) ($p<0.01$). In contrast, carers dependent on pensions/grants as the main source of income had significantly worse SF-36v2 physical health component scores (M=62.88, SD=25.03) than carers not dependent on pensions/grants (M=77.08, SD=18.99) ($p<0.01$). Analysis of SF-36v2 mental health

component scores showed similar patterns of significance. Carers dependent on salaries/wages as the main source of income had significantly better SF-36v2 mental health component scores (M=73.44, SD=13.64) than carers not dependent on salaries/wages (M=64.62, SD=18.51) ($p<0.01$). In contrast, carers dependent on pensions/grants as the main source of income had significantly worse SF-36v2 mental health component scores (M=63.21, SD=18.65) than carers not dependent on pensions/grants (M=73.07, SD=14.07) ($p<0.01$). Trends suggested that carers with no income had worse SF-36v2 scores (M=60.00, SD=19.71) than carers with income (M=70.41, SD=16.04) ($p<0.04$).

Household Receipt of Grants and Carer Receipt of Grants

Analyses of the number of grants received per household showed several patterns of significance. The number of old age pension and disability grants received in households was positively correlated with SF-36v2 ($r= -0.21$, $p<0.01$; $r= -0.16$, $p<0.01$ respectively). Carers with higher numbers of old age pensions or disability grants in their households were more likely to have poorer health and functioning. The number of foster care grants and government housing subsidies received per household were not correlated with SF-36v2 at $p<0.01$ level but showed trend associations ($r= -0.05$, $p<0.04$; $r=0.05$, $p=0.05$ respectively). Analysis of SF-36v2 physical health component scores showed similar patterns; the number of old age pensions and disability grants received per household was inversely correlated to SF-36v2 physical health component scores ($r= -0.22$, $p<0.01$; $r= -0.16$, $p<0.01$ respectively). The number of foster care grants and government housing subsidies received per household were not correlated with SF-36v2 physical health component scores at $p<0.01$ level but showed trend associations ($r= -0.06$, $p<0.02$; $r=0.06$, $p<0.018$ respectively). Analysis

of SF-36v2 mental health component scores showed similar patterns; the number of old age pensions and disability grant received in households was inversely correlated with SF-36v2 mental health component scores ($r= -0.16$, $p<0.01$; $r= -0.13$, $p<0.01$ respectively).

Analyses were also conducted on carers' personal receipt of grants. Carers receiving the old age pension were significantly more likely to have poorer SF-36v2 scores (M=54.04, SD=18.76) than carers not receiving the pension (M=73.68, SD=16.45) ($p<0.01$). Similarly, carers receiving the disability grant were significantly more likely to have poorer SF-36v2 scores (M=58.29, SD=19.72) than carers without the grant (M=72.45, SD=17.29) ($p<0.01$). Trends also suggested that carers receiving the government housing subsidy had better SF-36v2 scores (M=73.63, SD=15.42) than carers without the subsidy (M=71.70, SD=17.75) ($p<0.04$). Further analysis of SF-36v2 physical component scores showed similar patterns of association. Carers receiving the old age pension were significantly more likely to have poorer SF-36v2 component scores (M=50.65, SD=22.64) than carers without the pension (M=75.58, SD=20.29) ($p<0.01$). Carers receiving the disability grant were significantly more likely to have poorer SF-36v2 component scores (M=56.65, SD=23.72) than carers without the grant (M=73.98, SD=21.38) ($p<0.01$). Further analysis of SF-36v2 mental health component scores showed similar patterns. Carers receiving the old age pension were significantly more likely to have poorer SF-36v2 mental health component scores (M=57.43, SD=16.87) than carers without the pension (M=71.75, SD=15.35) ($p<0.01$). Carers receiving the disability grant were significantly more likely to have poorer SF-36v2 mental health component scores (M=59.93, SD=17.91) than carers without the grant (M=70.88, SD=15.79) ($p<0.01$). These associations between receipt of the disability grant and poor health outcomes may be indicative of grants reaching those

with disabilities; the associations between receipt of the old age pension and poorer health outcomes may be indicative of individuals with poor health having a higher likelihood of receiving grants. Additional data is needed to determine the causal relationship between these factors.

A summary of associations between demographic, social and economic variables and general health and functioning is found in ***Table 5.5***.

Table 5.5: Bivariate Associations between Demographic, Social, and Economic Factors and General Health and Functioning

Demographic, Social, and Economic Variables	SF-36v2 Overall Score (n=1592)		SF-36v2 Physical Health Subscore (n=1596)		SF-36v2 Mental Health Subscore (n=1595)	
	Correlation coefficient or Mean and Standard Deviation	p[1]	Correlation coefficient or Mean and Standard Deviation	p	Correlation coefficient or Mean and Standard Deviation	p
Age (r)	-0.48	<.01	-0.47	<.01	-0.41	<.01
Gender (M, SD)		<.01		<.01		<.01
Male	76.77 (14.91)		79.67 (18.67)		73.87 (14.03)	
Female	71.00 (17.93)		72.14 (22.07)		69.83 (16.29)	
Education (r)	0.40	<.01	0.39	<.01	0.35	<.01
Social support (r)	0.09	<.01	0.12	<.01	0.05	<.05
Family support	0.06	<.013	0.10	<.01	--	ns
Friend support	0.06	<.016	0.06	<.017	0.06	<.03
Significant others support	0.08	<.01	0.10	<.01	--	ns
Number of children in household (r)	-0.08	<.01	-0.09	<.01	-0.05	=.05
Number of persons in household (r)	-0.09	<.01	-0.10	<.01	-0.06	<.02
Dwelling type (M, SD)		ns		ns		<.04
Informal dwelling	71.44 (18.24)		73.25 (22.09)		69.58 (16.84)	
Formal dwelling	72.12 (16.97)		73.03 (21.43)		71.20 (15.14)	
Economic asset index (r)	0.15	<.01	0.16	<.01	0.11	<.01
Main source of income (M, SD)						
Salaries/wages		<.01		<.01		<.01
Yes	75.68 (14.57)		77.87 (18.53)		73.44 (13.64)	
No	64.53 (20.38)		64.44 (24.49)		64.62 (18.51)	
Pensions/grants		<.01		<.01		<.01
Yes	63.04 (20.75)		62.88 (25.03)		63.21 (18.65)	
No	75.10 (15.04)		77.08 (18.99)		73.07 (14.07)	
Other income		ns		ns		ns
Yes	70.43 (17.24)		69.94 (21.52)		70.91 (15.80)	
No	71.82 (17.68)		73.30 (21.78)		70.30 (16.10)	
Remittances		ns		ns		ns

Demographic, Social, and Economic Variables	SF-36v2 Overall Score (n=1592)		SF-36v2 Physical Health Subscore (n=1596)		SF-36v2 Mental Health Subscore (n=1595)	
Yes	72.28 (19.44)		73.82 (22.39)		70.74 (18.39)	
No	71.75 (17.62)		73.13 (21.77)		70.33 (16.04)	
No Income		<.04		ns		<.03
Yes	60.55 (16.79)		61.11 (17.33)		60.00 (19.71)	
No	71.84 (17.64)		73.23 (21.79)		70.41 (16.04)	
Frequency of grants received in household (r)						
Old age pension	-0.21	<.01	-0.22	<.01	-0.16	<.01
Disability grant	-0.16	<.01	-0.16	<.01	-0.13	<.01
Government housing subsidy	0.05	=.05	0.06	<.018	--	ns
Child support grant	--	ns	--	ns	--	ns
Foster care grant	-0.052	<.04	-0.06	<.02	--	ns
Carer receipt of grants (M, SD)						
Old age pension		<.01		<.01		<.01
Yes	54.04 (18.76)		50.65 (22.64)		57.43 (16.87)	
No	73.68 (16.45)		75.58 (20.29)		71.75 (15.35)	
Disability grant		<.01		<.01		<.01
Yes	58.29 (19.72)		56.65 (23.72)		59.93 (17.91)	
No	72.45 (17.29)		73.98 (21.38)		70.88 (15.79)	
Government housing subsidy		<.04		ns		ns
Yes	73.63 (15.42)		76.58 (20.00)		70.69 (13.98)	
No	71.70 (17.75)		73.01 (21.87)		70.35 (16.15)	

Note: Column sums may not add to n=1599 due to missing values

[1] ***p*-values associated with linear regressions and t-tests for continuous variables**

6.2 Depression

Age

Age was positively correlated with depression (CES-D) as a continuous variable ($r=0.17$, $p<0.01$). As age increased, CES-D scores worsened. Further analysis of CES-D as a categorical variable confirmed these patterns. Individuals who met the threshold criteria for clinically significant depression were older ($M=42.67$, $SD=15.11$) than individuals who fell below the threshold criteria for clinically significant depression ($M=37.98$, $SD=42.67$) ($p<0.01$).

Gender

Gender was significantly associated with CES-D as a continuous variable. Females had worse CES-D scores ($M=12.74$, $SD=9.92$) than males ($M=11.02$, $SD=8.40$) ($p<0.01$). However, further analysis of CES-D as a categorical variable showed that females were equally likely to meet the threshold criteria for clinically significant depression (31.03%) as males (24.88%).

Education

Education was inversely correlated with CES-D as a continuous variable ($r= -0.18$, $p<0.01$). As education increased, CES-D scores improved. Analysis of CES-D as a categorical variable confirmed this pattern. Individuals who met the threshold criteria for clinically significant depression were significantly less educated ($M=9.35$, $SD=41.14$) than individuals who fell below the threshold criteria for clinically significant depression ($M=11.06$, $SD=3.60$) ($p<0.01$).

Social Support

Overall social support was not significantly correlated with CES-D as a continuous variable. Analysis of specific support categories showed no significant correlations between various support sources and CES-D. Support from friends was not correlated with CES-D scores at the $p<0.01$ level but showed trend associations ($r=0.05$, $p<0.04$). Further analysis of CES-D as a categorical variable confirmed no significant correlation between social support and CES-D.

Number of Children in Household

The number of children per household was not significantly correlated with CES-D as a continuous variable. Similarly, analysis of CES-D as a categorical variable showed no significant associations. The number of children in households where carers met the threshold criteria for clinically significant depression (M=0.02, SD=1.01) was similar to the number of children in households where carers fell below the threshold criteria (M=0.02, SD=0.98).

The image originally presented here has been removed.

Figure 5.3: Photo of Children Playing in the Fieldwork Community

Number of Persons in Household

The number of people per household was not correlated with CES-D scores. Analysis of CES-D as a categorical variable confirmed these patterns. There were no significant association between the number of people living in households and carers meeting the threshold criteria for clinically significant depression (M= -0.00, SD=1.02) compared to carers falling below the threshold criteria (M=0.00, SD=0.99).

Dwelling Type

In terms of dwelling types, analysis of CES-D as a continuous variable showed carers living in informal dwellings were significantly more likely to have poor CES-D scores (M=13.46, SD=10.57) than carers living in formal dwelling (M=11.47, SD=8.60) ($p<0.01$). Analysis of CES-D as a categorical variable showed similar patterns. Carers in formal dwellings were significantly less likely to be depressed (25.37%) than carers living in informal dwellings (34.67%) ($p<0.01$, $\chi 2=16.24$).

Economic Asset Index and Main Source of Household Income

Economic asset index scores were inversely correlated with CES-D as a continuous variable ($r= -0.18$, $p<0.01$). As economic status improved, depression lessened. Further analysis of CES-D as a categorical variable confirmed this pattern. Carers meeting the threshold criteria for clinically significant depression had poorer economic asset index scores (M= -0.12, SD=0.80) than carers falling below the threshold criteria (M= 0.12, SD=0.59) ($p<0.01$). Analysis of primary sources of income suggested that carers dependent on salaries/wages as the main source of household income had significantly better CES-D scores (M=11.25, SD=8.12) than carers not dependent on salaries/wages (M=14.90, SD=10.89) ($p<0.01$). Carers with no

income had significantly worse CES-D scores (M=24.09, SD=9.22) than carers with income (M=12.45, SD=9.71) ($p<0.01$). Carers dependent on pensions/grants as the main source of household income had significantly worse CES-D scores (M=15.55, SD=11.12) than carers with not dependent on pensions/grants (M=11.38, SD=8.91) ($p<0.01$).

An analysis of CES-D as a categorical variable showed similar patterns of significance. Carers dependent on salaries/wages as the main source of household income were significantly less likely to meet the threshold criteria for clinically significant depression (24.64%) than carers not dependent on salaries/wages (40.82%) ($p<0.01$, $\chi 2=45.09$). Carers with no source of income were more likely to meet the threshold for clinically significant depression (81.82%) than carers with some income (29.97%) ($p<0.01$, $\chi 2=13.90$). Carers dependent on pensions/grants as the main source of household income were significantly more likely to meet the threshold criteria for clinically significant depression (43.21%) than carers not dependent on pensions/grants (25.39%) ($p<0.01$, $\chi 2=48.05$).

Household Receipt of Grants and Carer Receipt of Grants

Analyses were run on the number of grants received in households and CES-D as a continuous variable. Trends suggested that higher numbers of disability grants was positively correlated with CES-D scores ($r=0.06$, $p<0.013$). As the number of disability grants increased in the household, the likelihood of depression increased. Analyses of the other grants and CES-D scores showed no other significant correlations. Further analysis of CES-D as a categorical variable showed no significant association between the number of grants received in carer households and depression.

Analyses were also conducted on carers' personal receipt of grants. Carers receiving the old age pension were significantly more likely to have poorer CES-D scores (M=14.80, SD=10.57) than carers without the old age pension (M=12.27, SD=9.63) ($p<0.01$). Similarly, carers receiving the disability grant were significantly more likely to have poorer CES-D scores (M=15.74, SD=11.94) than carers without the disability grant (M=12.36, SD=9.60) ($p<0.01$). However, analysis of CES-D as a categorical variable showed differing patterns. There was no association between carers' personal receipt of grants and CES-D scores. Trends did suggest that carers receiving the old age pension were more likely to meet the threshold criteria for clinical depression (37.66%) than those without the old age pension (29.44%) ($p<0.04$, $\chi 2=4.46$).

A summary of associations between demographic, social and economic variables and depression is found in ***Table 5.6***.

Table 5.6: Bivariate Associations between Demographic, Social, and Economic Factors and Depression (n=1599)

Demographic, Social, and Economic Variables	CES-D (numerical) (n=1596)		CES-D (categorical) (n=1596)	
	Correlation coefficient or Mean and Standard Deviation	p[1]	Mean and Standard Deviation or N, %	p
Age	0.17	<.01	Not depressed, 37.98 (42.67) Depressed, 42.67 (15.11)	<.01
Gender		<.01		ns
Male	11.02 (8.40)		Not depressed, 163 (75.12%) Depressed, 54 (24.88%)	
Female	12.74 (9.92)		Not depressed, 949 (70.51%) Depressed, 427 (31.03%)	
Education	-0.23	<.01	Not depressed, 11.06 (3.60) Depressed, 9.35 (4.14)	<.01
Social support	--	ns	Not depressed, 63.55 (12.65) Depressed, 63.87 (14.43)	ns
Family support	--	ns	Not depressed, 22.99 (5.00) Depressed, 22.65 (5.75)	ns
Friend support	0.05	<.04	Not depressed, 17.17 (8.09) Depressed, 17.92 (8.44)	ns
Significant others support	--	ns	Not depressed, 23.40 (4.80) Depressed, 23.30 (4.88)	ns
Number of children in household	--	ns	Not depression, 2.53 (1.63) Depression, 2.53 (1.57)	ns
Number of persons in household	--	ns	Not depressed, 5.51 (2.58) Depressed, 5.51 (2.66)	ns
Dwelling type		<.01		<.01
Informal dwelling	13.46 (10.57		295 (34.67%)	
Formal dwelling	11.47 (8.60)		189 (25.37%)	
Economic asset index	-0.18	<.01	Not depressed, 0.12 (0.59) Depressed, -0.12 (0.80)	<.01
Main source of income				
Salaries/wages		<.01		<.01
Yes	11.25 (8.82)		Not depressed, 255 (24.64%)	
No	14.90 (10.89)		Depressed, 229 (40.82%)	

Demographic, Social, and Economic Variables	CES-D (numerical) (n=1596)		CES-D (categorical) (n=1596)	
Pensions/grants		<.01		<.01
Yes	15.55 (11.12)		Not depressed, 191 (43.21%)	
No	11.38 (8.91)		Depressed, 293 (25.39%)	
Other income		ns		ns
Yes	10.57 (8.72)		Not depressed, 18 (24.32%)	
No	12.63 (9.79)		Depressed, 466 (30.62%)	
Remittances		ns		ns
Yes	12.91 (9.29)		Not depressed, 11 (32.35%)	
No	12.52 (9.76)		Depressed, 473 (30.28%)	
No Income		<.01		<.01
Yes	24.09 (9.22)		Not depressed, 9 (81.82%)	
No	12.45 (9.71)		Depressed, 475 (29.97%)	
Frequency of grants received in household				
Old age pension	--	ns	Not depressed, 0.17 (0.44) Depressed, 0.18 (0.43)	ns
Disability grant	0.06	<.013	Not depressed, 0.08 (0.27) Depressed, 0.11 (0.32)	ns
Government housing subsidy	--	ns	Not depressed, 0.05 (0.27) Depressed, 0.04 (0.20)	ns
Child support grant	--	ns	Not depressed, 1.54 (1.40) Depressed, 1.43 (1.38)	ns
Foster care grant	--	ns	Not depressed, 0.05 (0.28) Depressed, 0.05 (0.28)	ns
Carer receipt of grants				
Old age pension		<.01		<.04
Yes	14.80 (10.57)		Not depressed, 58 (37.66%)	
No	12.27 (9.63)		Depressed, 423 (29.44%)	
Disability grant		<.01		ns
Yes	15.74 (11.94)		Not depressed, 29 (38.67%)	
No	12.36 (9.60)		Depressed, 452 (29.82%)	
Government housing subsidy		ns		ns
Yes	10.82 (7.96)		Not depressed, 16 (24.24%)	
No	12.59 (9.81)		Depressed, 465 (30.49%)	

Note: Column sums may not add to n=1599 due to missing values

[1] *p*-values associated with linear regressions and t-tests for continuous variables and chi-square tests for categorical variables

6.3 Anxiety

Age

Age was positively correlated with anxiety (K10) as a continuous variable ($r=0.20$, $p<0.01$). As age increased, K10 scores worsened. Analysis of K10 as a categorical variable confirmed that age was significantly associated with anxiety ($p<0.01$, $F=25.61$). Additional post-hoc Tukey tests showed that individuals falling within the clinical threshold of low or no risk for anxiety (defined as $10\leq K10\leq 15$) were significantly younger than those meeting the clinical threshold for moderate anxiety (defined as $16\leq K10\leq 29$) ($p<0.01$) and those meeting the clinical threshold for high anxiety (defined as $30\leq K10\leq 50$) ($p<0.01$). Similarly, individuals meeting the clinical threshold for moderate anxiety were significantly younger than those meeting the clinical threshold for high anxiety ($p<0.01$).

Gender

Gender was significantly associated with K10 as a continuous variable ($p<0.01$). Females were significantly more likely to have worse K10 scores ($M=20.31$, $SD=6.51$) than males ($M=18.99$, $SD=6.26$) ($p<0.01$). Analysis of K10 as a categorical variable displayed no significant associations between gender and K10 at $p<0.01$. However, trends suggested that females were more likely to meet the clinical threshold for moderate or high anxiety (73.86%) compared to males (64.05%) ($p=0.011$, $\chi 2=9.04$).

Education

Education was inversely correlated with K10 as a continuous variable (r= -0.24, p<0.01). Carers with more education had better K10 scores. Analysis of K10 as a categorical variable confirmed this association (p<0.01, F=32.73). Additional post-hoc Tukey tests confirmed that individuals meeting the clinical threshold criteria for no or low anxiety had significantly higher levels of education than those meeting the clinical threshold criteria for moderate anxiety (p<0.01) and high anxiety (p<0.01). Similarly, individuals meeting the clinical threshold criteria for moderate anxiety had significantly higher levels of education than those meeting the clinical threshold criteria for high anxiety (p<0.01).

Social Support

Overall social support was not correlated with K10 as a continuous variable at the p<0.01 levels but trends suggested high levels of social support were related to poorer K10 scores (r=0.06, p<0.014). The direction of the correlation was surprising; carers with more overall support were more likely to be anxious. Analyses of various types of support showed that only one category – support from friends – was directly correlated to K10 scores (r=0.09, p<0.01). Analysis of K10 as a categorical variable showed additional patterns of significance. Overall social support was significantly associated with K10 scores (p<0.01, F=6.80). Addition post-hoc Tukey tests showed that individuals meeting the clinical threshold criteria for no or low anxiety were significantly less likely to have support than those meeting the clinical threshold criteria for moderate anxiety (p<0.01). In terms of specific types of support, support from friends was significantly associated with K10 scores (p<0.01, F=5.71). Additional post-hoc tests showed that individuals meeting the clinical threshold criteria

for no or low anxiety were significantly less likely to receive support from friends than individuals meeting the clinical threshold criteria for moderate anxiety ($p<0.01$). Trends also suggested that support from family members was associated with K10 scores ($p<0.04$, $F=3.14$).

Number of Children in Household

The number of children in the household was not correlated or associated with K10 scores.

Number of Persons in Household

The number of people in the household was not correlated or associated with K10 scores.

Dwelling Type

Carers living in informal dwellings had similar K10 scores ($M=20.38$, $SD=6.78$) to carers living in formal dwellings ($M=19.89$, $SD=6.18$). Analysis of K10 as a categorical variable showed no additional patterns of significance.

Economic Asset Index and Main Source of Household Income

Economic asset index scores were inversely correlated with K10 as a continuous variable ($r= -0.16$, $p<0.01$). As economic asset index scores improved, levels of anxiety decreased. Analysis of K10 as a categorical variable confirmed that economic asset index scores were significantly associated with K10 scores ($p<0.01$, $F=24.86$). Additional post-hoc Tukey tests showed that individuals meeting the clinical threshold criteria for no or low anxiety had significantly better economic asset index

scores than those meeting the clinical threshold criteria for high anxiety ($p<0.01$). Similarly, individuals meeting the clinical threshold criteria for moderate anxiety had significantly better economic asset index scores than those meeting the clinical threshold criteria for high anxiety ($p<0.01$).

Analyses of primary sources of income suggested that carers dependent on salaries/wages for the main source of household income were significantly more likely to experience better K10 scores (M=19.25, SD=6.02) than carers not dependent on salaries/wages (M=21.81, SD=7.05) ($p<0.01$). Similarly, carers with some source of income were significantly more likely to have better K10 scores (M=20.10, SD=6.48) than carers with no income (M=27.73, SD=6.93) ($p<0.01$). In contrast, carers dependent on pensions/grants as the main source of household income were significantly more likely to have poorer K10 scores (M=22.36, SD=7.06) than carers not dependent on pensions/grants (M=19.31, SD=6.09) ($p<0.01$). There were no significant associations between other types of income sources and K10 scores. However, trends suggested that carers dependent on other types of income as the main source of household income had better K10 scores (M=18.77, SD=5.62) than carers not dependent on other types of income (M=20.22, SD=6.55) ($p<0.04$). Analysis of K10 as a categorical variable largely confirmed patterns of significance.

There were significant associations between sources of income and K10 ($p<0.01$, $\chi 2=35.45$). Carers dependent on salaries/wages as the main source of income were significantly more likely to meet the clinical threshold criteria for no or low anxiety (30.50%) than carers not dependent on salaries/wages (21.75%). Carers dependent on salaries/wages as the main source of household income were significantly less likely to meet the clinical threshold criteria for moderate anxiety (63.42%) than

carers not dependent on salaries/wages (64.35%). Carers dependent on salaries/wages as the main source of household income were significantly less likely to meet the clinical threshold criteria for high anxiety (6.08%) than carers not dependent on salaries/wages (13.90%). There were significant associations between carers dependent on pensions/grants as the main source of income and K10 ($p<0.01$, $\chi2=49.99$). Carers dependent on pensions/grants as the main source of income were significantly less likely to meet the clinical threshold criteria for no or low anxiety (19.00%) than carers not dependent on pensions/grant (30.65%). Carers dependent on pensions/grants as the main source of household income were significantly more likely to meet the clinical threshold criteria for moderate anxiety (65.16%) than carers not dependent on pension/grants (63.20%). Carers dependent on pensions/grants as the main source of household income were significantly more likely to meet the clinical threshold criteria for high anxiety (15.84%) than carers not dependent on pensions/grants. There were no significant associations between other sources of income and K10 at the $p<0.01$ level but trends suggested that these variables are related ($p<0.04$, $\chi2=6.59$). These trends showed that carers dependent on other sources of income as the main source of household income were more likely to meet the clinical threshold criteria for no or low anxiety (37.84%) than carers not dependent on this type of income (26.92%). Carers dependent on other sources of income as the main source of household income were less likely to meet the clinical threshold criteria for moderate anxiety (59.46%) than carers not dependent on this income (63.95%). Carers dependent on other sources of income as the main source of household income were less likely to meet the threshold criteria for high anxiety (2.70%) than carers not dependent on this income (9.13%).

Household Receipt of Grants and Carer Receipt of Grants

The number of disability grants received by carer households was positively correlated with K10 as a continuous variable ($r=0.10$, $p<0.01$). Analysis of K10 as a categorical variable showed no significant associations between the number of grants received in carer households and K10. However, trends suggested that the number of disability grants received in households was related to K10 ($p<0.012$, $F=4.46$). In terms of carer personal receipt of grants, those receiving the old age pension were significantly more likely to have poorer K10 scores ($M=22.53$, $SD=7.10$) than carers without the old age pension ($M=19.88$, $SD=6.38$) ($p<0.01$). Carers receiving the disability grant were significantly more likely to have worse K10 scores ($M=23.36$, $SD=7.29$) than carers without disability grants ($M=19.97$, $SD=6.41$) ($p<0.01$). Analysis showed a significant association between the old age pension and K10 scores ($p<0.01$ $\chi 2=17.83$). Carers with old age pensions were significantly less likely to meet the clinical threshold criteria for no or low anxiety (13.64%) than carers without pensions (28.93%). Carers with old age pensions were significantly more likely to meet the clinical threshold criteria for moderate anxiety (73.38%) than carers without pensions (62.80%). Carers with old age pensions were significantly more likely to meet the clinical threshold criteria for high anxiety (12.99%) than carers without old age pensions (8.28%). Analysis showed a significant association between the disability grant and K10 scores ($p<0.01$ $\chi 2=14.83$). Carers with disability grants were significantly less likely to meet the clinical threshold criteria for no or low anxiety (13.33%) than carers without disability grants (28.15%). Carers with disability grants were significantly more likely to meet the clinical threshold criteria for moderate anxiety (68.00%) than carers without disability grants (63.61%). Carers with disability

grants were significantly more likely to meet the clinical threshold criteria for high anxiety (18.67%) than carers without disability grants (8.24%).

A summary of associations between demographic, social and economic variables and anxiety is found in ***Table 5.7***.

Table 5.7: Bivariate Associations between Demographic, Social, and Economic Factors and Anxiety (n=1599)

Demographic, Social, and Economic Variables	K10 (numerical) (n=1597)		K10 (categorical) (n=1597)	
	Correlation coefficient or Mean and Standard Deviation	*p*[1]	Mean and Standard Deviation or N, %	*p*
Age	0.20	<.01	--	<.01 Tukey Test: <.01 No or low anxiety<moderate anxiety No or low anxiety<high anxiety Moderate anxiety<high anxiety
Gender		<.01		=.011
Male	18.99 (6.26)		No or low anxiety, 78 (35.94%) Moderate anxiety, 122 (56.22%) High anxiety, 17 (7.83%)	
Female	20.31 (6.51)		No or low anxiety, 360 (26.14%) Moderate anxiety, 895 (65.00%) High anxiety, 122 (8.86%)	
Education	-0.24	<.01	--	<.01 Tukey Test: <.01 No or low anxiety>moderate anxiety No or low anxiety>high anxiety Moderate anxiety>high anxiety
Social support	0.062	<.014	--	<.01 Tukey Test: <.01 Mo or low anxiety<moderate anxiety
Family support	--	ns		<.04
Friend support	0.09	<.01		<.01 Tukey Test: <.01 No or low anxiety<moderate anxiety
Significant others support	--	ns		ns
Number of children in household	--	ns	--	ns
Number of persons in household	--	ns	--	ns

Demographic, Social, and Economic Variables	K10 (numerical) (n=1597)		K10 (categorical) (n=1597)	
Dwelling type		ns	No or low anxiety, 238 (27.93%) Moderate anxiety, 527 (61.85%) High anxiety, 87 (10.21%)	ns
Informal dwelling	20.38 (6.78)			
Formal dwelling	19.89 (6.18)		No or low anxiety, 200 (26.85%) Moderate anxiety, 491 (65.91%) High anxiety, 54 (7.25%)	
Economic asset index	-0.16	<.01	--	<.01 Tukey Test: <.01 No or low anxiety>high anxiety Moderate anxiety>high anxiety
Main source of income				
Salaries/wages		<.01		<.01
Yes	19.25 (6.02)		No or low anxiety, 316 (30.50%) Moderate anxiety, 657 (63.42%) High anxiety, 63 (6.08%)	
No	21.81 (7.05)		No or low anxiety, 122 (21.75%) Moderate anxiety, 361 (64.35%) High anxiety, 78 (13.90%)	
Pensions/grants		<.01		<.01
Yes	22.36 (7.06)		No or low anxiety, 84 (19.00%) Moderate anxiety, 288 (65.16%) High anxiety, 70 (15.84%)	
No	19.31 (6.09)		No or low anxiety, 354 (30.65%) Moderate anxiety, 730 (63.20%) High anxiety, 71 (6.15%)	
Other income		<.04		<.04
Yes	18.77 (5.62		No or low anxiety, 28 (37.84%) Moderate anxiety, 44 (59.46%) High anxiety, 2 (2.70%)	
No	20.22 (6.55)		No or low anxiety, 410 (26.92%)	

Demographic, Social, and Economic Variables	K10 (numerical) (n=1597)		K10 (categorical) (n=1597)	
			Moderate anxiety, 974 (63.95%) High anxiety, 139 (9.13%)	
Remittances		ns		ns
Yes	19.41 (7.21)		No or low anxiety, 9 (26.47%) Moderate anxiety, 22 (64.71%) High anxiety, 3 (8.82%)	
No	20.17 (6.50)		No or low anxiety, 429 (27.45%) Moderate anxiety, 996 (63.72%) High anxiety, 138 (8.83%)	
No Income		<.01		ns
Yes	27.73 (6.93)		No or low anxiety, 1 (9.09%) Moderate anxiety, 7 (63.64%) High anxiety, 3 (27.27%)	
No	20.10 (6.48)		No or low anxiety, 437 (27.55%) Moderate anxiety, 1011 (64.75%) High anxiety, 138 (8.70%)	
Frequency of grants received in household				
Old age pension	--	ns	--	ns
Disability grant	0.10	<.01	--	<0.012
Government housing subsidy	--	ns	--	ns
Child support grant	--	ns	--	ns
Foster care grant	--	ns	--	ns
Carer receipt of grants				
Old age pension		<.01		<.01
Yes	22.53 (7.10)		No or low anxiety, 21 (13.64%) Moderate anxiety, 113 (73.38%) High anxiety, 20 (12.99%)	

Demographic, Social, and Economic Variables	K10 (numerical) (n=1597)		K10 (categorical) (n=1597)	
No	19.88 (6.38)		No or low anxiety, 416 (28.93%) Moderate anxiety, 903 (62.80%) High anxiety, 119 (8.28%)	
Disability grant		<.01		<.01
Yes	23.36 (7.29)		No or low anxiety, 10 (13.33%) Moderate anxiety, 51 (68.00%) High anxiety, 14 (18.67%)	
No	19.97 (6.41)		No or low anxiety, 427 (28.15%) Moderate anxiety, 965 (63.61%) High anxiety, 125 (8.24%)	
Government housing subsidy		ns		ns
Yes	19.20 (5.49)		No or low anxiety, 18 (27.27%) Moderate anxiety, 44 (66.67%) High anxiety, 4 (6.06%)	
No	20.17 (6.53)		No or low anxiety, 419 (27.46%) Moderate anxiety, 972 (63.70%) High anxiety, 135 (8.85%)	

Note: Column sums may not add to n=1599 due to missing values

[1] *p*-values associated with linear regressions, t-tests, and one-way ANOVAs for continuous variables and chi-square tests for categorical variables

6.4 Post-traumatic Stress Disorder

Age

Age was not significantly associated with post traumatic stress (HTQ scores) as a categorical variable. Carers meeting the clinical threshold criteria for PTSD were of similar age (M=42.36, SD=14.83) as carers falling below the clinical threshold criteria for PTSD (M=40.09, SD=11.54).

Gender

Gender was not significantly associated with HTQ as a categorical variable. Females were equally likely to meet the clinical threshold criteria for PTSD (2.48%) as males (0.90%)

Education

Education was not significantly associated with HTQ as a categorical variable. Carers who met the clinical threshold criteria for PTSD had similar levels of education (M=10.05, SD=3.61) as carers who did not meet the clinical threshold criteria for PTSD (M=10.52, SD=3.89).

Social Support

Levels of overall social support were not significantly associated HTQ as a categorical variable. However, trends suggested that carers falling below the clinical threshold criteria for PTSD had higher levels of overall social support (M=61.02, SD=13.56) than carers meeting the clinical threshold criteria (M=54.45, SD=16.74) ($p<0.03$). Analyses of specific social support categories also suggested that support

from family, friends, and significant others were not significantly associated with HTQ as a categorical variable. However, trends suggested that carers falling below the clinical threshold criteria for PTSD had higher levels of levels of support from family (M=22.00, SD=5.65) than carers meeting the clinical threshold (M=17.73, SD=8.07) ($p<0.02$). Similarly, trends suggested that carers falling below the clinical threshold criteria for PTSD had higher levels of support from significant others (M=22.76, SD=5.33) than carers meeting the clinical threshold criteria (M=20.36, SD=6.25) ($p<0.04$). Carers falling below the clinical threshold criteria for PTSD had similar levels of social support from friends (M=16.26, SD=8.19) as carers meeting the clinical threshold criteria for PTSD (M=16.36, SD=8.87).

Number of Children in Household

The number of children in the household was not significantly associated with HTQ. Carers meeting the clinical threshold criteria for PTSD had similar numbers of children in their households (M=0.32, SD=0.84) as carers falling below the clinical threshold criteria (M=0.08, SD=1.03).

Number of Persons in Household

The number of persons in the household was not associated with HTQ. Carers meeting the clinical threshold criteria for PTSD had similar numbers of persons in the household (M=0.14, SD=0.73) as carers falling below the clinical threshold criteria (M=0.07, SD=1.07).

Dwelling Type

Dwelling type was not significantly associated with HTQ.

Economic Asset Index and Main Source of Household Income

Economic asset index scores were not associated with HTQ. In terms of the main source of household income, carers depending upon salaries/wages as the main source of household income were less likely to meet the clinical threshold criteria for PTSD ($p<0.01$, $\chi2=10.36$). In contrast, carers depending upon pensions/grants as the main source of household income were more likely to meet the threshold criteria for PTSD ($p<0.01$, $\chi2=15.56$).

Household Receipt of Grants and Carer Receipt of Grants

In terms of household receipt of grants, households receiving more old age pensions were significantly less likely to meet the clinical threshold criteria for PTSD ($p<0.01$). In terms of carers' receipt of grants, carers receiving a disability grant were significantly more likely to meet the clinical threshold criteria for PTSD ($p<0.01$, $\chi2=7.35$).

6.5 Alcohol Use

Age

Age was not correlated or associated with alcohol use (AUDIT scores).

Gender

Gender was significantly associated with AUDIT as a continuous variable with men more likely to use alcohol than women ($p<0.01$). Analysis of AUDIT as a categorical variable confirmed an association between gender and alcohol ($p<0.01$, $\chi2=65.92$). Females were less likely to exhibit alcohol dependence (hazardous drinking

1.18%, high hazardous drinking 0.37%, dependence 0.74%) than males (hazardous drinking 8.80%, high hazardous drinking 1.85%, dependence 2.78%).

Education

Education was not correlated or associated with AUDIT scores.

Social Support

Overall social support was not correlated with AUDIT as a continuous variable. Analyses of specific forms of support showed that support from friends was directly correlated with AUDIT ($r=0.07$, $p<0.01$). As social support from friends increased, AUDIT scores worsened. However, when AUDIT was analyzed as a categorical variable, there was no significant association between overall social support or specific support categories and alcohol use.

Number of Children in Household

The number of children in the household was not significantly correlated or associated with AUDIT.

Number of Persons in Household

The number of persons in the household was not correlated or associated with AUDIT.

Dwelling Type

Dwelling types were not significantly correlated or associated with AUDIT.

Economic Asset Index

Economic asset index scores were not correlated with AUDIT scores. Analysis of the household's main source of income showed no associations between sources of income and AUDIT as a continuous variable. However, trends suggested that households dependent on salaries/wages as the main source of household income had significantly better AUDIT scores (M=0.65, SD=2.71) than households not dependent on salaries/wages (M=1.05, SD=3.94) ($p<0.03$). When AUDIT was analyzed as a categorical variable, there were no significant associations between various sources of household income and AUDIT scores.

Household Receipt of Grants and Carer Receipt of Grants

In terms of household receipt of grants, analysis of AUDIT as a continuous variable showed significant patterns. The number of child support grants received in the household was directly correlated with alcohol use with an inverse relationship ($r= -0.08$, $p<0.01$). That is, households with more child support grants were less likely to use alcohol. Trends suggested that the number of disability grants in the households was directly correlated with AUDIT scores ($r=0.05$, $p<0.04$). That is, households in with more disability grants were more likely to use alcohol. When AUDIT was analyzed as a categorical variable, households with higher numbers of child support grants were significantly associated with AUDIT scores ($p<0.01$, $F=3.85$). Again, the pattern of association suggested that households with more child support grants were less likely to use alcohol. In terms of carers' receipt of grants, no grant was significantly related to AUDIT as a continuous or categorical variable. A summary of associations between demographic, social and economic variables and post-traumatic stress and alcohol use is found in ***Table 5.8***.

Table 5.8: Bivariate Associations between Demographic, Social, and Economic Variables and Post Traumatic Stress Disorder and Alcohol Use (n=1599)

Demographic, Social, and Economic Variables	HTQ (categorical) (n=957)		AUDIT (numerical (n=1596)		AUDIT (categorical) (n=1577)	
	Mean and Standard Deviation or N, %	*p*[1]	Correlation coefficient or Mean and Standard Deviation	*p*	Mean and Standard Deviation or N, %	*p*
Age	No PTSD, 40.09 (14.83) PTSD, 42.36 (11.54)	ns	--	ns	--	ns
Gender		ns		<.01		<.01
Male	With PTSD, 111 (0.90%)		2.27 (5.19)		No alcohol problems, 187 (86.57%) Hazardous drinking, 19 (8.80%) High hazardous drinking, 4 (1.85%) Alcohol dependence, 6 (2.78%)	
Female	With PTSD, 846 (2.48%)		0.55 (2.69)		No alcohol problems, 1328 (97.72%) Hazardous drinking, 16 (1.18%) High hazardous drinking, 5 (0.37%) Alcohol dependence, 10 (0.74%)	
Education	No PTSD, 10.52 (3.89) PTSD, 10.05 (3.61)	ns	--	ns	--	ns
Social support	No PTSD, 61.02 (13.56) PTSD, 54.45 (16.74)	<.03	--	ns	--	ns
Family support	No PTSD, 22.00 (5.65) PTSD, 17.73 (8.07)	<.02	--	ns	--	ns
Friend support	No PTSD, 16.26 (8.19) PTSD, 16.36 (8.87)	ns	0.07	<.01	--	ns
Significant others support	No PTSD, 22.76 (5.33) PTSD, 20.36 (6.25)	<.04	--	ns	--	ns
Number of children in household	No PTSD, 0.08 (1.03) PTSD, 0.32 (0.84)	ns	--	ns	--	ns
Number of persons in household	No PTSD, 0.07 (1.07) PTSD, 0.14 (0.73)	ns	--	ns	--	ns

Demographic, Social, and Economic Variables	HTQ (categorical) (n=957)		AUDIT (numerical (n=1596)		AUDIT (categorical) (n=1577)	
Dwelling type		ns		ns		ns
Informal dwelling	PTSD, 13 (2.57%)		0.78 (3.23)		No alcohol, 250 (95.79%) Hazardous drinking, 8 (3.07%) High hazardous drinking, 3 (1.15%) Alcohol dependence, 0 (0%)	
Formal dwelling	PTSD, 9 (2.00%)		0.80 (3.17)		No alcohol, 1268 (96.28%) Hazardous drinking, 27 (2.05%) High hazardous drinking, 6 (0.46%) Alcohol dependence, 16 (1.21%)	
Economic asset index	No PTSD, -0.01 (0.70) PTSD, -0.19 (0.75)	ns	--	ns	--	ns
Main source of income						
Salaries/wages		<.01		<.03		ns
Yes	No PTSD, 573 (61.22%) PTSD, 6 (27.27%)		0.65 (2.71)		No alcohol, 992 (65.35%) Hazardous drinking, 22 (62.86%) High hazardous drinking, 4 (44.4%) Alcohol dependence, 6 (37.50%)	
No	--		1.05 (3.94)		--	
Pensions/grants		ns		ns		ns
Yes	No PTSD, 273 (29.17%) PTSD, 15 (68.18%)		1.05 (3.94)		No alcohol, 416 (27.40%) Hazardous drinking, 11 (31.43%) High hazardous drinking, 4 (44.44%) Alcohol dependence, 8 (50.00%)	
No	--		0.68 (2.86)		--	
Other income		ns		ns		ns
Yes	No PTSD, 55 (100%) PTSD, 0 (0%)		0.99 (4.37)		No alcohol, 68 (95.77%) Hazardous drinking, 1 (1.41%) High hazardous drinking, 0 (0%) Alcohol dependence, 2 (2.82%)	
No	--		0.78 (3.14)		--	

Demographic, Social, and Economic Variables	HTQ (categorical) (n=957)		AUDIT (numerical (n=1596)		AUDIT (categorical) (n=1577)	
Remittances		ns		ns		ns
Yes	No PTSD, 28 (2.99%) PTSD, 0 (0%)		1.39 (3.72)		No alcohol, 31 (2.04%) Hazardous drinking, 1 (2.86%) High hazardous drinking, 1 (11.11%) Alcohol dependence, 0 (0%)	
No	--		0.77 (3.19)		--	
No Income		ns		ns		ns
Yes	No PTSD, 7 (0.75%) PTSD, 1 (4.55%)		0.00 (0.00)		No alcohol, 11 (0.72%) Hazardous drinking, 0 (0%) High hazardous drinking, 0 (0%) Alcohol dependence, 0 (0%)	
No	--		0.79 (3.21)		--	
Frequency of grants received in household						
Old age pension	No PTSD, 0.20 (0.46) PTSD, 0.05 (0.21)	<.01	--	ns	--	ns
Disability grant	No PTSD, 0.09 (0.29) PTSD, 0.27 (0.55)	ns	0.05	<.03	--	ns
Government housing subsidy	No PTSD, 0.04 (0.19) PTSD, 0.00 (0.00)	ns	--	ns	--	ns
Child support grant	No PTSD, 1.55 (1.45) PTSD, 1.36 (1.22)	ns	-0.083	<.01	--	<.01
Foster care grant	No PTSD, 0.05 (0.29) PTSD, 0.18 (0.66)	ns	--	ns	--	ns

Demographic, Social, and Economic Variables	HTQ (categorical) (n=957)		AUDIT (numerical (n=1596)		AUDIT (categorical) (n=1577)	
Carer receipt of grants						
Old age pension		ns		ns		ns
Yes	No PTSD, 101 (10.83%) PTSD, 1 (4.55%)		0.61 (2.13)		No alcohol, 149 (9.85%) Hazardous drinking, 4 (11.43%) High hazardous drinking, 0 (0%) Alcohol dependence, 0 (0%)	
No	--		0.81 (3.30)		--	
Disability grant		<.01		ns		ns
Yes	No PTSD, 47 (5.04%) PTSD, 4 (18.18%)		1.12 (3.70)		No alcohol, 70 (4.63%) Hazardous drinking, 3 (8.57%) High hazardous drinking, 0 (0%) Alcohol dependence, 1 (6.25%)	
No	--		0.77 (3.18)		--	
Government housing subsidy		ns		ns		ns
Yes	No PTSD, 28, 3.00%) PTSD, 0 (0%)		0.91 (2.96)		No alcohol, 63 (4.16%) Hazardous drinking, 2 (5.71%) High hazardous drinking, 1 (11.11%) Alcohol dependence, 0 (0%)	
No	--		0.78 (3.22)			

Note: Column sums may not add to n=1599 due to missing values

[1] ***p*-values associated with linear regressions, t-tests, and one-way ANOVAs for continuous variables and chi-square tests for categorical variables**

7. Summary

This chapter provided a summary overview of health outcomes. First, analyses assessed outcomes in the overall sample. Carers scored in the 70th percentile for general physical and mental health and functioning. Further analyses demonstrated carers had worse mental health than physical health. In terms of mental health, carers had high prevalence of depression and anxiety. PTSD and alcohol abuse were also concerning but carers had much lower prevalence of these outcomes. Second, bivariate analyses explored differences in health outcomes between orphan and non-orphan carers. Orphan carers were significantly more likely than non-orphan carers to have poor general mental and physical health and functioning, depression, and PTSD. Orphan and non-orphan carers were equally likely to experience anxiety and have alcohol dependence. Third, bivariate analyses explored differences between AIDS-orphan, other-orphan, and non-orphan carers. These analyses reaffirmed trends in the orphan and non-orphan carers analysis but offered some additional insight. AIDS-orphan carers performed worse than non-orphans in terms of general physical and mental health and functioning; depression; and PTSD. Other-orphan carers performed worse than AIDS-orphan and non-orphan carers in the area of depression and PTSD. These

Figure 5.5: Photo of Mother and Child

findings are vital, suggesting that interventions targeting AIDS-orphan carers may miss out other-orphan carers, a group in much need of assistance.

This chapter also explored the relationship between health outcomes and various descriptive variables. Bivariate analyses suggested that nearly all variables are correlated with overall health and functioning and physical and mental health component scores. Additional analyses of specific mental health illnesses suggest that most variables are significantly related to depression, anxiety, PTSD, and alcohol use. PTSD and alcohol use tend to have fewer patterns of significance than other mental health illnesses.

CHAPTER VI RESULTS: HEALTH RISKS ASSOCIATED WITH CARE PROVISION

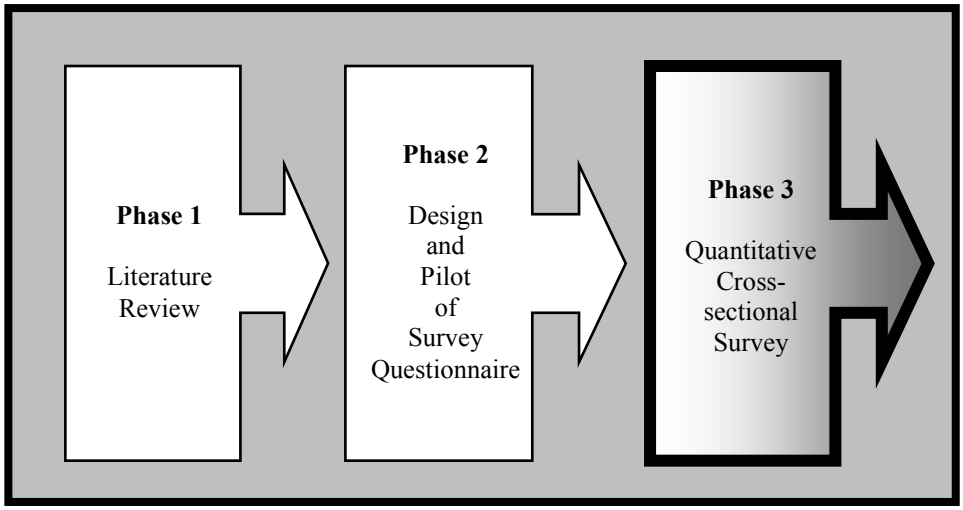


Figure 6.1: Quantitative Cross-sectional Survey

Summary

The primary objective of this chapter was to build on results from bivariate analyses which showed that orphan carers reported significantly more negative health than non-orphan carers. This chapter presents multivariate regression analyses of the risk and protective co-factors that might explain differences in carer health outcomes.

The first set of multivariate analyses explored whether carer type (*i.e.,* orphan carer or non-orphan carer) was associated with health outcomes after adjusting for socioeconomic characteristics. These analyses showed that when adjusting for age, gender, education, and economic assets, there were no independent associations between carer type and health. These sociodemographic factors fully accounted for the association between carer type and health.

The second set of analyses tested whether hypothesized aspects of care provision were associated with poor health amongst orphan carers. Variables which reflected the socio-economic conceptual model of health, described in ***Chapter III, Figure 3.4***, were entered into regression models in blocks. Regression models showed that carer type was significantly associated with poor health even when accounting for factors related to care provision (*i.e.* social support and number of children in the household). However, carer type was no longer associated with health when accounting for social grants in the household. These findings highlight the potential for social policy grants to reduce negative health disparities between orphan carers and non-orphan carers. Findings also identified a number of other potential risk and protective co-factors for intervention.

Summary (continued)

Finally, the chapter explored whether three risk and protective co-factors (*e.g.,* gender, age and education) combined with being an orphan carer had a multiplicative effect upon health outcomes. Surprisingly, none of the interactions were significant. Being female, older, and less educated *and* being an orphan carer did not have an interactive effect in worsening health outcomes.

1. Introduction

The chapter begins by detailing the data analytical approach. Then the chapter assesses the third study question, "Is carer type an independent risk factor for health outcomes?" Based on whether carer type (*i.e.*, orphan versus non-orphan carers) functioned as a risk factor for health, this chapter goes on to explore the sub-question, "What socio-ecological factors explain health disparities associated with caring for an orphan?" For these analyses, regressions were used to explore whether variables related to care provision are independently associated with general health and functioning, physical health and functioning, mental health and functioning, and depression amongst orphan carers. Finally, the chapter explored the fourth study question, "Do certain risk and protective factors have a multiplicative effect upon orphan carer health?" This question guides analyses in this chapter, focusing specifically on developing analyses from ***Chapter V*** which established that orphan carers faced greater health risks and identified risk and protective factors for carer health.

2. Analytical Approach

Question 3: Is carer type an independent risk factor for health outcomes?

Sub-question 3.1: What socio-ecological factors explain health disparities associated with caring for an orphan?

Question 4: Do certain risk and protective factors have a multiplicative effect upon orphan carer health?

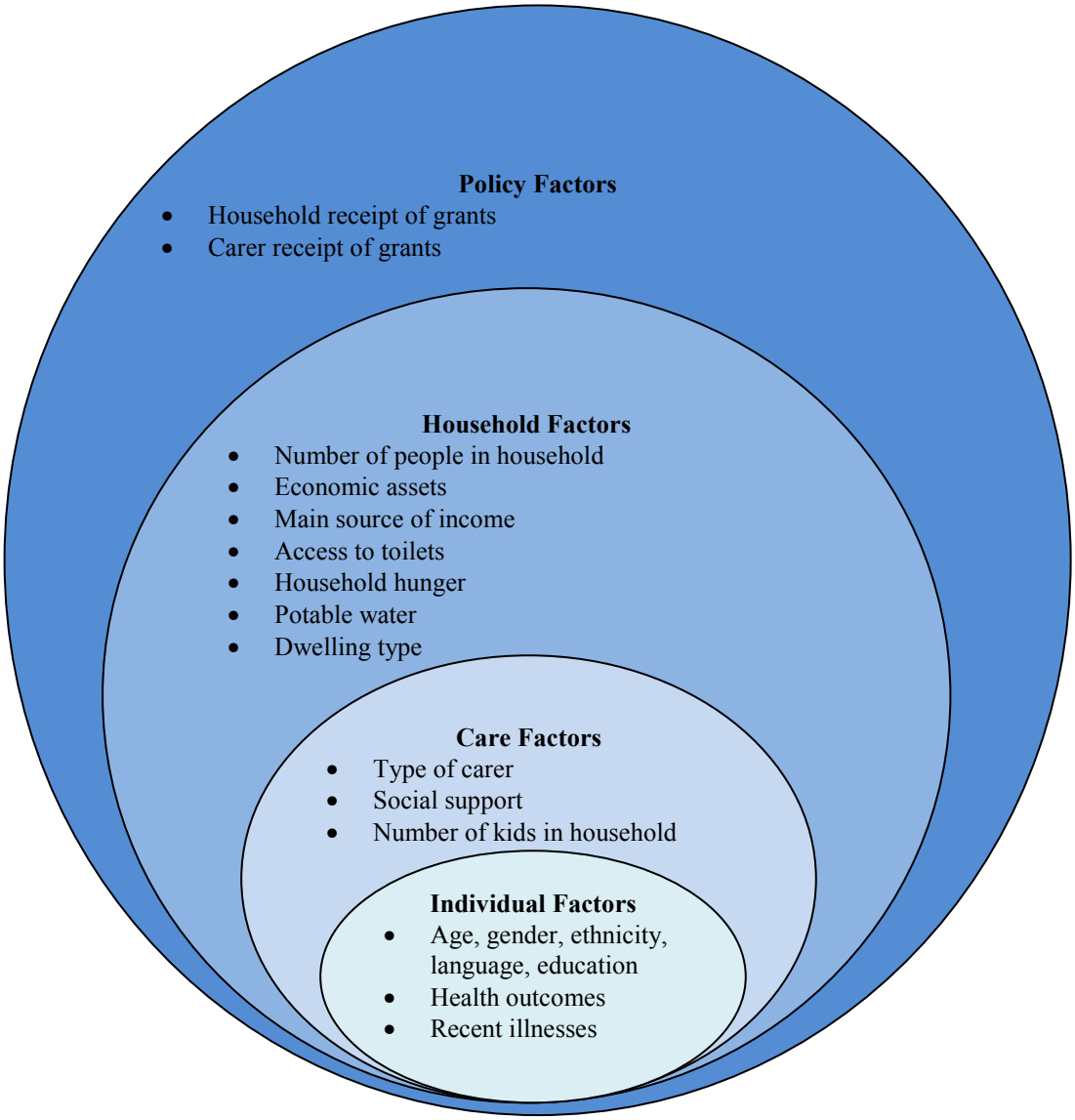
Multivariate analyses focused on orphan versus non-orphan carer comparisons, as bivariate analyses in ***Chapter V*** demonstrated clear health disparities for orphan versus non-orphan carers with orphan carers facing significantly worse health outcomes. The following specific findings from ***Chapter V, Section 4*** provided the basis for multivariate analyses. First, bivariate analyses showed that orphan carers had significantly worse general health and functioning (SF-36v2), physical health and functioning (SF-36v2 subscores), and mental health and functioning (SF-36v2 physical subscore) than non-orphan carers. Bivariate analyses also showed that orphan carers were significantly more likely to meet the clinical threshold criteria for depression (CES-D categorical variable) than non-orphan carers. Finally, bivariate analyses revealed that orphan carers were significantly more likely to meet the threshold criteria for PTSD than non-orphan carers. Multivariate analyses examined these health variables (*i.e.,* SF-36v2, SF-36v2 physical health subscore, SF-36v2 mental health subscore, CES-D). Anxiety, alcohol use, and drug use were excluded from multivariate analyses because orphan and non-orphan carers did not exhibit significant differences for these. Post-traumatic stress was excluded from multivariate analyses because of sample size limitations on this measure.

The first set of multivariate regressions assessed whether carer type (*i.e.,* orphan vs. non-orphan carer) was significantly associated with health measures, adjusting for sociodemographic co-factors that showed a bivariate association with each health outcome at $p<0.25$ (see ***Chapter V, Section 6***) (Hosmer and Lemeshow 1989). Correlational analysis was conducted to identify a potential for multicollinearity amongst independent variables. If independent variables were multicollinear (*e.g.*, tolerance statistic of <0.10 and a variance

inflation factor of >10), one of the multicollinear variables was excluded from regression analysis. Since these analyses suggested that carer type *(i.e.*, orphan vs. non-orphan carer) was not significantly associated with health measures when adjusting for certain sociodemographic factors, a more nuanced model of factors associated with carer health was conducted.

In this second set of multivariate linear and logistic regression analyses, models went beyond tests of whether carer type (orphan vs. non-orphan carer) was significantly associated with health measures. These models also tested whether variables related to care provision (*i.e.,* carers' level of social support and the number of children cared for) were significant predictors for health outcomes above and beyond other socio-ecological level factors. If care provision variables were not predictors for health outcomes, than additional socio-ecological level factors were included in the models to identify possible risk and protective co-factors for health. Unlike the first set of multivariate linear and logistic regressions, variables were not limited to sociodemographic co-factors that showed a bivariate association with each health outcome at $p<0.25$. Instead these models also included all potential risk and protective factors within the socio-ecological model of health, regardless of whether these variables showed bivariate association with health measures in ***Chapter V***. The socio-ecological model was used to organize potential risk and protective factors for health (***Figure 5.2***).

Figure 6.2: Socio-ecological Conceptual Organization of Risk and Protective Factors



Hypothesized risk and protective co-factors were organized into groupings based on the socio-ecological model and entered into regression models in forward-entry blocks grouped into the following categories: care provision, household, policy, and individual factors.

The final set of exploratory analyses examined interactions between carer group and age, gender, and education on health measures. Interaction terms were based on dichotomous coded variables for age, gender, and education. Categories for continuous variables were

based on median cut-offs. Age was recoded into carers <39 years or carers ≥40 years. Gender was recoded such as female was represented by a code of 1 and males represented by a code of 0. Education was recoded such as carers who completed middle school were represented by a code of 1 and carers who complete a portion of middle school or less were represented by a code of 0. Interaction terms were based on a multiplicative function of these dummy-coded variables with carer group (0=non-orphan carer; 1=orphan carer).

3. Exploring Whether Carer Type is Independently Associated with Health Measures

Bivariate analyses showed that orphan carers had significantly worse general health and functioning (SF-36v2), physical health and functioning (SF-36v2 subscores), mental health and functioning (SF-36v2 physical subscore), and depression (CES-D) than non-orphan carers. Based on these findings, the first set of multivariate regressions assessed whether carer type (*i.e.,* orphan vs. non-orphan carer) was significantly associated with health measures when adjusting for sociodemographic co-factors. Multivariate linear regressions were conducted with general health and functioning as the dependent variable. ***Table 6.1, Model 1*** showed that when adjusting for age, gender, education, economic assets, and main source of income, carer type showed no independent association with general health and functioning (β=0.03, $p<0.20$). Instead, age (β= -0.38, $p<0.01$), gender (β= -0.08, $p<0.01$), education (β=0.14, $p<0.01$), economic assets (β=0.14, $p<0.01$), and main source of income (β=0.12, $p<0.01$) were significantly associated with general health and functioning ($F=54.77$, $p<0.01$).

Similar multivariate linear regressions were conducted with physical and mental health subscores as dependent variables. Multivariate binomial logistic regressions were also conducted with depression as a dichotomous dependent variable. These analyses showed

similar results. When adjusting for age, gender, education, and economic assets, carer type showed no independent associations with physical health and functioning (β=0.03, p<0.22) (***Model 2***), mental health and functioning (β=0.02, p<0.36) (***Model 3***), or depression (OR=0.19, 95% CI=0.94-1.51) (***Model 4***). A summary of these analyses is found in ***Table 6.1.***

Table 6.1: Multivariate Regressions Testing Associations of Carer Type with Health

	Model 1 General Health and Functioning (SF-36v2)	Model 2 Physical Health and Functioning (SF-36v2 Subscore)	Model 3 Mental Health and Functioning (SF-36v2 Subscore)	Model 4 Depression (CES-D)
Care Type				
Orphan vs. non-orphan carers	0.03	0.03	0.02	0.19 (0.94-1.51)
Sociodemographic Co-factors with Bivariate Associations with Health Outcomes				
Age	-0.38**	-0.38**	-0.33**	1.85** (1.43-2.40)
Gender	-0.08**	-0.08**	-0.07**	--
Education	0.14**	0.13**	0.13**	0.76* (0.59-0.98)
Economic asset index	0.14**	0.15**	0.10**	0.64** (0.48-0.84)
Family support	0.05*	0.08**	--	--
Friend support	-0.01	-0.02	0.003	--
Significant others support	0.004	0.01	--	--
Number of children in household	-0.01	-0.02	0.002	--
Dwelling type	--	--	0.01	0.81 (0.61-1.07)
Main source of income	0.12**	0.11**	0.13**	0.59** (0.46-0.74)
Number of old age pensions	-0.002	-0.03	0.03	--
Number of disability grants	-0.07**	-0.08**	-0.05*	--
Number of government housing subsidies	0.06**	0.07**	--	--
Number of child support grants	--	--	--	--
Number of foster care grants	0.00	-0.004	--	--
Model Statistics				
R	0.57	0.57	0.49	--
R^2	0.33	0.33	0.24	--
Adjusted R^2/Nagelkerke R^2	0.32	0.33	0.23	0.10
F	54.77	55.63	43.97	--
Overall p-value	<0.01	<0.01	<0.01	--

4. Care Provision Variables as Predictors for Health

A second set of multivariate analyses were used to examine the associations of hypothesized co-factors derived from the socio-ecological model on carer health. These analyses were conducted to (a) test whether variables related to care provision (*i.e.,* carers' social support and number of children being cared for) buffered the effect of carer type on health; and in the case that care provision variables did not buffer the effect of carer type on health (b) identify other potentially important risk or protective factors for carer health within the socio-ecological model.

4.1 General Health and Functioning and Physical and Mental Health Subscores

Multivariate linear regressions were conducted with general health and functioning (SF-36v2) as the dependent variable. Carer type (*i.e.,* orphans vs. non-orphan carers) was entered in the first block (***Table 6.2, Model 1***), care provision variables in the second block (***Table 6.2, Model 2***), household variables in the third block (***Table 6.2, Model 3***), policy variables in the fourth block (***Table 6.2, Model 4***), and individual variables in the fifth block (***Table 6.2, Model 5***).

Each of the models were significant ($p<0.01$). Each additional block increased explanatory power, as exhibited by increasing adjusted R-squares. For example, whilst ***Model 1*** with carer type explained just 17 percent of the variance in general health and functioning, ***Model 5*** with carer type, care provision, household, policy, and individual level variables explained 28 percent of the variance in general health and functioning.

Model 1 shows the simple bivariate association of carer type and health, without adjusting for any socio-ecological variables. Surprisingly, when adjusting for the variables

related to care provision (*i.e.,* number of children in the household and levels of social support to carers), being an orphan carer was still significantly associated with poor general health and functioning (β= -0.12, p<0.01) (F=8.31, p<0.01) (***Model 2***). Whilst care provision factors did not buffer the effect of carer type on health, subsequent findings suggested some potentially important points for intervention.

In ***Model 4***, the addition of policy factors into the model reduced the association between carer type and health (β= -0.05, p<0.03) (F=18.32, p<0.01), suggesting that households receiving or not receiving at least one old age pension, disability grant, government housing subsidy, and child support grant reduced disparities in general health and functioning between orphan and non-orphan carers (***Model 4***). Demographic characteristics were entered into ***Model 5***, showing that gender (β= -0.27, <0.01), and education (β=0.14, <0.01) remained important co-factors of health (F=28.47, p<0.01) (***Model 5***). This model also showed that general health and functioning was significantly associated with support from family members, economic assets, source of income, levels of household hunger, source of drinking water, and housing type. There were little changes between ***Models 2*** through ***5***, suggesting a fairly stable pattern of association between these variables and carer health.

Multivariate linear regressions were also run for additional dependent variables for health including the SF-36v2 physical health and functioning subscore and the SF-36v2 mental health and functioning subscore. In general, these analyses showed similar patterns as the analyses on general health and functioning (***Tables 6.3 and 6.4***). However, some variables differed when comparing ***Models 5*** in ***Tables 6.3*** and ***6.4.*** Physical health and functioning was significantly associated with family support, number of children in the

household, economic asset index, flushable toilet, potable water, and housing type (***Table 6.3, Model 5***), whilst mental health and functioning was significantly associated with friend support, hunger, source of drinking water, and at least one child support grant (***Table 6.4, Model 5***), possibly indicating differing points of entry for physical and mental health interventions.

4.2 Depression

Multivariate logistic regressions were run with depression (CES-D) as the dichotomous dependent variable. Carer type (*i.e.,* orphans vs. non-orphan carers) was entered in the first block (***Table 6.5, Model 1***), care provision variables in the second block (***Table 6.5, Model 2***), household variables in the third block (***Table 6.5, Model 3***), policy variables in the fourth block (***Table 6.5, Model 4***), and individual variables in the final block (***Table 6.5, Model 5***).

In all models, orphan carers were significantly more likely to meet the clinical threshold criteria for depression than non-orphan carers (***Model 1***, OR=1.39, 95% CI=1.12-1.75; ***Model 2***, OR=1.48, 95% CI=1.18-1.86; ***Model 3***, OR=1.40, 95% CI=1.09-1.79; ***Model 4***, OR=1.36, 95% CI=1.06-1.76; ***Model 5***, OR=1.32, 95% CI=1.02-1.71). Orphan carers were significantly more likely to meet the clinical threshold criteria for depression by a large percentage, with estimates suggesting that orphans had a 32% to 48% higher chance of meeting the threshold for depression than non-orphan carers (***Model 2 and Model 5***). In the final model, depression was significantly associated with caring for an orphan, source of income, hunger, source of drinking water, and gender. There were little changes between ***Models 2*** through ***5***, suggesting a fairly stable pattern of association between these variables and carer health.

These data highlight some potential areas for effective intervention. For example, carers were 55% less likely to be depressed when the primary source of household income was salaries (***Table 6.4, Model 5***, OR=0.55, 95%CI=0.42-0.71). Carers were three and a half times more likely to meet the clinical threshold for depression if they were hungry (***Table 6.4, Model 5***, OR=3.52, 95% CI=2.69-4.62). Carers were 73% less likely to be depressed when they had piped water (***Table 6.4, Model 5***, OR=0.73, 95%CI=0.54-0.99). Carers were nearly twice as likely to meet the clinical threshold for depression if they were female (***Table 6.4, Model 5***, OR=1.98, 95%CI=1.51-2.60). These results suggested that targeting these specific areas for intervention (*e.g.,* employment, hunger, and water) may have an influence on depression; interventions that target women are also warranted. It was surprising to find that variables related to care provision (*e.g.,* social support and number of children in the home) were not significantly related to depression. Interventions that address social support as a way to reduce depression might not be as effective as interventions in these other identified areas.

A summary of these analyses exploring associations of hypothesized co-factors derived from the socio-ecological model on carer health is found in ***Tables 6.2, 6.3, 6.4,*** and ***6.5.***

Table 6.2: Multivariate Regressions Testing Associations of Care Provision, Household, Policy, and Individual Factors with General Health and Functioning (SF-36v2)

	Model 1	Model 2	Model 3	Model 4	Model 5
Block 1: Carer Type					
All orphan vs. Non-orphan carers	-0.13**	-0.12**	-0.09**	-0.05*	-0.04
Block 2: Care Provision Variables					
Family support		0.04	0.03	0.03	0.06*
Friend support		0.03	0.04	0.04	0.02
Significant others support		0.04	0.004	-0.002	-0.01
Number of children in household		-0.03	-0.03	-0.06*	-0.04
Block 3: Household Variables					
Economic asset index[1]			0.03	0.05	0.07*
Main Source of Income			0.27**	0.20**	0.16**
Access to flushable toilet			0.04	0.05	0.04
Hunger			-0.10**	-0.12**	-0.05*
Source of drinking water			0.01	0.01	0.09**
Water safe			0.03	0.04	0.002
Formal or informal housing			-0.04	-0.02	0.04*
Block 4: Policy Variables					
At least one old age pension				-0.18**	-0.03
At least one disability grant				-0.12**	-0.10**
At least one government housing subsidy				0.07**	-0.08**
At least one child support grant				0.09**	0.05*
At least one foster care grant				-0.01	0.05*
Block 5: Individual Variables					
Age					0.00
Gender					-0.27**
Ethnicity					0.01
Language					-0.02
Education					0.14**
Model Statistics					
R	0.13	0.16	0.34	0.40	0.54
R^2	0.18	0.03	0.12	0.17	0.29
Adjusted R^2	0.17	0.02	0.11	0.16	0.28
F	28.92	8.31	17.67	18.32	28.47
Overall p-value	<0.01	<0.01	<0.01	<0.01	<0.01

*** p<0.05, ** p<0.01, [1] Continuous variables were re-coded into dichotomous categorical variables based on mean cut-offs**

Table 6.3: Multivariate Regressions Testing Associations of Care Provision, Household, Policy, and Individual Factors with Physical Health and Functioning (SF-36v2 Physical Subscore)

	Model 1	Model 2	Model 3	Model 4	Model 5
Block 1: Carer Type					
All orphan vs. Non-orphan carers	-0.14**	-0.12**	-0.09**	-0.05*	-0.04
Block 2: Care Provision Variables					
Family support		0.07*	0.05	0.06*	0.09**
Friend support		0.01	0.01	0.02	-0.003
Significant others support		0.04	0.002	-0.002	-0.01
Number of children in household		-0.04	-0.04	-0.07**	-0.05*
Block 3: Household Variables					
Economic asset index			0.07	0.10*	0.12**
Main Source of Income			0.26**	0.19**	0.15**
Access to flushable toilet			0.07	0.09*	0.07*
Hunger			-0.04	-0.06*	-0.03
Source of drinking water			-0.02	-0.02	-0.03
Water safe			0.04	0.05*	0.05*
Formal or informal housing			-0.10**	-0.08*	-0.09**
Block 4: Policy Variables					
At least one old age pension				-0.19**	-0.12**
At least one disability grant				-0.13**	-0.09**
At least one government housing subsidy				0.08**	0.06**
At least one child support grant				0.08**	0.04
At least one foster care grant				-0.02	-0.001
Block 5: Individual Variables					
Age					-0.26**
Gender					-0.09**
Ethnicity					-0.003
Language					-0.02
Education					0.14**
Model Statistics					
R	0.14	0.18	0.34	0.42	0.53
R^2	0.02	0.03	0.12	0.17	0.28
Adjusted R^2	0.02	0.03	0.11	0.16	0.27
F	30.60	10.24	17.51	19.12	27.97
Overall p-value	<0.01	<0.01	<0.01	<0.01	<0.01

*** p<0.05, ** p<0.01**

Table 6.4: Multivariate Regressions Testing Associations of Care Provision, Household, Policy, and Individual Factors with Mental Health and Functioning (SF-36v2 Mental Subscore)

	Model 1	Model 2	Model 3	Model 4	Model 5
Block 1: Carer Type					
All orphan vs. Non-orphan carers	-0.11**	-0.10**	-0.07**	-0.04	-0.03
Block 2: Care Provision Variables					
Family support		-0.01	-0.02	-0.01	0.02
Friend support		0.06*	0.07**	0.07**	0.05*
Significant others support		0.03	0.01	0.003	-0.01
Number of children in household		-0.01	-0.01	-0.04	-0.02
Block 3: Household Variables					
Economic asset index			-0.03	-0.02	-0.002
Main Source of Income			0.24**	0.19**	0.15**
Access to flushable toilet			-0.02	-0.01	-0.02
Hunger			-0.17**	-0.18**	-0.16**
Source of drinking water			0.06*	0.06*	0.05*
Water safe			0.01	0.02	0.02
Formal or informal housing			0.04	0.06	0.05
Block 4: Policy Variables					
At least one old age pension				-0.12**	-0.05*
At least one disability grant				-0.09**	-0.05*
At least one government housing subsidy				0.05*	0.03
At least one child support grant				0.09**	0.05*
At least one foster care grant				-0.01	0.003
Block 5: Individual Variables					
Age					-0.26**
Gender					-0.08**
Ethnicity					0.03
Language					-0.06
Education					0.12**
Model Statistics					
R	0.11	0.13	0.33	0.37	0.48
R^2	0.01	0.02	0.11	0.14	0.23
Adjusted R^2	0.01	0.01	0.10	0.13	0.22
F	17.99	5.09	15.83	14.27	21.40
Overall p-value	<0.01	<0.01	<0.01	<0.01	<0.01

*** p<0.05, ** p<0.01**

Table 6.5: Summary of Odds Ratios and Confidence Intervals for Multivariate Regressions Testing Associations of Care Provision, Household, Policy, and Individual Factors with Depression (CES-D)

	Model 1	Model 2	Model 3	Model 4	Model 5
Block 1: Carer Type					
All orphan vs. Non-orphan carers	1.39** (1.12-1.75)	1.48** (1.18-1.86)	1.40** (1.09-1.79)	1.36* (1.06-1.76)	1.32* (1.02-1.71)
Block 2: Care Provision Variables					
Family support		0.92 (0.70-1.21	1.02 (0.75-1.38)	0.99 (0.73-1.35)	0.91 (0.67-1.24)
Friend support		1.14 (0.90-1.42)	1.08 (0.85-1.37)	1.07 (0.85-1.36)	1.12 (0.88-1.43)
Significant others support		0.88 (0.66-1.17)	0.95 (0.69-1.30)	0.98 (0.71-1.35)	1.00 (0.72-1.39)
Number of children in household		0.78 (0.62-0.99)	0.76* (0.59-0.98)	0.83 (0.64-1.09)	0.78 (0.60-1.03)
Block 3: Household Variables					
Economic asset index			0.98 (0.68-1.40)	1.01 (0.70-1.47)	0.97 (0.67-1.42)
Main Source of Income			0.51** (0.40-0.65)	0.50** (0.39-0.65)	0.55** (0.42-0.71)
Access to flush toilet			0.87 (0.61-1.25)	0.85 (0.59-1.23)	0.85 (0.58-1.24)
Hunger			3.46** (2.66-4.50	3.59** (2.75-4.69)	3.52** (2.69-4.62)
Source of drinking water			0.73* (0.54-0.99)	0.73* (0.54-0.99)	0.73* (0.54-0.99)
Water safe			0.69 (0.18-2.72)	0.67 (0.17-2.69)	0.62 (0.15-2.56)
Formal or informal housing			0.83 (0.61-1.13)	0.80 (0.58-1.10)	0.83 (0.60-1.15)
Block 4: Policy Variables					
At least one old age pension				0.99 (0.70-1.39)	0.77 (0.54-1.10)
At least one disability grant				0.99 (0.66-1.50)	0.81 (0.53-1.23)

At least one government housing subsidy				0.57* (0.33-0.98)	0.62 (0.36-1.08)
At least one child support grant				0.76* (0.58-1.00)	0.84 (0.63-1.11)
At least one foster care grant				1.21 (0.67-2.20)	1.13 (0.61-2.07)
Block 5: Individual Variables					
Age					1.39 (0.97-1.99)
Gender					1.98** (1.51-2.60)
Ethnicity					0.39 (0.01-11.57)
Language					0.77 (0.33-1.81)
Education					0.82 (0.63-1.07)
Model Statistics					
Nagelkerke R^2	0.01	0.01	0.15	0.16	0.19

*** p<0.05**
**** p<0.01**

5. Multiplicative Health Risks for Orphan Carers

Previous analyses established that orphan carers reported worse health compared with non-orphan carers, and that age, gender, education were co-factors in this relationship. It follows that these factors may have an interactive effect with orphan type to worsen health outcomes. That is, female orphan carers might report worse health than male orphan carers; older orphan carers might report worse health than younger orphan carers; and low-educated orphan carers might report worse health than better-educated orphan carers. These interaction effects were tested in regression analyses.

5.1 Exploring Interactions between Age, Gender, Education and Caring for an Orphan

Being older, female, and having lower levels of education *combined with* caring for orphans was expected to worsen health outcomes. Surprisingly, results from regression models did not confirm this hypothesis. For general health and functioning (SF-36v2), being an orphan carer (β= -0.09, $p<0.01$) and age (β= -0.39, $p<0.01$) were each significantly associated with health outcomes ($F=157.94$, $p<0.01$) (***Table 6.6, Age, Model 1)***. However, the interaction of carer type by age (β= -0.05, $p<0.18$) was not significantly related to general health and functioning ($F= 105.94$, $p<0.01$) (***Table 6.6, Age, Model 2***). These findings were consistent for analyses of physical health and functioning subscores (SF-36v2 subscore) (***Table 6.6, Age, Model 3-4***), mental health and functioning subscores (SF-36v2 subscore) (***Table 6.6, Age, Model 5-6***), and depression (CES-D) (***Table 6.6, Age, Model 7-8***).

Tests were also run on the interaction between gender and carer type on health. For general health and functioning (SF-36v2), being an orphan carer (β= -0.13, p<0.01) and gender (β= -0.11, p<0.01) were each significantly associated with health (F=23.56, p<0.01) (***Table 6.6, Gender, Model 1)***. However, the interaction term of carer type by gender (β= 0.03, <0.70) was not significantly related to general health and functioning (F=15.74, p<0.01) (***Table 6.6, Gender, Model 2***). These findings were consistent for analyses of physical health and functioning subscores (SF-36v2 subscore) (***Table 6.6, Gender, Model 3-4***), mental health and functioning subscores (SF-36v2 subscore) (***Table 6.6, Gender, Model 5-6***), and depression (CES-D) (***Table 6.6, Gender, Model 7-8***).

Lastly, tests were conducted on the interaction between education and carer type on health. For general health and functioning (SF-36v2), being an orphan carer (β= -0.11, p<0.01) and education (β=0.33, p<0.01) were each significantly associated with health (F=110.84, p<0.01) (***Table 6.6, Gender, Model 1)***. However, the interaction term of carer type multiplied by education (β=0.05, p<0.19) was not significantly related to general health and functioning (F=74.51, p<0.01) (***Table 6.6, Gender, Model 2***). These findings were consistent for analyses of physical health and functioning subscores (SF-36v2 subscore) (***Table 6.6, Gender, Model 3-4***), mental health and functioning subscores (SF-36v2 subscore) (***Table 6.6, Gender, Model 5-6***), and depression (CES-D) (***Table 6.6, Gender, Model 7-8***). A summary of analyses of interaction terms of carer type with age, gender, and education are found in ***Table 6.6.***

Table 6.6: Interaction Effects of Age, Gender, and Education Combined with Caring for an Orphan on Health

	Model 1 General Health and Functioning (SF-36v2) (*β*)	Model 2 General Health and Functioning (SF-36v2) (*β*)		Model 3 Physical Health and Functioning (SF-36v2 subscore) (*β*)	Model 4 Physical Health and Functioning (SF-36v2 subscore) (*β*)		Model 5 Mental Health and Functioning (SF-36v2 subscore) (*β*)	Model 6 Mental Health and Functioning (SF-36v2 subscore) (*β*)		Model 7 Depression (CES-D) (*odds ratio, 95% CI*)	Model 8 Depression (CES-D) (*odds ratio, 95% CI*)
Interaction of Carer Type and Age											
Carer type	-0.09**	-0.06**		-0.09**	-0.06		-0.07**	-0.04		1.29* (1.02-1.61)	1.29* (0.90-1.86)
Age[1]	-0.39**	-0.37**		-0.36**	-0.34**		-0.36**	-0.34**		2.05* (1.65-2.56)	2.06* (1.57-2.70)
Carer type x Age	--	-0.05		--	-0.06		--	-0.04		--	0.99 (0.62-1.59)
Interaction of Carer Type and Gender											
Carer type	-0.13**	-0.15*		-0.13**	-0.17*		-0.10**	-0.11		1.38* (1.20-1.72)	0.95* (0.47-1.91)
Gender[2]	-0.11**	-0.11**		-0.11**	-0.12**		-0.08**	-0.08**		1.33* (0.96-1.85)	1.18* (0.80-1.73)
Carer type x Gender	--	0.03		--	0.04		--	0.01		--	1.52 (0.73-3.18)
Interaction of Carer Type and Education											
Carer type	-0.11**	-0.14**		-0.11**	-0.13**		-0.08**	-0.12**		1.31* (1.05-1.65)	1.28* (0.94-1.73)
Education[3]	0.33**	0.30**		0.31**	0.30**		0.29**	0.27**		0.51* (0.41-0.64)	0.51* (0.38-0.66)
Carer type x Education	--	0.05		--	0.04		--	1.51		--	1.07 (0.68-1.69)

*** p<0.05, ** p<0.01**

[1] Age was recoded into carers <39 years or carers ≥40 years, with a cut-off based on average age (M=39.39 years)

[2] Gender was recoded such as female was represented by a code of 1 and males represented by a code of 0

[3] Education was recoded such as carer who completed middle school were represented by a code of 1 and carers who complete a portion of middle school or less were represented by a code of 0

6. Summary

The first set of analyses tested whether carer type (*i.e.,* orphan vs. non-orphan carer) was independently associated with general health and functioning, physical health and functioning, mental health and functioning, and depression, adjusting for sociodemographic characteristics. For these, general health and functioning, physical health and functioning, and mental health and functioning, carer type was no longer associated with health after adjusting for age, gender, education, and economic assets.

A second set of analyses explored whether variables derived from the socio-ecological model of health were associated with health in this sample of carers, and whether they could potentially reduce health disparities between orphan and non-orphan carers. Analyses suggested that, very surprisingly, variable related to care provision did not reduce health disparities between orphan and non-orphan carers; health differences between these groups persisted after adjusting for support from family, friends, and significant others, and number of children in the household.

Figure 6.3: Photo of a Grandmother

However, analyses suggested that the presence of even one old age pension, disability grant, government housing subsidy, or child support grant may reduce health disparities between orphan and non-orphan carers.

A final set of analyses explored whether age, gender, and education exacerbated health problems amongst individuals caring for an orphan. Contrary to hypotheses, these analyses revealed no interactive effects of being older, female, and less educated combined with caring for an orphan on health.

CHAPTER VII: DISCUSSION AND CONCLUSION

1. Introduction

This study provides empirical and policy insights into the wellbeing of adults caring for AIDS-orphaned children in a community with one of the highest rates of HIV globally. It contributes empirical evidence on an understudied population directly and substantially affected by AIDS-related deaths by: (a) identifying who is caring for AIDS-orphaned children in a high HIV prevalence community using a representative sample; (b) assessing health-related outcomes amongst carers and comparing health of different carers using psychometrically sound tools; and, (c) using a theoretical model to guide the identification of risk and protective factors for carer health. Findings offered policy insights into how to support and mitigate negative impacts of care provision by firstly, offering data to assess whether an AIDS exclusivist policy approach is applicable for addressing the health of this population and secondly, providing evidence as to modifiable risk and protective factors policy makers and practitioners might focus on for design of interventions. This information fills an important gap in the literature. Thus far, literature has examined how AIDS-related deaths affect orphan outcomes such as health and education (for example, see Cluver and Gardner 2007; Cluver et al. 2007; K. Ford and Hosegood 2005). Also, studies have examined macro-economic household level affects (for example, see Bachmann and Booysen 2003, 2004; Collins and Leibbrandt 2007). However, research has largely failed to engage in the impact of AIDS-related deaths on family members caring for children (Kuo and Operario 2009). This study provides a deeper understanding of the range and types of impacts AIDS may have on family members. As a result, it helps build the foundation for a more holistic approach towards minimizing negative AIDS-

related impacts on the family. This chapter draws together interpretation of key findings, their implications for policy and practice, and directions for future research.

2. Key Findings and Interpretation

The study identified health as a serious issue for carers in Umlazi Township, an urban community experiencing high HIV prevalence, socioeconomic deprivation, and crime in South Africa. Even more concerning was that orphan carers (*i.e.,* AIDS-orphan and other-orphan carers) experienced significant health disparities compared to non-orphan carers. Further analyses showed that orphan carers were older, less educated, had fewer economic assets, and more likely to be women. These sociodemographic co-factors accounted for the association between being an orphan carer and health disparities. The study also identified a number of risk and protective factors for intervention design. The following discussion reiterates these essential findings organized by study question, situates these findings within the broader literature, and when applicable, highlights possible interpretations for findings.

2.1 Who are carers of children in a community directly and substantially impacted by HIV and AIDS?

The representative nature of the data collected and the high response rate enabled one to draw some insightful conclusions regarding who cares for children in Umlazi Township. Orphan carers comprised a third of all carers in this community. The high prevalence of orphan carers showed not only the large impact of AIDS on families (29% of children losing one or both parents to AIDS) but also the impact of violence, which was the primary cause of non-health related parental deaths (4% of children lost parents to shootings, stabbings, and beatings). The majority of children

(99%) were being cared for by extended family, primarily grandmothers or aunts and uncles. Maternal relatives were much more likely to care for children than paternal relatives. Moreover, no child-headed households were identified during representative community sampling. This prevalence data offered a measure of the extent HIV and AIDS has impacted family and community care structures. Moreover, these findings provided one of the few quantifiable assessments of who is caring for AIDS-orphaned children in South Africa.

Findings were consistent with previous studies. The finding that children were being cared for primarily by extended family was consistent with the literature which also documented strong trends regarding familial care (Monasch and Boerma 2004). Findings suggested that carers were typically related to children and female; these findings were consistent with other studies showing similarly that carers are usually female relatives (Foster et al. 1995; Howard et al. 2006; Yamano et al. 2006). Study findings which also showed that carers were primarily grandparents and that there were no child-headed households. These findings substantiated the largely anecdotal evidence from previous studies which have focused on grandmothers and child-headed households without rigorous representative data (Foster et al. 1995; Howard et al. 2006; Jones 2006; Madhavan 2004). Findings suggested that while the attention on grandmother carers may be warranted, the focus on child-headed households may be less applicable within the South African context. Even though the majority of carers were extended family and no child-headed households were found, this should not be taken as an indication that households did not face serious AIDS-related impacts. Certainly, as the discussion indicates further on, households faced a number of economic, social, and health challenges which reflected a level of AIDS-related strain upon family support systems.

Analyses of carers' characteristics supported the hypothesis that orphan carers had a distinctive demographic and socioeconomic profile compared to non-orphan carers. Overall, carers were predominantly female and an average age of 40 years. Carers' demographic and socioeconomic characteristics reflected high levels of deprivation in Umlazi Township including low levels of education, more than half of carers living in informal dwellings, and a third dependent on grants as the main source of household income. When carers were disaggregated into orphan and non-orphan carers for comparison, orphan carers showed different characteristics. Orphan carers were significantly more likely to be female, older, have less social support, less education, and more people in their household than non-orphan carers. Separating out AIDS-orphan carers from the other-orphan carers showed that AIDS-orphan carers were the worst off in terms of their demographic and socioeconomic profile. Over and above other-orphan carers, AIDS-orphan carers were more likely to be older and have less social support. AIDS-orphan carers also had less education than non-orphan carers. Surprisingly, different types of carers experienced similar levels of economic assets. However, overall findings suggested that orphan carers more generally, and AIDS-orphan carers more specifically, were exceptional in terms of their demographic and socioeconomic profile. That orphan carers experienced a different demographic and socioeconomic profile than non-orphan carers suggested that individuals caring for orphans may experience a number of vulnerabilities related to being poorer and disadvantaged in terms of age, gender, education, and access to social support, etc. The later discussion will engage in how these vulnerabilities might function as co-factors for disparities in health.

The finding that orphan and non-orphan carers experienced similar levels of economic assets was surprising. This may result from the high levels of overall

economic deprivation in Umlazi Township, with few differences from household to household. Another reason for this surprising finding may be that social welfare grants were reaching those in need within the study community, and thus leveling out economic assets between households with income and without. Even though households had similar levels of economic assets, findings strongly suggested that orphan and non-orphan carers experienced different demographic and socioeconomic characteristics.

2.2 What is the self-reported physical and mental health of carers?

The health of child carers in this community was poor. Mean general health and functioning scores were less than optimal, falling into the third quartile of the SF-36v2 scale. Levels of depression were high, with 30 percent of carers classified as meeting the threshold for clinically significant depression. Also concerning were levels of anxiety, with 73 percent of carers meeting the threshold for clinical levels of anxiety. Less than 5 percent of carers experienced PTSD. Similarly, a relatively small number of carers met the clinical threshold for hazardous drinking or alcohol dependence (3.79%) and the clinical threshold for drug problems (0.04%). Overall, findings suggested an urgent need for physical and mental health interventions for carers in Umlazi Township.

The finding of high levels of anxiety without corresponding levels of depression was surprising given the high comorbidity of these disorders (Hirschfeld 2001). High levels of anxiety without corresponding levels of depression may be related to the high levels of violence within the fieldwork site (see ***Chapter I, Section 3, Table 1.2*** and ***Chapter IV, Section 6.2, Graph 4.9***). While a number of studies have identified linkages between violence and anxiety (Hill et al. 1996; White et al. 1998), this

explanation may not be fully adequate given that studies have also shown elevated levels of depression due to exposure to violence (Clark et al. 2008). The discrepancy in prevalence of anxiety and depression may also be explained by the stresses of raising children, combining children into an existing family dynamic, and unmet life expectations, all which were identified during the exploratory qualitative study (see ***Chapter I, Section 2.1, Table 1.1***). The discrepancy between anxiety and depression may also be due to the presence of physical ailments that mimic symptoms of anxiety but are correlated with other health issues. For example, hunger might result in physical symptoms such as dizziness/fainting which could be misreported as symptoms of anxiety. While the availability of survey variables for verifying the reason for this discrepancy was limited, the variable regarding hunger may offer some insight. Hunger was reported at the household level with 39 percent of the sample reporting someone in their household sometimes or always going hungry and having physical symptoms of hunger. Obviously, the uses of these data are limited because one cannot disaggregate carer hunger from the hunger of other family members. However, high levels of hunger in the family may indicate that carers experienced physical symptoms that mimic symptoms of anxiety or that hunger and anxiety are linked in complex ways.

A second set of findings emerged when health outcomes were compared by carer type. Orphan carers experienced significantly worse general health and functioning, depression, and PTSD than non-orphan carers. There were no differences between carer types in terms of anxiety or alcohol use. When orphan carers were separated into AIDS-orphan and other-orphan carers for comparison, the directionality of difference was less clear, perhaps even going against the hypothesis that AIDS-orphan carers would have the worst health outcomes. In general health and functioning, AIDS-orphan carers had the worst outcomes but other-orphan carers had

the worst outcomes for depression and PTSD. Whilst patterns were less clear when orphan carers were disaggregated into AIDS-orphan and other-orphan carers, findings overwhelmingly pointed towards the conclusion that orphan carers experience significantly worse health outcomes than non-orphan carers. These findings suggested that while the health of all carers was of serious concern, orphan carers had significantly worse health and may be in particular need for physical and mental health interventions.

The finding that orphan carers experienced worse outcomes than non-orphan carers was a pattern that was largely confirmed by literature on poor health outcomes amongst surrogate carers (Burton 1992; Irving et al. 1995; McMillan 1996; Raveis et al. 1998; Solomon and Marx 2000). However, the result that AIDS-orphan carers did not consistently experience the worst health outcomes compared to other-orphan carers was not hypothesized but may be explained by examining the context of carers' lives. As noted previously, carers lived in a high crime and high violence township. The carers most directly affected by violence were those caring for other-orphaned children. The most frequent causes of parental deaths within this group of children were stabbings and shootings (see ***Chapter IV, Section 6.2, Graph 4.9***). That children came to live with these carers under such violent conditions may be linked to corresponding levels of PTSD amongst carers of other-orphaned children; this might also explain some of the unexpected directional pattern of health disparities in which carers of other-orphaned children experienced worse depression and PTSD than AIDS-orphan carers.

2.3 Is carer type an independent risk factor for health outcomes?

Findings thus far suggested that caring for an orphan may have functioned as a crucial risk factor for poor health. Multivariate analyses were used to evaluate possible reasons for why orphan carers experienced worse health. During bivariate analyses, being an orphan carer was significantly related to poorer health outcomes. However, when adjusting for age, gender, education, and economic assets in multivariate analyses, there were no independent associations between carer type and general health and functioning. Similarly, when adjusting for age, education, and economic assets, there were no independent associations or lesser significance between carer type and depression. The emerging story was that these particular sociodemographic factors fully accounted for the association between carer type and health, offering one explanation for why orphan carers experienced health disparities. The poor outcomes amongst these orphan carers suggested that they needed more support, and that support might be targeted towards female, older, less educated, and poorer carers. Such support may also have positive implications for the children under their care.

A number of studies confirm that age, gender, education, and economic assets function as fundamental risk and protective factors for health. For example, there is extensive literature documenting the inverse correlation between age and health (for example, see Crimmins et al. 1994; House et al. 1994; Kim et al. 2009; Knight et al. 2003; Mirowsky and Ross 1992; Mojtabai and Olfson 2005). This literature is consistent with study findings which showed that older carers experienced poorer health outcomes. There is also extensive literature documenting the positive nd ADDIN EN.CITE Guralnik et al. 1993; Ross and Wu 1995; Winkleby et al. 1992). This literature is

consistent with findings which showed that less educated carers experienced poorer health outcomes. Studies also show a relationship between gender and health (for example, see Emslie et al. 2002; Grotvedt and Stavem 2005; Kolip 2005) although the directionality of the relationship varies. Findings from this study showed an association between females and poor health outcomes; the particular directionality of difference for females in this study may reflect patterns of gender vulnerability specific to South Africa or sub-Saharan Africa. Numerous studies show a positive correlation between economic status and health (for example, see Adler et al. 1994; Adler and Ostrove 2006; House et al. 1990; Kaplan et al. 1987; Marmot et al. 1997; Williams 1990). This literature is consistent with findings from this study which showed an association between fewer economic assets and poor health. What is more interesting is identifying how these variables might drive orphan and non-orphan carer differences in health.

A number of explanations are proposed for why being older, female, having less education, and owning fewer economic assets was associated with worse health amongst orphan carers. In the case of age, a number of studies identify pathways through which aging results in poor health. Aging can result in a loss of control over physical activities, raising levels of stress and restricting an elderly person's ability to seek medical care (Rodin 1986). Older individuals may also experience real or perceived isolation and lack social networks, all linked with poor physical health (Cornwell and Waite 2009). Aging may be correlated with loss of income resulting in poor health (Deaton and Paxson 1998). Specific to developing countries, the high prevalence of early childhood conditions including poor nutrition and exposure to disease can have a cumulative effect over time resulting in a high prevalence of chronic conditions in older age (Zunzunegui et al. 2008). Specific to South Africa, the roll out

of old age pensions may be shared amongst a broad range of family members due to poverty and result in a neglect of the needs of the elderly recipient (Moller and Welch 1990; Moller and Sotshongaye 1996). In the case of gender, studies identify a number of pathways through which being female results in poor health. Females may have difficulty accessing employment or domestic duties may restrict ability to work (Bird and Fremont 1991; Jennings et al. 1984). Unemployment may lead to economic hardship or stress which impacts negatively upon health (Pearlin et al. 1981). Gender inequalities such as discrimination against female children in health and care along with lack of decision-making power in regards to income expenditure may also lead to worse health outcomes for females (Okojie 1994). In the case of education, there are a number of pathways for poor health. Individuals with higher education are more likely to have full-time employment and high incomes, giving them the ability to access health resources (Linn et al. 1985). Individuals with higher education are also more likely to lead healthier lifestyles (E. Ford et al. 1991; Shea et al. 1991) and receive preventative medical care (Ross and Wu 1995). In the case of economic assets, a number of studies suggest that economic factors determine health. Socioeconomic status may determine what environment one lives with a number of studies linking environmental factors such as living environment, neighborhood, and community factors to health outcomes (Haan et al. 1987; I. Kawachi and Berkman 2003; Krieger 1991; Menec et al. 2010). Income inequality may impact upon health by influencing an individual's access to life opportunities and material resources, all important precursors to good health (Williams 1990). For example, Kaplan et al.'s (1996) study showed that areas with higher income inequality spent less on education and have worse educational outcomes. Inequality may also impact health by affecting social processes such as access to social support (Ichiro Kawachi et al. 1999). However, there is also a

bidirectional linkage between income and health with poor health serving as a factor that can drive lower income (A Case and Deaton 2005). Fieldwork observations in Umlazi Township suggested that lack of economic assets may be one of the major causes of poor health. For example, orphan carers were more likely to live in informal houses with limited or no electricity resulting in the use of paraffin stoves which can exacerbate chronic pulmonary illnesses; both of these variables were associated with economic asset scores. Orphan carers struggled with finding money for transport due to additional financial strains caring for higher numbers of children in their family; certainly these financial struggles impacted their ability to go to the community clinic and hospital for health check-ups. Orphan carers also described how much of their time is taken up with caring for children, finding less time to go to church or see family members and friends. AIDS-orphan carers specifically talked about the issue of stigma and how this resulted in feelings of isolation where friends or neighbors refused to provide monetary or social support. These economic factors are likely to contribute to barriers to maintaining or achieving better health outcomes. Together, all of these factors – age, gender, education, and economic assets - may be linked into a wider process of social exclusion related to the history of apartheid and AIDS in South Africa. This social exclusion may increase the vulnerabilities that orphan carers experience and requires not only design of interventions to address the specific risk factors that may be related to poor health, but broader social programs that can build on the capabilities on individuals to address deprivations (Sen 1992). Whilst longitudinal data would be more helpful to confirm the direction of association, these previous studies identify several likely pathways for negative outcomes in orphan carers.

2.4 What socio-ecological factors explain health disparities associated with caring for an orphan?

When adjusting for age, gender, education, and economic assets in multivariate analyses, there were no independent associations between carer type and general health and functioning. Based on these findings, additional analyses were conducted to evaluate whether variables related to care provision (*i.e.,* carer's social support and number of children in the household) reduced the relationship between carer type and carer health. Surprisingly, when adjusting for care provision variables, being an orphan carer was still significantly associated with poor health suggesting that non-care related factors may play a role in influencing the poor health of orphan carers. Indeed findings suggest that while care-related factors had some effect on orphan carer health, the cumulative effect of risk factors at all levels of the socio-ecological model (individual, care-related, household, and policy) have a strong association with poor health outcomes amongst orphan carers.

Findings confirmed the importance of studying the care process within context. A number of factors directed related to care provision (*i.e.,* type of carer, number of children in the home, and support for carers) interact with non-care factors (*i.e.,* household factors, social policy on grants) to drive disparities in orphan carer health. More importantly though, these findings offered insights into developing more refined theoretical approaches towards the study of challenges orphan carers encounter. That the addition each cluster of system-factors in the socio-ecological model offered increasing gains in explaining orphan carer health, suggested that orphan carer disparities were the result of cumulative risk factors. Trying to understand how factors interact to result in cumulative disadvantage demands a more refined theoretical

approach. Possible theoretical approaches that could be tested include the cumulative advantage/disadvantage theory which tries to understand the process through which inequality is generated (Merton 1968). Whilst Merton originally proposed this theory to analyze why some scientists succeed but not others, the theory has been applied in a number of fields. Most insightful is the extension of this theory into gerontology where it is used to understanding how inequalities in family attributes, education, economics, etc. result in the accumulation of risk over time that can result in disparities in the health of elderly individuals (Crystal and Shea 1990; Dannefer 2003; Ferraro and Shippee 2009). In sum, these findings point towards the need to apply a more refined theoretical approach towards the study of the disparate challenges faced by orphan carers, particularly in regards to understanding how various aspects of risk accumulate to have an exponential effect in gaps in orphan carer outcomes compared to others. This study offered directions for developing new theoretical questions regarding the impact of AIDS upon the family.

Findings also identified several possible risk and protective factors for health by examining associations of variables derived from the socio-ecological model of health. Grants, particularly the old age pension, disability grant, government housing subsidy, and child support grant, reduced the association between carer type and health. This suggests that grants may play a particularly important role in reducing orphan disparities in health. In addition to these grants, a number of modifiable risk and protective factors were strongly associated with general health and functioning. Carers who were more educated, with higher levels of support from family, and in households with more economic assets, dependent upon salaries for household income, access to piped water, and living in formal houses were more likely to report better general health and functioning. Conversely, carers in households with any level of hunger were

more likely to report poorer general health and functioning. Similarly, a number of modifiable risk and protective factors were also strongly associated with depression. Carers in households with salaries as the main source of household income and with access to piped water were less likely to report depression. Conversely, carers in households reporting any level of household hunger were more likely to report depression.

Identifying these risk and protective co-factors constitutes an important step towards design of interventions to support and improve carer health. However, some findings need to be interpreted with some caution. For example, the finding that the receipt of an old age pension, disability grant, and government housing subsidy was associated with poorer general health and functioning (***Chapter VI, Table 6.2, Model 5***) seems surprising. However, the surprising direction of association may be a result of grants being taken up by those most in need; that is, the old age pension and disability grant are more likely to be received in households where carers are already in poor health or in households with others of poor health. Some literature supports this explanation. For example, the old age pension in particular has been shown to be associated with poor health outcomes in recipients including increasing rates of physical abuse (Steyn and Schneider 2001). Similarly, other literature suggests that older age has been associated with poor mental health (for example, see Crimmins et al. 1994; House et al. 1994; Kim et al. 2009; Knight et al. 2003; Mirowsky and Ross 1992; Mojtabai and Olfson 2005). Moreover, while it is clear some grants may serve as a form of poverty alleviation (A. Case and Deaton 1998; Lund 1999; Maitra and Ray 2003), which can in turn function as a protective pathway for health, it is less clear whether grants act as protective factors for carer health through an individual or household pathway. Even though most grants (*e.g.,* old age pension, disability grant,

child support grant, and foster care grant) are targeted at individuals, some evidence suggests that grants may be shared widely throughout the household (Booysen 2004; Ferreira 2006). Determining the pathway through which these grants work as risk or protective factors is important, since different pathways have different implications for carer health. For example, if these grants act as protective factors through a household pathway, the effect of these grants as protective factors may lessen as household numbers expand with additional orphans. Findings that also need further interpretation

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health outcomes. Findings suggested that even though adjusting for age, gender, and education resulted in no independent relationship between carer type and health outcomes, these co-factors did not interact with carer type to escalate the negative health outcomes faced by orphan carers.

A number of studies have suggested that these factors can interact to impact health (Wang et al. 2009; Wykle and Musil 1993); for example, being female and having poorer economic status may have a multiplicative effect upon poor health than just being a female. However, these interactions may not always occur as in the case of this study. Even if gender, age, and education do not have an interactive effect with carer type to increase poor health, these variables still function as important co-factors for orphan carer disparities in health.

3. Implications for Policy and Practice

Taken together, this study has a number of important policy and practice implications. First, the study highlights the high burden of physical and mental health faced by carers in high HIV prevalence, poor, violent urban South African communities. This suggests that policy makers and practitioners might prioritize strategies to address these health problems. Despite large burdens of illness, mental health in developing countries has been largely neglected. Spending on mental health resources in the global South is severely under-resourced with 90 percent of global mental health resources located in high-income countries. Governments in developing countries spend less than one percent of their total health budgets on mental health and mental health professionals in these areas are inadequate for service needs (World Health Organization 2005). To an extent, this is the result of a lack of prioritization but also reflects wider shortages in health personnel and inadequate health systems.

Another policy implication of this study relates to the policy debate on AIDS exceptionalism (see ***Chapter I***). In this study, orphan carers experienced significantly worse health than non-orphan carers. However, when AIDS-orphans were disaggregated from other-orphan carers, patterns were less clear. This suggested that taking an AIDS exceptionalist approach in which AIDS-orphan carers are singled out for the roll-out of physical and mental health interventions, might result in a missed opportunity for improving outcomes of all orphan carers. Study findings highlighted how the polarization of the AIDS-exceptionalist debate and points towards the need to take a nuanced intervention approach towards supporting individuals affected by AIDS. More generally, interventions to support AIDS-affected individuals such as carers may benefit from an approach that does not focus on targeting AIDS-affected groups since such an approach may be difficult to achieve from a practical standpoint due to stigma. By targeting interventions at both AIDS-orphan and other-orphan carers, interventions may be even more effective in reaching AIDS-orphan carers since caring for an orphan, rather than caring for an AIDS-orphan, becomes the primary manner for identifying carers in need of mental and physical health interventions. Decisions to take an AIDS-exceptionalist approach should be evaluated on a case by case basis, and approaches for interventions that target AIDS-affected populations or populations more generally need to be made on the basis of rigorous evidence.

Finally, the study has identified a number of potential entry-points for interventions for orphan carers. While some factors cannot be subject to intervention (*i.e.,* age, gender), other risk and protective factors offer promising points for interventions to improve the health of carers generally. For example, levels of education can be addressed and may improve on the strategies that carers use to cope with health challenges and stresses associated with caring for orphans. Similarly,

grants function as an important source of income for carers and households. Ensuring that grant programs continue to identify those in need and remove barriers to obtaining grants will remain indispensable to maintenance of health. Moreover, improving the housing situation of carers, specifically in regards to providing formal housing and access to potable water may be other points of intervention. Employment may also help address orphan health disparities. Finally, addressing the issue of household hunger through food parcels and other feeding programs might reduce disparities in health. Interventions needed to be tested carefully first to ensure effectiveness and sustainability.

4. Study Limitations

This study offers a number of insights into the lives of carers in Umlazi. However, the study also is limited in several ways. First, while every effort was made to rigorously translate and back-translate assessment tools (see details regarding translation in ***Chapter III, Section 3.2.4***), translation may not have captured equivalent constructs of illness. In the case certain tools (*e.g.,* SF-36, CES-D, AUDIT, and HTQ), this is less of a concern since studies have specifically tested the conceptual equivalence of translations for South African populations (Smit et al. 2006a; Ware et al. 2007). However, in the case of measure of clinical anxiety and drug use (*e.g.,* K10 and DUDIT), this study faced the possibility that concepts of illness may be inadequately captured during translation.

A findings should be interpreted with caution because clinical cut-offs were derived from data on Western populations. This may have resulted in the possibility application of culturally invalid clinical cut-offs since the study population was predominantly black-African, Zulu South Africans. However, these sorts of concerns

reflect broader limitations encountered by cross-cultural mental health research (Jain and Jadhav 2009; Swartz 1987). Accurate assessment of mental health in diverse cultural communities requires valid measures while on the other hand, the availability of measures validated for sub-Saharan African contexts are very limited (Ballenger et al. 2001; Bhui et al. 2003; Draguns and Tanaka-Matsumi 2003). This study tried to minimize these limitations by using a hierarchical selection process that focused firstly of tools with strong psychometric properties translated and validated for South African populations. When such tools were unavailable, a second best choice focused on tools with strong psychometric properties that had been used in South African populations. In the absence of second-best tools, the final choice was those with strong psychometric properties that had been used in other developing country populations (see details on tool selection in ***Chapter III, Section 3.2.1***).

Third, this study would have been strengthened by using tools comparable to national prevalence data on health outcomes. The first nationally representative household survey of adult mental health in South Africa used the CIDI to generate mental health diagnoses. Twelve-month prevalence estimates from KZN province from this study showed that the prevalence of mood disorders was 5.2%, anxiety disorders was 9.5% and substance use was 4.5% (Stein et al. 2007). It was difficult to assess whether the prevalence of depression (30.33%) and anxiety (63.78%) in this study far exceeded these provincial rates or whether the differences were due to the higher yield in self-report measures compared to clinician-administered measures (Coyne et al. 2000). While clinician administered tools would not have been appropriate in the community-level survey conducted in this study, similar measurement tools would enabled equal comparisons between study findings and national prevalence data.

Finally, the study had a cross-sectional design. This type of study design does not allow for any interpretation about temporal order or mechanistic pathways. Such temporal and mechanistic pathways could have been utilized in the design of interventions targeting specific pathways for health. The limitations discussed previously can be addressed through future studies.

5. Directions for Future Research

This study supported the hypothesis that the health of orphan carers was a serious concern that has largely been ignored in previous studies on AIDS-orphan carers. Future studies can build upon this evidence and explore a number of new areas helpful for boosting resilience in this population. First, studies on similar populations could improve on study design. For example, similar studies may want to consider moving to a study site with more varied levels of socioeconomic deprivation since this may show a shift in patterns with different carers exhibiting significant differences in economic assets. Moreover, utilizing an anxiety tool with better specificity would be helpful in future studies. Studies utilizing tools which have been validated for cultural equivalence and using clinical norms based on similar populations would improve upon the quality of data gathered. Finally, similar studies may want to expand upon the types of risk and protective factors assessed. For example, variables such as use of paraffin stoves, transport and other access barriers to medical care, and stigma were not assessed in this study but may play an important risk or protective role in carer health. In addition to these suggested improvements in similar studies, there are a number of areas that have been identified as a potential for follow-on studies.

A number of future studies could contribute to the evidence base. First a number of studies could contribute to more refined theoretical models of carer health

by testing the cumulative disadvantage/advantage theory. Such testing would require focusing upon the modifiable risk and protective factors identified in this study, and testing the mechanisms through which these factors influence carer health using a longitudinal design. This type of study design would yield data on the particular pathways through which these risk factors interact over time within the etiologic process to influence health outcomes. This type of study design would also be helpful for identifying successful strategies of resilience which are just as fundamental as identifying the types of risk mechanisms leading to negative outcomes.

Secondly, future studies need to be conducted on the linkages between carer outcomes and child and family wellbeing. For example, while this study identified a number of risk and protective co-factors (*e.g.,* age, gender, education, economic assets) for orphan carers' health disparities, additional studies could elaborate on how these co-impact upon children's outcomes. The literature suggests that there may be possible linkages between carers' characteristics and the poor outcomes seen in fostered children (Madhavan 2004). Studies are also needed to examine how specific dynamics of the care relationship impact carer health. For example, children's characteristics and behaviors may impact upon carer health. Finally, studies are needed to examine how family dynamics influence carer and child outcomes. For example, specific shocks to the family including parental illness and death may impact carer and child wellbeing. Possible study designs include a matched pair longitudinal study design. Such a study might for example, follow carers and their children over two years to allow for interpretation of temporal order and mechanistic pathways.

Finally, future studies are needed for the design and efficacy testing of individual- family- and community- based interventions to address carer health as well

as the specific health disparities faced by orphan carers. These studies could be designed around the modifiable risk and protective factors identified in this study. Intervention studies also need to focus upon the particular challenges entailed in rolling out interventions in South African communities including human resource constraints, health system limitations, and economic and logistical issues.

6. Conclusion

This study provides a comprehensive assessment of health challenges faced by child carers in a community with one of the highest rates of HIV prevalence globally and which also faces a number of challenges including high rates of violence, crime, and poverty. The socio-ecological model was used as a conceptual guide for approaching the study of carer health and very importantly helped situate carers and their health issues within the broader context of their care relationships, households, communities, and the particular policy context of South Africa. An approach that is context-specific is important not only to understanding how challenges might relate to the particular temporal and cultural environment that carers are located. Also such approaches provide crucial information for the formulation of context-appropriate interventions.

The study identified health as a crucial issue for carers more generally. More importantly, the study drew attention towards the health of orphan carers, who experience significantly worse health than non-orphan carers. Strategies designed to support carers and the children under their care need to address the severe burden of physical and mental illness in this population. When orphan carers were disaggregated into AIDS-orphan and other-orphan carers for comparison, AIDS-orphan carers did not always experience the worse health. This surprising result challenged the policy

orthodoxy and demonstrated that a singular focus on AIDS-orphan carers may constitute a missed opportunity to meet the needs of another important cohort of carers in this community. Indeed, the study draws attention to how HIV and AIDS is situated within a larger set of interlinked challenges that come together to make carers and their families prone to vulnerability. Very importantly, this study helped identify possible approaches towards interventions. It is hoped that this research will contribute rigorous and timely scientific evidence to policies and programs serving these carers, and in so doing, reduce burdens associated with HIV/AIDS-related illness and deaths.

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Urban Focus Group 2, facilitated by Caroline Kuo, KwaZulu-Natal, August 16, 2006.

1.2 Interviews with NGOs/CBOs

Respondent A, NGO/CBO 1, telephone interview by Caroline Kuo, Kwa-Zulu Natal, July 27, 2006.

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APPENDIX 1: ENGLISH VERSION OF QUESTIONNAIRE

CARE PROVIDER SURVEY

IDENTIFICATION OF DWELLING AND FIELD STAFF INFORMATION

Enumeration Area Number: _____

Land Parcel Number or ERF Number of Dwelling: _____

Address:

(*dwelling number*) _____ (*street name)* _____

(*village, suburb, locality*) _____ (*postal code)*_____

Interviewer 1 Name: _____

Interviewer 2 Name (*fill in if applicable*): _____

How many visits did you make to the house? _____

Original Interview Date (*day/month/year*): _____

Beginning time: _____ End time: _____

Date of Followup Interview (*day/month/year*): _____

Circle type of response	Result Code	Details of Non-response
1	Completed	
2	Partly complete	
3	No children in household	
4	Refused	
5	Vacant dwelling	
6	Referral(s) made	
7	Child Caregiver	

PRELIMINARY SURVEY QUESTIONS

Read out: **Good morning/afternoon. I am** (*state first interviewer name here*) **and I am** (*state second interviewer name here*)**. I am/we are conducting a study on the experiences of adults caring for children in your community. Are there any children living in this household at least four nights on average per week during the last four weeks?** (c*ircle one answer choice*)

Yes No

If they answer no, read out: **Since my/our team is trying to understand childcare in your community, I/we will try another home where children are living. Thank you for your time. Have a wonderful day.**

If they answer yes, read out: **I am/we are most interested in speaking to the person or persons who provides the majority of care for children in this household, that is, the person who looks after them most. This is probably the person who gets them ready for school in the morning. May I/we speak to this person or persons? Is this person or persons 18 years of age or older?** (c*ircle one answer choice*)

Yes No

If they answer no, read out: **How old is the child care provider?** *(write age in years*) _____. **Why is the child the main care provider?** (*fill in answer)* _____.
This study only focuses on child care providers aged 18 or older only. Thank you for your time. Have a wonderful day.

If there is more than one primary child care provider, read out: **Since there is more than one person who provides the majority of care for children in this household, I/we will randomly choose one person to speak to** (*flip a coin to determine which person to speak to*).

Read out: **Can I speak to** (*state name of person*)**?**
If this person is not available, try again at another time.

If the primary child care provider is available, read out:
Do you have a few minutes for me/us to tell you about this study? *Go over participant information sheet/consent form. If person consents to participate, have them sign a copy of the consent form. Provide a copy for the potential participant to keep.*

If they want to participate, read out: **Can you speak to me/us now? If not, can I/we wait or come back on** (*fill in day)* _____ *(fill in time)* _____. **Can I/we have a contact phone number***?* (*fill in phone number*) _____.

If they do not want to participate, read out: **Thank you for your time. Have a wonderful day.**

CONTACT INFORMATION FOR SURVEY PARTICIPANT

Name (*first name*) _____ (*surname)* _____

Telephone number (*if available*): _____

Cellphone number (*if available*): _____

Postal Address: (*number*) _____ (*street name)* _____

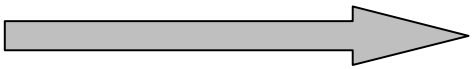
(*village/suburb/locality*) _____ (*postal code*) _____

Read out: **We may have to contact you in the future. This may be difficult if you move or your telephone changes. If we are unable to get in touch with you, who could we contact who would know your information? This is probably a family member or close friend who you would remain close to even if you move.**

Name of contact: _____
Relationship: _____
Phone Number of contact: _____

Read out: **Is there somewhere to speak in private?**

Note to Survey Staff: Use the following format to assign a privacy code.
EA# - Land Parcel/ERF# - Care provider's firstname and surname initials



PRIVACY CODE:

MAIN SURVEY QUESTIONS

SECTION 1: HOUSEHOLD INFORMATION AND DEMOGRAPHIC INFORMATION

Read out: **I would like to collect some information about this house and the people who live here. I would like to draw this information with you. Let me show you an example of what this information will look like.**

Note to Survey Staff: Refer to the example drawing on the extra page labeled, "Section 1: Household and Demographic Information – Example Drawing of House and Occupants". Work with the child care provider to draw the following information using the extra pages labeled, "Section 1: Household and Demographic Information – Drawing of Home and Occupants and Drawing of Home an Occupants (Extra Page)". You will need to refer to the drawing as the survey progresses.

1.1 (M) **Can you help me draw the rooms in this house?** *Label rooms. Include toilet and bathrooms. Be sure to include outside buildings if part of the property.*

Note to Survey Staff: Fill in questions 1.2-1.4 using your own observation. Do not ask the participant to answer these questions.

1.2 (G) Dwelling Type: (c*ircle one answer choice*)

1 = dwelling/house or brick structure on a separate stand or yard
2 = traditional dwelling/hut/structure made of traditional materials
3 = flat or apartment in a block of flats
4 = town/cluster/semi-detached house (simplex, duplex, triplex)
5 = dwelling/house/flat/room in backyard
6 = informal dwelling/shack in backyard
7 = informal dwelling/shack not in backyard, e.g. in an informal/squatter settlement
8 = room/flatlet on a property or a larger dwelling
9 = caravan/tent
10 = other (specify): _____

1.3 (SADH) What is the main material of the floor? (c*ircle one answer choice*)

1 = earth/sand/dung
2 = bare wood planks
3 = cement
4 = vinyl
5 = carpet
6 = ceramic tiles
7 = parquet or polished wood
8 = other (specify): _____

1.4 (SADH) What is the main material of the walls? (c*ircle one answer choice*)

1 = plastic/cardboard
2 = mud
3 = mud and cement
4 = corrugated iron/zinc
5 = prefab
6 = bare brick / cement block
7 = plaster / finished
8 = other (specify): _____

1.5 (SADH) **Where do you sleep?** *Use an adult male or female figure and label the caregiver as person number "1" in the face area.*

1.6 (M) **How old are you?** *Write age in years, for example "58 Y".*

1.7 (M) **What is your first name and surname?** *Write their first name and surname underneath the age.*

1.8 (G and M) What is the highest level of education that you have successfully completed? ***Fill in the correct code below the first name and surname, for example, "1 edu".***

1 edu= No Schooling
2 edu = Grade R/0
3 edu = Grade 1/Sub A
4 edu = Grade 2/Sub B
5 edu = Grade 3/Standard 1
6 edu = Grade 4/Standard 2
7 edu = Grade 5/Standard 3
8 edu = Grade 6/Standard 4
9 edu = Grade 7/Standard 5
10 edu = Grade 8/Standard 6/Form 1
11 edu = Grade 9/Standard 7/Form 2
12 edu = Grade 10/Standard 8/Form 3
13 edu = Grade 11/Standard 9/Form 4
14 edu = Grade 12/Standard 10/Form 5/Matric
15 edu = NTC I
16 edu = NTC II
17 edu = NTC III
18 edu = Certificate with less than Grade 12/Standard 10; Diploma with less than Grade 12/Standard 10
19 edu = Certificate with Grade 12/Standard 10; Diploma with Grade 12/Standard 10
20 edu = Bachelors Degree; Honours Degree
21 edu = Higher Degree (Masters, Doctorate)
22 edu = Other (*specify*): _____
23 edu = Don't know

1.9a (G) **What population group do you belong to?** *Fill in the correct codes below the education level, for example, "1 P".*

1 P = African/Black
2 P = Colored
3 P = Indian/Asian
4 P = White
5 P = Other *(specify):* _____

1.9b (G) **What is your native language?** *Fill in the correct codes below the population group, for example, "1 L".*

1 L= isiZulu/Zulu
2 L = isiXhosa/Xhosa
3 L = isiNdebele/South Ndebele/North Ndebele
4 L = Sepedi/Northern Sotho
5 L = Sesotho/Southern Sotho/Sotho
6 L= Setswana/Tswana
7 L = Siswati/Swazi
8 L = Tshivenda/Venda
9 L = Xitsonga/Tsonga
10 L = Afrikaans
11 L = English
12 L = Other *(specify):* _____

Read out: **Now I would like to learn about any people who stayed in this household at least 4 nights on average per week in the last 4 weeks.**
Note to Survey Staff: Ask questions 1.10 to 1.15 for each person in the household who has stayed in the house 4 nights on average per week in the last 4 weeks. Do not forget babies.

1.10 (SADH) **Who else sleeps in each room of the house?** *Use adult/child male/female figures and label these individuals as person number "2", "3", "4", etc. in the face area.*

1.11 (G) **How old is . . . . ?** *Write age in years, for example "58 Y" or if the person is under 1 year, write age in months, "8M".*

1.12 (M) **What is . . .'s first name and surname?** *Write their first name and surname underneath the age.*

1.13 (M) **Is anyone in this house of a different population group or language group than you?** (*circle one answer choice)*

1 = Yes/Yebo → *Go to questions 1.14a and 1.14b and repeat for each person in the house*
2 = No/Cha → *Go to question 1.15*

Ask only if participant answered "Yes" to question 1.13.
1.14a (G) **What population group does . . . belong to?** *Fill in the correct codes below the education level, for example, "1 P".*

1 P = African/Black
2 P = Colored
4 P = White
5 P = Other *(specify in drawing)*

Ask only if participant answered "Yes" to question 1.13.
1.14b (G) **What is . . .'s native language?** *Fill in the correct codes below the population group, for example, "1 L".*

1 L= isiZulu/Zulu
2 L = isiXhosa/Xhosa
3 L = isiNdebele/South Ndebele/North Ndebele
4 L = Sepedi/Northern Sotho
5 L = Sesotho/Southern Sotho/Sotho
6 L= Setswana/Tswana
7 L = Siswati/Swazi
8 L = Tshivenda/Venda
9 L = Xitsonga/Tsonga
10 L = Afrikaans
11 L = English
12 L = Other *(specify in drawing)*

1.15 (M) **What is . . . .'s relationship to you** (*i.e. the caregiver – person number "1"*)**?** *Fill in the correct code for each person below the population/language group if applicable. For example, "12 rel".*

1 rel = husband/wife/partner
2 rel = father/mother/step father/step mother
3 rel = grandparent/great grandparent
4 rel = in-laws
5 rel = aunt/uncle
6 rel = biological or step son/daughter
7 rel = brother/sister/step brother/step sister
8 rel = maternal grandchild
9 rel = paternal grandchild
10 rel = maternal great grandchild
11 rel = paternal great grandchild
12 rel = maternal niece or nephew
13 rel = paternal niece or nephew
14 rel = non-related child who was a neighbour's child
15 rel = non-related child who was a friend's child
16 rel = non-related foster child that you previously did not know through a neighbor or friend
17 rel = other (*specify in drawing)*

Note to Survey Staff: Return to question 1.10. Repeat questions 1.10 to 1.15 for every person in the household

SECTION 2: CHILDREN IN HOUSEHOLD

Read out: **Now I would like to collect some information about the children who are 17 years of age or younger living in this home. First I am going to ask about their schooling.**

Question Number	*Note to Survey Staff: If there are not enough spaces, please continue using another blank survey. Only fill in information for children 17 years and younger. Match the person number to the number you assigned to the child in the drawing.*														
		Person Number														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
2.1 (G)	**What is the highest level of education that . . . . has successfully completed?** 1 = No Schooling 2 = Grade R/0 3 = Grade 1/Sub A 4 = Grade 2/Sub B 5 = Grade 3/Standard 1 6 = Grade 4/Standard 2 7 = Grade 5/Standard 3 8 = Grade 6/Standard 4 9 = Grade 7/Standard 5 10 = Grade 8/Standard 6/Form 1		1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ ☐

Question Number	*Note to Survey Staff: If there are not enough spaces, please continue using another blank survey. Only fill in information for children 17 years and younger. Match the person number to the number you assigned to the child in the drawing.*															
		Person Number														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
	11 = Grade 9/Standard 7/Form 2		9☐	9☐	9☐	9☐	9☐	9☐	9☐	9☐	9☐	9☐	9☐	9☐	9☐	9☐
	12 = Grade 10/Standard 8/Form 3		10☐	10☐	10☐	10☐	10☐	10☐	10☐	10☐	10☐	10☐	10☐	10☐	10☐	10☐
	13 = Grade 11/Standard 9/Form 4		11☐	11☐	11☐	11☐	11☐	11☐	11☐	11☐	11☐	11☐	11☐	11☐	11☐	11☐
	14 = Grade 12/Standard 10/Form 5/Matric		12☐	12☐	12☐	12☐	12☐	12☐	12☐	12☐	12☐	12☐	12☐	12☐	12☐	12☐
	15 = NTC I		13☐	13☐	13☐	13☐	13☐	13☐	13☐	13☐	13☐	13☐	13☐	13☐	13☐	13☐
	16 = NTC II		14☐	14☐	14☐	14☐	14☐	14☐	14☐	14☐	14☐	14☐	14☐	14☐	14☐	14☐
	17 = NTC III		15☐	15☐	15☐	15☐	15☐	15☐	15☐	15☐	15☐	15☐	15☐	15☐	15☐	15☐
	18 = Certificate with less than Grade 12/Standard 10; Diploma with less than Grade 12/Standard 10		16☐	16☐	16☐	16☐	16☐	16☐	16☐	16☐	16☐	16☐	16☐	16☐	16☐	16☐
			17☐	17☐	17☐	17☐	17☐	17☐	17☐	17☐	17☐	17☐	17☐	17☐	17☐	17☐
	19 = Certificate with Grade 12/Standard 10; Diploma with Grade 12/Standard 10		18 ☐	18 ☐	18 ☐	18 ☐	18 ☐	18 ☐	18 ☐	18 ☐	18 ☐	18 ☐	18 ☐	18 ☐	18 ☐	18 ☐
			19 ☐	19 ☐	19 ☐	19 ☐	19 ☐	19 ☐	19 ☐	19 ☐	19 ☐	19 ☐	19 ☐	19 ☐	19 ☐	19 ☐
	20 = Other (*specify by writing sideways*)		20 ☐	20 ☐	20 ☐	20 ☐	20 ☐	20 ☐	20 ☐	20 ☐	20 ☐	20 ☐	20 ☐	20 ☐	20 ☐	20 ☐
	21 = Don't know		21 ☐	21 ☐	21 ☐	21 ☐	21 ☐	21 ☐	21 ☐	21 ☐	21 ☐	21 ☐	21 ☐	21 ☐	21 ☐	21 ☐
2.2 (G and M)	**Is …… currently enrolled and attending school?** 1 = Yes 2 = No → *go to question 2.5*		1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐
2.3 (M)	*Ask only if participant answered "Yes" to question 2.2.*															

Question Number	*Note to Survey Staff: If there are not enough spaces, please continue using another blank survey. Only fill in information for children 17 years and younger. Match the person number to the number you assigned to the child in the drawing.*	Person Number														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
	How much are the school fees for . . . 's school? *(specify by writing sideways or indicate don't know)*															
2.4 (G)	*Ask only if participant answered "Yes" to question 2.2.* **This academic year, has …… benefited from any school fee exemptions and/or bursaries? This is where a social worker or government writes a letter for you so that the child can attend for free or for a lower fee.** 1 = Yes 2 = No 3 = Don't know		1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐	1☐ 2☐ 3☐
2.5 (G and K)	*Ask only if participant answered "No" to question 2.2.* **What is the main reason why … . is currently not attending school?** 1 = too old/young 2 = has completed school/education 3 = school/education institution is too far away 4 = no money for fees or other school related expenses 5 = he/she is working (at home or job) 6 = education is useless or uninteresting		1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐	1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐

Question Number	*Note to Survey Staff: If there are not enough spaces, please continue using another blank survey. Only fill in information for children 17 years and younger. Match the person number to the number you assigned to the child in the drawing.*															
		Person Number														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
	7 = illness 8 = pregnancy 9 = failed exams or unable to cope with work 10 = got married 11 = looking after sick family member 12 = looking after younger children/ domestic work 13 = was expelled from school 14 = fear of bullying by other children or teacher 15 = denied place in class 16 = social unrest/violence in community 17 = other (*specify)*		11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐	11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐
2.6	**Does … receive a . . .** (*read out choices from below)***?** **a) Child support grant** a1 = Yes a2 = No a3 = Don't know **b) Foster care grant** b1 = Yes b2 = No b3 = Don't know		a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐
Read out: **Now I want to ask about their parents. Many parents are absent or have died in our communities so these questions may be difficult. I want to remind you that you can take a break if you need to. You can also choose not to talk about this or to stop the interview completely. You will not be penalized if this is what you decide. If you would like to take a break or stop the interview, simply**																

Question Number	*Note to Survey Staff: If there are not enough spaces, please continue using another blank survey. Only fill in information for children 17 years and younger. Match the person number to the number you assigned to the child in the drawing.*	Person Number														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
let me know.																
2.7a (G)	**Is ……'s biological father part of this household?** 1 = Yes → *go to question 2.8a* 2 = No → *go to question 2.7b*		1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐
2.7b (M)	*Ask only if the participant answered "No" to question 2.7a.* **Why is the biological father absent from this household?** 1 = works away from home to provide financial support to household 2 = uninvolved in household life 3 = death → *Go to question 2.7c* 4 = other (*specify by writing sideways*) 5 = don't know		1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐
2.7c	*Ask only if the participant answered "3" to question 2.7b.* **Was the father's death due to a . . . (***read out from below)* 1 = **health related reason?**→ *will need to use extra sheets titled, "Section 2: Children in Home – Sibling Relationships and Cause of Parental Death"* 2 = **non-health related reason**		1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐

Question Number	*Note to Survey Staff: If there are not enough spaces, please continue using another blank survey. Only fill in information for children 17 years and younger. Match the person number to the number you assigned to the child in the drawing.*	Person Number														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
	(motor vehicle accident, violent crime, etc.)? *(specify by writing sideways)*															
2.8a (G)	**Is ……'s biological mother part of this household?** 1 = Yes →*go to question 2.9a* 2 = No → *go to question 2.8b*		1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐
2.8b (M)	*Ask only if the participant answered "No" to question 2.8a.* **Why is the biological mother absent from this household?** 1 = works away from home to provide financial support to household 2 = uninvolved in household life 3 = death → *Go to question 2.8c* 4 = other (*specify by writing sideways*) 5 = don't know		1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐	1☐ 2☐ 3☐ 4☐ 5☐
2.8c (M)	*Ask only if the participant answered "3" to question 2.8b.* **Was the mother's death due to a . . . (***read out from below)* 1 = **health related reason?**→ *will need to use extra sheets titled, "Section 2: Children in Home – Sibling Relationships and Cause of Parental Death" '* 2 = **non-health related reason (motor vehicle accident, violent crime, etc.)?**		1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐	1☐ 2☐

Question Number	*Note to Survey Staff: If there are not enough spaces, please continue using another blank survey. Only fill in information for children 17 years and younger. Match the person number to the number you assigned to the child in the drawing.*														
		Person Number													
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
	(specify by writing sideways)															

Note to Survey Staff: Refer to question 2.7b and 2.8b to see if any children had a father and/or mother who died. Draw each of these children on the extra page titled, "Section 2: Children in Home – Sibling Relationships."

Read out: **For the children in the home who have lost one or both parents, I would like to learn how they are related to each other.**

2.9a (M) **Which of these children have the same mother and father? What are the first name and surname initials for the mother? What are the first name and surname initials for the father?** (*Repeat for each group of siblings with the same mother and father).*
2.9b (M) **Which of these children have the same mother but different fathers?** (*Repeat for each group of siblings with the same mother and different fathers).* **What are the first name and surname initials for the mother? What are the first name and surname initials for the fathers?**

2.9c (M) **Which of these children have the same father but different mothers?** (*Repeat for each group of siblings with the same father and different mothers).* **What are the first name and surname initials for the mothers? What are the first name and surname initials for the father?**
Note to Survey Staff: Look at questions 2.7b and 2.8b. Label the death status of each parent (e.g. dead or alive). Look at questions 2.7c and 2.8b. Label whether the death was health or non-health.

Read out: **You are so brave to look after these children. This research will be more helpful if we understand the reasons for why children's parents are passing away in this community. I/we know this may be hard to talk about, especially with lots of people are dying in this community so I/we are going to ask you to answer some questions about why people died in a private way. I/we will hand you a piece of paper asking questions about how the parent(s) died for each child. I/we will not look at your answers and your name will not be on this paper. You will put your answers in a sealed envelope. The only person to see this paper will be Caroline Kuo, Director of the Project.**

Note to Survey Staff: Use the extra sheet titled, "Section 2: Children in Home - Cause of Parental Death" Prepare the extra sheet by doing the following ***BEFORE*** *you hand the paper with questions 2.10 to 2.15to the caregiver.*

1. *Write in the privacy code on the paper;*
2. *Write in the privacy code on the envelope;*
3. *Draw the appropriate stick figures for each child whose parent has died, including siblings on the same paper. Fill in the person number inside the face of the figure. Be sure this person number matches the original drawing in Section 1: Household and Demographic Information.*
4. *Repeat steps 3 for every other child or sibling group who has lost one or both parents.*

SECTION 3: CAREGIVER STRAIN AND HEALTH

Read out: **The most important part of this survey is to learn about the types of challenges you face as a caregiver. The next set of questions will focus on learning more about the challenges you face in terms of your health, which can impact your ability to provide care for children in the home. The following questions ask for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.**

3.1 (SF) **In general, would you say your health is . . .** (*read out from below*)**?**

Excellent? 1 ☐ **Very good?** 2 ☐ **Good?** 3 ☐ **Fair?** 4 ☐ **Poor?** 5 ☐

3.2 (SF) **Compared to one year ago, how would you rate your health in general now? (***read out from below*)

Much better now than one year ago? 1 ☐	**Somewhat better now than one year ago?** 2 ☐	**About the same as one year ago?** 3 ☐	**Somewhat worse now than one year ago?** 4 ☐	**Much worse now than one year ago?** 5☐

Question Number	*Read out:* **The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**	*Read out:* **Would you say . . .** (*read out from below*)		
		Yes, limited a lot?	**Yes, limited a little?**	**No, not limited at all?**
3.3a(SF)	**Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.**	1 ☐	2 ☐	3 ☐
3.3b(SF)	**Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.**	1 ☐	2 ☐	3 ☐
3.3c(SF)	**Lifting or carrying groceries.**	1 ☐	2 ☐	3 ☐
3.3d(SF)	**Climbing several steep hills.**	1 ☐	2 ☐	3 ☐
3.3e(SF)	**Climbing one steep hill.**	1 ☐	2 ☐	3 ☐
3.3f (SF)	**Bending, kneeling, or stooping.**	1 ☐	2 ☐	3 ☐
3.3g(SF)	**Walking more than a kilometre.**	1 ☐	2 ☐	3 ☐
3.3h(SF)	**Walking several hundred metres.**	1 ☐	2 ☐	3 ☐
3.3i (SF)	**Walking one hundred metres.**	1 ☐	2 ☐	3 ☐
3.3j(SF)	**Bathing or dressing yourself.**	1 ☐	2 ☐	3 ☐

Question Number	*Read out:* **During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**	*Read out:* **Would you say . . .** (*read out from below*)				
		All of the time?	**Most of the time?**	**Some of the time?**	**A little of the time?**	**None of the time?**

3.4a(SF)	**Cut down on the amount of time you spent on work or other activities.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.4b(SF)	**Accomplished less than you would like.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.4c(SF)	**Were limited in the kind of work or other activities.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.4d(SF)	**Had difficulty performing the work or other activities (for example, it took extra effort).**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
	Read out: **During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**	**All of the time?**	**Most of the time?**	**Some of the time?**	**A little of the time?**	**None of the time?**
3.5a (SF)	**Cut down on the amount of time you spent on work or other activities.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.5b(SF)	**Accomplished less than you would like.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.5c (SF)	**Did work or other activities less carefully than usual.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

3.6 (SF) **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? Would you say . . .** (*read out from below*)

Not at all? 1 ☐ **Slightly?** 2 ☐ **Moderately?** 3 ☐ **Quite a bit?** 4 ☐ **Extremely?** 5 ☐

3.7 (SF) **How much bodily pain have you had during the past 4 weeks? Would you say . . .** (*read out from below*)

None? 1 ☐ **Very Mild?** 2 ☐ **Mild?** 3 ☐ **Moderate?** 4 ☐ **Severe?** 5 ☐ **Very Severe?** 6 ☐

3.8 (SF) **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework? Would you say . . .** (*read out from below*)

Not at all? 1 ☐ **Slightly?** 2 ☐ **Moderately?** 3 ☐ **Quite a bit?** 4 ☐ **Extremely?** 5 ☐

Question Number	*Read out:* **These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks…**	*Read out:* **Would you say . . .** (*read out from below)*				
		All of the time?	**Most of the time?**	**Some of the time?**	**A little of the time?**	**None of the time?**

3.9a(SF)	**Did you feel full of life?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.9b(SF)	**Have you been very nervous?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.9c(SF)	**Have you felt so down in the dumps that nothing could cheer you up?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.9d(SF)	**Have you felt calm and peaceful?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.9e (SF)	**Did you have a lot of energy?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.9f(SF)	**Have you felt downhearted and depressed?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.9g(SF)	**Did you feel worn out?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.9h(SF)	**Have you been happy?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.9i (SF)	**Did you feel tired?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

3.10 (SF) **During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Would you say . . .** (*read out from below*)

All of the time? 1 ☐ **Most of the time?** 2 ☐ **Some of the time?** 3 ☐ **A little of the time?** 4 ☐ **None of the time?** 5 ☐

Question Number	*Read out:* **How true or false is each of the following statements for you?**	*Read out:* **Would you say . . .** (*read out from below)*				
		Definitely true?	**Mostly true?**	**Don't know?**	**Mostly false?**	**Definitely false?**
3.11a(SF)	**I seem to get sick a little easier than other people.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.11b(SF)	**I am as healthy as anybody I know.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.11c(SF)	**I expect my health to get worse.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.11d(SF)	**My health is excellent.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

3.12 (G) **During the past month, did you suffer from any illnesses or injuries?** (c*ircle one answer choice*)

1 = Yes → *Go to question 3.13*
2 = No → *Go to section 4*

Note to Survey Staff: Ask question 3.13 only if the participant said "Yes" to 3.12.

3.13 (G) **What sort of illnesses or injuries did you suffer from? Did you suffer from ……?** (c*ircle all that apply)*

1 = **Flu or acute respiratory tract infection**
2 = **Diarrhoea**
3 = **Severe trauma (e.g. due to violence, motor vehicle accident, gunshot, assault, beating)**
4 = **TB or severe cough with blood**
5 = **Abuse of alcohol or drugs**
6 = **Depression or mental illness**
7 = **Diabetes**

8 = **High or low blood pressure**
9 = **HIV/AIDS**
10 = **Other sexually transmitted disease**
11 = **Other illness or injury** (*specify):* _____

SECTION 4: PSYCHOSOCIAL MEASURE

Read out: **Now, I want to learn more about how you have been feeling emotionally and mentally.**

Question Number (Kess)	**During the last 30 days . . .** (*read statement below)*	**Would you say . . .** (*read statement below)*				
		None of the time?	**A little of the time?**	**Some of the time?**	**More of the time?**	**All of the time?**
4.1a	**about how often did you feel tired out for no good reason?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.1b	**about how often did you feel nervous?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.1c	**about how often did you feel so nervous that nothing could calm you down?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.1d	**about how often did you feel hopeless?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.1e	**about how often did you feel restless or fidgety?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.1f	**about how often did you feel so restless you could not sit still?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.1g	**about how often did you feel depressed?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.1h	**about how often did you feel that everything was an effort?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.1i	**about how often did you feel so sad that nothing could cheer you up?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.1j	**about how often did you feel worthless?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Question Number (CESD)	**I will read out a list of statements about how you might have felt or behaved during the past week. I would like to find out how often you have felt like this during the past week . . .** (*read statement below)*	**Would you say . . .** (*read statement below)*			
		Rarely or none of the time (Less than 1 day)?	**Some of the time (1-2 days)?**	**Occasionally or Moderately (3-4 days)?**	**Most of the time (5-7 days)?**
4.2a	**I have been bothered by things that don't usually bother me.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2b	**I did not feel like eating, my appetite was poor.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2c	**I felt that I could not shake off the blues (sadness) even with help from my family or**	1 ☐	2 ☐	3 ☐	4 ☐

	friends.				
4.2d	**I felt that I was not as good as other people.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2e	**I had trouble keeping my mind on what I was doing (concentration).**	1 ☐	2 ☐	3 ☐	4 ☐
4.2f	**I felt depressed or sad.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2g	**I felt that everything I did was an effort.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2h	**I have no hope for the future.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2i	**I thought my life has been a failure.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2j	**I felt fearful or afraid.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2k	**My sleep was restless.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2l	**I was unhappy.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2m	**I talked less than usual.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2n	**I felt lonely.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2o	**People were unfriendly.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2p	**I did not enjoy life.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2q	**I cried frequently for no reason.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2r	**I felt sad.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2s	**I felt that people disliked me.**	1 ☐	2 ☐	3 ☐	4 ☐
4.2t	**I could not get "going" during the day.**	1 ☐	2 ☐	3 ☐	4 ☐

Read out: **We are now going to talk about a number of difficult or stressful events that sometimes happen to people.**

Question Number (LEC)	**Can you tell me if you have ever experienced any of the following, witnessed it happening to someone else, or heard about these events happening to someone you know?**	Happened to care provider	Witnessed event happening to someone they know	Heard about event happening to someone they know	Never Happened
4.3a	**Natural disaster (such as a flood, earthquake, or severe drought?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3b	**Fire or explosion?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3c	**Transport accident (taxi, train, car, plane or boat)?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3d	**Serious accident at work, home or when playing sports or having fun?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3e	**Physical assault (being attacked, beaten, slapped, kicked)?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3f	**Assaulted with a weapon (being shot, stabbed, threatened with a knife, gun or bomb)?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3g	**Sexual assault (rape, attempted rape, forced to perform sexual acts or threats of harm)?**	1 ☐	2 ☐	3 ☐	4 ☐

4.3h	**Other unwanted or uncomfortable sexual experience?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3i	**Exposure in a war-zone (in combat or as civilian)?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3j	**Captivity (being kidnapped, abducted, held hostage or prisoner of war)?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3k	**Life-threatening illness or injury?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3l	**Exposed to sudden or violent death (murder or suicide)?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3m	**Sudden, unexpected death of someone close to you?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3n	**Serious injury, harm or death you caused to someone else?**	1 ☐	2 ☐	3 ☐	4 ☐
4.3o	**Another life-threatening experience not mentioned here?**	1 ☐	2 ☐	3 ☐	4 ☐

If the care provider experience, witnessed, or heard about any of the events above, and they specify that it upsets or bothers them, move on to question 4.4-4.5. Otherwise, skip ahead to question 4.6.

4.4 (HTS) **Please specify the event(s) that you feel is most upsetting and still bothering you.**

_____

_____.

Question Number (HTS)	**Sometimes, people experience symptoms after a traumatic experience. Have you experienced any of the following during the past week?**	**Would you say . . .** (*read out from below)*			
		Not at all?	**A little?**	**Quite a bit?**	**Extremely?**
4.5a	**Thoughts or memories that keep coming back of that event/s you specified**	1 ☐	2 ☐	3 ☐	4 ☐
4.5b	**Feeling as though the event is happening again**	1 ☐	2 ☐	3 ☐	4 ☐
4.5c	**Nightmares about the event/s that keep coming back**	1 ☐	2 ☐	3 ☐	4 ☐
4.5d	**Feeling detached or withdrawn from people**	1 ☐	2 ☐	3 ☐	4 ☐
4.5e	**Unable to feel emotions**	1 ☐	2 ☐	3 ☐	4 ☐
4.5f	**Feeling jumpy, easily startled**	1 ☐	2 ☐	3 ☐	4 ☐
4.5g	**Difficulty concentrating (focus your mind on tasks)**	1 ☐	2 ☐	3 ☐	4 ☐
4.5h	**Trouble sleeping**	1 ☐	2 ☐	3 ☐	4 ☐
4.5i	**Feeling on guard (mistrusting others)**	1 ☐	2 ☐	3 ☐	4 ☐
4.5j	**Having outbursts of anger**	1 ☐	2 ☐	3 ☐	4 ☐
4.5k	**Avoiding activities that remind you of the traumatic or hurtful event**	1 ☐	2 ☐	3 ☐	4 ☐
4.5l	**Inability to remember parts of the most traumatic or hurtful events**	1 ☐	2 ☐	3 ☐	4 ☐
4.5m	**Feeling less interested in daily activities**	1 ☐	2 ☐	3 ☐	4 ☐
4.5n	**Feeling as if you don't have a future**	1 ☐	2 ☐	3 ☐	4 ☐

Question Number (HTS)	**Sometimes, people experience symptoms after a traumatic experience. Have you experienced any of the following during the past week?**	**Would you say . . .** (*read out from below)*			
		Not at all?	**A little?**	**Quite a bit?**	**Extremely?**
4.5o	**Avoiding thoughts and feelings associated with the traumatic or hurtful events**	1 ☐	2 ☐	3 ☐	4 ☐
4.5p	**Sudden emotional or physical reaction when reminded of the most hurtful part of the traumatic event**	1 ☐	2 ☐	3 ☐	4 ☐
4.5q	**Feeling that people do not understand what is happening to you**	1 ☐	2 ☐	3 ☐	4 ☐
4.5r	**Having difficulty doing your job or daily tasks because of what happened to you**	1 ☐	2 ☐	3 ☐	4 ☐
4.5s	**Blaming yourself for things that have happened**	1 ☐	2 ☐	3 ☐	4 ☐
4.5t	**Feeling guilty for having survived**	1 ☐	2 ☐	3 ☐	4 ☐
4.5u	**Feeling there is no hope**	1 ☐	2 ☐	3 ☐	4 ☐
4.5v	**Feeling ashamed of the hurtful or traumatic event that happened to you**	1 ☐	2 ☐	3 ☐	4 ☐
4.5w	**Feeling as if you are going crazy**	1 ☐	2 ☐	3 ☐	4 ☐
4.5x	**Spending time thinking why these events happened to you**	1 ☐	2 ☐	3 ☐	4 ☐
4.5y	**Feeling that you are the only one who suffered these events**	1 ☐	2 ☐	3 ☐	4 ☐
4.5z	**Feeling others are hostile or want to harm you**	1 ☐	2 ☐	3 ☐	4 ☐
4.5aa	**Feeling that you have no-one to rely on**	1 ☐	2 ☐	3 ☐	4 ☐
4.5bb	**Finding out or being told by other people that you have done something that you cannot remember**	1 ☐	2 ☐	3 ☐	4 ☐
4.5cc	**Feeling as if you are split into two people and one of you is watching what the other one is doing**	1 ☐	2 ☐	3 ☐	4 ☐
4.5dd	**Feeling someone you trusted betrayed you**	1 ☐	2 ☐	3 ☐	4 ☐

Read out: **Now, I want to learn more about whether you use alcohol.**

4.6 (AUDIT) **During the past 12 months have you had a drink containing alcohol?** (c*ircle one answer choice*)

1 = Yes

2= No → *go to question 4.7i*

4.7a (AUDIT) **How often do you have a drink containing alcohol?** (*tick the correct answer)*

Never ☐ Monthly or less ☐ 2 to 4 times per month ☐ 2 to 3 times per week ☐ 4 or more times per week ☐

4.7b (AUDIT) **How many drinks containing alcohol do you have on a typical day when you are drinking?** (*tick the correct answer)*

1 or 2 ☐ 3 or 4 ☐ 5 or 6 ☐ 7 to 9 ☐ 10 or more ☐

Question Number (AUDIT)		**Would you say . . .** *(read statements from below)*				
		Never?	**Less than monthly?**	**Monthly?**	**Weekly?**	**Daily or almost daily?**
4.7c	**How often do you have six or more drinks on one occasion?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.7d	**How often during the last year have you found that you were not able to stop drinking once you started?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.7e	**How often during the last year have you failed to do what is normally expected from you because of drinking?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.7f	**How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.7g	**How often during the last year have you had a feeling of guilt or remorse after drinking?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.7h	**How often during the last year have you been unable to remember what happened the night before because you had been drinking?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.7i	**Have you or someone else been injured as a result of your drinking?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

4.7j (AUDIT) **Has a relative or friend, or a doctor or other health worker been concerned about your drinking or suggested that you cut down?** *(tick the correct answer)*

No 1☐ **Yes, during the last year** 2☐ **Yes, but not in the last year** 3☐

Read out: **Now I want to learn about whether you use drugs. Drugs might include:**

Cannibis/ Marijuana	Amphetamines	Cocaine	Opiates	Hallucinogens	Solvents/Inhalants	GHB and other
Hash	methamphetamine	crack	smoked heroin	ecstasy	thinner	GHB
Hash oil	Phenmetraline	freebase	heroin	LSD	trichloroethylene	steroids
	Khat	coca leaves	opium	mescaline	gasoline/petrol	laughing gas
	Betel Nut			peyote	gas	poppers
	Ritaline			PCP, angel dust	solution	anticholinergic
				Psilocybin	glue	compounds
				DMT		

Question Number (DUDIT)		Would you say . . . (*read statements from below)*				
		Never?	Once a month or less often?	2-4 times a month?	2-3 times a week?	4 times a week or more often?
4.8a	**How often do you use drugs other than alcohol?** → *if the provider answers never, skip to question 4.9*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.8b	**Do you use more than one type of drug on the same occasion?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

4.8c (DUDIT) **How many times do you take drugs on a typical day when you use drugs?**

0 ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7 or more ☐

Question Number (DUDIT)		Would you say . . . (*read statements from below)*				
		Never?	Less often than a month?	Every month?	Every week?	Daily or almost every day?
4.8d	**How often are you influenced heavily by drugs?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.8e	**Over the past year, have you felt that your longing for drugs was so strong that you could not resist it?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.8f	**Has it happened, over the past year that you have not been able to stop taking drugs once you started?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.8g	**How often over the past year have you taken drugs and then neglected to do something you should have done?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.8h	**How often over the past year have you needed to take a drug the morning after heavy drug use the day before?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4.8i	**How often over the past year have you had guilty feelings or a bad conscience because you used drugs?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

4.8j (DUDIT) **Have you or anyone else been hurt (mentally or physically) because you used drugs?**

No 1☐ **Yes, but not over the past year** 2☐ **Yes, over the past year** 3☐

4.8k (DUDIT) **Has a relative or a friend, a doctor or a nurse, or anyone else been worried about your drug use or said to you that you should stop using drugs?**

No 1☐ **Yes, but not over the past year** 2☐ **Yes, over the past year** 3☐

Read out: **Now I want to ask about you using health services.**

4.9 (G) **During the past month, did you consult a health worker such as a nurse, doctor or traditional healer as a result of illness or injury?** (c*ircle one answer choice*)

1 = Yes
2 = No → *Go to question 4.11*

4.10 (G and K) **For your most recent consultation, what kind of health worker did you consult?** (c*ircle all that apply)*

1 = Nurse
2 = Doctor
3 = Medical specialist
4 = Pharmacist
5 = Dentist
6 = Spiritual Healer (church related)
7 = Traditional Healer
8 = Any other health care provider (Including psychologist, physiotherapist, chiropractor, homeopath, optometrist) *(specify)* _____
9 = Community health worker
10 = Don't know

Note to Survey Staff: Ask question 4.11 only if participant answered "No" to question 4.9.

4.11(G, M, and K) **Why did you not consult any health worker during the past month?** (c*ircle one answer choice*)

1 = not necessary
2 = shortage of money for consultation or medicine
3 = shortage of money for transport
4 = sick person too busy
5 = no one available to go with him/her
6 = health facility too far away
7 = queues/waits too long
8 = staff unhelpful or lack skills to help
9 = no medicine at the facility
10 = could not decide what to do
11 = religious reason
12 = fear/embarrassment
13 = other *(specify):* _____
14 = don't know

SECTION 5: COPING

Read out: **Now I want to learn about the people who support you when you face challenges.**

5.1 (M) **About how many close friends and close relatives or other special people do you have (people you feel at ease with and can talk to about what is on your mind)?** *Write in number of close friends and close relatives and special people*: _____

Question Number (MSPSS)	**I am going to read you several statements and I am going to ask how much you disagree or agree with them. (***Read out statements below.)*	**Would you say you . . .** *(read out statements below)*						
		Very strongly disagree?	**Strongly disagree?**	**Mildly disagree?**	**Neutral?**	**Mildly agree?**	**Strongly agree?**	**Very strongly agree?**
5.2a	**There is a special person who is around when I am in need.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.3b	**There is a special person with whom I can share my joys and sorrows.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2c	**My family really tries to help me.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2d	**I get the emotional help and support I need from my family.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2e	**I have a special person who is a real source of comfort to me.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2f	**My friends really try to help me.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2g	**I can count on my friends when things go wrong.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2h	**I can talk about my problems with my family.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2i	**I have friends with whom I can share my joys and sorrows.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2j	**There is a special person in my life who cares about my feelings.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2k	**My family is willing to help me make decisions.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
5.2l	**I can talk about my problems with my friends.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐

SECTION 6: LIVING SITUATION

Read out: **Now, I/we would like to ask you some questions about your living situation.**

6.1 (SADH) **What is the main source of drinking water for members of your household? Is it . . .** (*read out answer choices below)?* (c*ircle one answer choice*)

1 = **piped water (tap) in dwelling**
2 = **piped water (tap) in site/yard**
3 = **bottled water**
4 = **public tap**
5 = **water carrier/tanker**
6 = **borehole/well**
7 = **dam/river/stream/spring**
8 = **rain-water tank**
9 = **other** *(specify):* _____

6.2 (G and M) **Is the water from the main source of drinking water safe to drink?** (c*ircle one answer choice*)

1 = Yes
2 = No
3 = Don't know

6.3 (SADH) **What kind of toilet facility does your household have? Is it a. . . .** (*read out answer choices below)?* (c*ircle one answer choice*)

1 = **flush toilet (own)**
2 = **flush toilet (shared)**
3 = **bucket latrine**
4 = **pit latrine**
5 = **no facility/bush/field**
6 = **other** *(specify):* _____

6.4 (SADH) **Let us speak about the household and what it can afford. Would you say that the people here often, sometime, seldom or never go hungry?** (c*ircle one answer choice*)

1 = never
2 = seldom
3 = sometimes
4 = often

6.5 (SADH) (G) **What is the main source of energy/fuel for this household for . . . .** (*read out below)?*

6.5a **Cooking?** *(fill in the correct code)* _____
6.5b **Heating?** *(fill in the correct code)* _____
6.5c **Lighting?** *(fill in the correct code)* _____

1 = electricity from MAINS
2 = electricity from generator
3 = gas
4 = paraffin
5 = wood
6 = coal
7 = candles
8 = animal dung
9 = solar energy
10 = other (*specify):* _____
11 = none

SECTION 7: ASSETS AND ECONOMIC INFORMATION

Read out: **Now I want to ask about the types of things your household has.**
Note to Survey Staff: Show the care provider the drawing of assets below when you ask this question. Circle the picture if the household owns the asset using: ◎ *. Cross out the picture if the household does not own the asset:* ⊘ *.*

7.1 (SADH) **Does your household have . . .** (*read out answer choices below*)

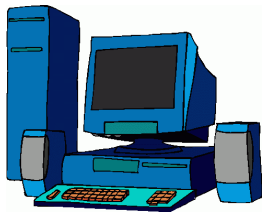
7.1a **electricity?**

7.1b **radio?**

7.1c **television?**

7.1d **telephone?**

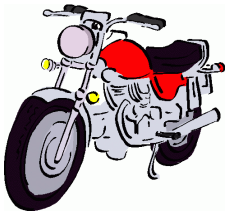
7.1e **refrigerator?**



7.1f **personal computer or pc?**

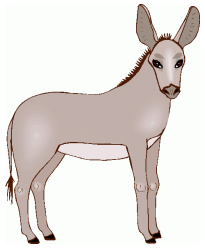
7.1g **washing machine?**

7.1h **bicycle?**

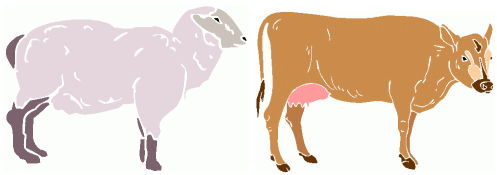


7.1i **motorcycle?**

7.1j **car?**



7.1k **donkey or horse?**



7.1l **sheep or cattle?**

Read out: **Now I want to ask some questions about this household's source of income.**

7.2a (G and K and M) **What is the main source of income for this household? Is it . . .** (*read out answer choices below)?* (c*ircle one answer choice*)

1 = **salaries and/or wages**
2 = **remittances**
3 = **pensions and grants**
4 = **sales of farm products and services**
5 = **other non-farm incomes**
6 = **loans from friend**
7= **loans from stockvel**
8 = **loans from landlord**
9 = **loans from bank or building society**
10 = **loans from MFI/Non-governmental organization**
11 = **loans from money lender**
12 = **no income**→ *go to question 7.2b*

Ask only if the participant answered code 12 to question 7.2a.

7.2b (G and M) **How does the household support itself with no income? Is it . . .** (*read out answer choices below)?* (c*ircle one answer choice*)

1 = **Supported by persons not in the household**
2 = **Supported by charity, church, welfare, etc.**
3 = **Unemployment Insurance Fund (UIF**
4 = **Savings or money previously earned**
5 = **Other sources** (*specify):* _____

Question Number	*Note to Survey Staff: Keep using the same person numbers as assigned in Section 1.*															
		Person Number														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
	Read out: **Now I want to ask you about social grants received by members of this household.**															
7.3 (G)	**Does … receive a . . .** (*read out answer choices from below)***?** *More than one code per person is fine.* **a) Old age pension** a1 = Yes a2 = No a3 = Don't know **b) Disability grant** b1 = Yes b2 = No b3 = Don't know **c) Care dependency grant** c1 = Yes	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐	a1☐ a2☐ a3☐ b1☐ b2☐ b3☐ c1☐ c2☐

Question Number	*Note to Survey Staff: Keep using the same person numbers as assigned in Section 1.*															
		Person Number														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
	c2 = No	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐	c3☐
	c3 = Don't know	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐	d1☐
	d) Grant in aid															
	d1 = Yes	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐	d2☐
	d2 = No															
	d3 = Don't know	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐	d3☐
	e) Social relief															
	e1 = Yes	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐	e1☐
	e2 = No	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐	e2☐
	e3 = Don't know															
	f) Government housing subsidy, such as RDP housing subsidy	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐	e3☐
	f1 = Yes	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐	f1☐
	f2 = No	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐	f2☐
	f3 = Don't know	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐	f3☐

Read out: **Thank you for your valuable time and for sharing this information with me/us. We really value what you do as a caregiver. While we would never share your name with others, we promise to tell the government and others more generally about what we have learned from you and other caregivers.**

While we promise not to share your name with others when we share the research findings, the questions that we ask you may show that you are in need of some help in terms of your health, etc. In these cases, would you like us to write a referral letter to the clinic, etc. on your behalf? (*circle the correct response)*

Yes No

This would mean that we have to share your name and contact details and the reason why we are contacting them on your behalf. This means that we have to tell them about your particular health issue. Do you understand this? (*circle the correct response)*

Yes No

Knowing that we have to share your contact details and some private information about you (such as your health), would you like us to still make a referral for you if necessary? (*circle the correct response)*

Yes No

Please keep on doing the wonderful job you are doing.

Before we finish, is there anything else you'd like to add which I haven't asked you about? (*take notes on any additional information they offer*):

_____

_____

_____

If you have any questions for or concerns, please feel free to call Caroline, the director of the project who is listed on the information sheet we gave you.

Would it be okay to come back or call and speak to you again should we need to follow-up?

Yes No

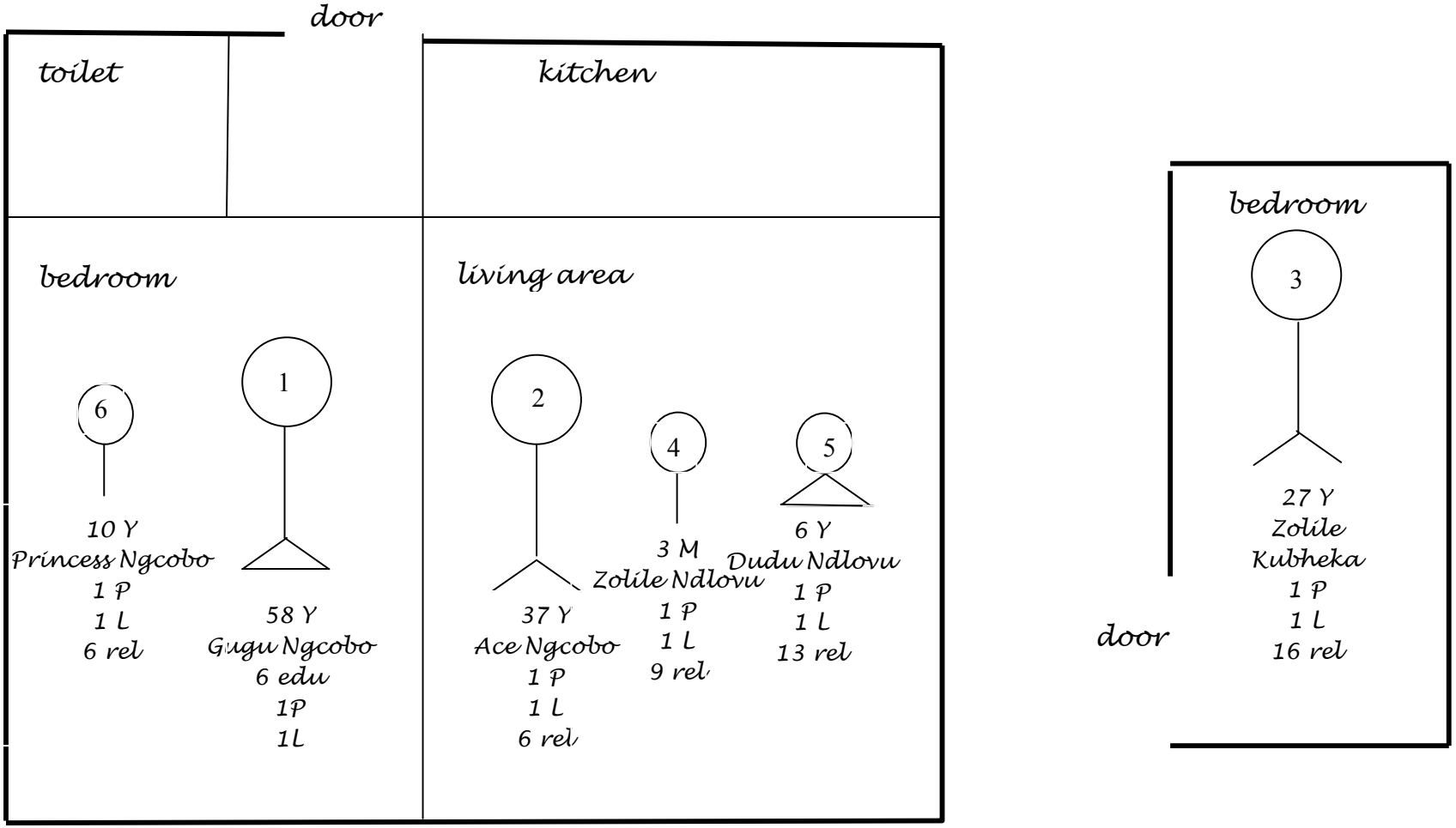
Finally, I want to tell you that many people from the US and England want to support your community. They have asked the director of this project to take their donations and put it into this community. Where do you want to see these resources go?

1. **Schools serving children in Umlazi F and G?**
2. **Clinics or hospitals serving caregivers in Umlazi F and G?**

Again, we would like to say thank you for your time and for sharing this valuable information with us!

Note to Survey Staff: Please go to the page 2 and fill in the end time of the interview.

Example Drawing of Home and Occupants



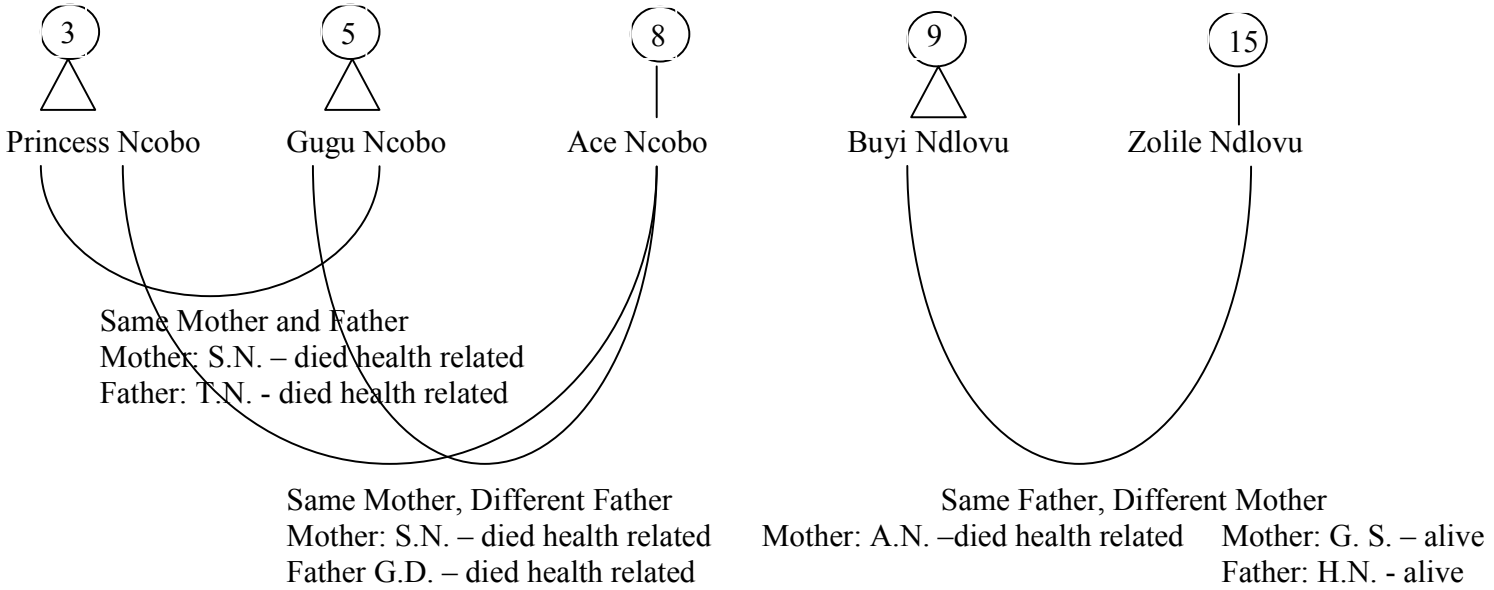
PRIVACY CODE:

SECTION 1: HOUSEHOLD AND DEMOGRAPHIC INFORMATION

1.1-1.15 Drawing of Home and Occupants

SECTION 2: CHILDREN IN THE HOME – SIBLING RELATIONSHIPS

Example Drawing of Children in the Home – Sibling Relationships



1 death questionnaire needed for Princess and Gugu

1 death questionnaire needed for Ace – mother questions crossed out because they were already answered in Princess and Gugu's questionnaire (they share the same mother)

1 death questionnaire needed for Buyi

3 total death questionnaires

2.9a-2.9c Drawing of Children and Sibling Relationships

PRIVACY CODE:

SECTION 2: CHILDREN IN THE HOME – CAUSE OF PARENTAL DEATH

PRIVACY CODE:

Child or Siblings and Name(s):

Directions: Please answer the questions below. If you do not understand the question, ask your interviewer. Remember, your answers are confidential.

Example Question and Answer: ***Do you like animals?***

If your answer is yes you draw a circle around "Yes" → *Yes* *No*

Father's Cause of Death

2.10a **Did the father pass away because of old age?**

Yes No

2.10b **Did the father pass away because of suicide?**

Yes No

Directions: If you answered yes to any of the questions above, stop and move on to the section called Mother's Cause of Death. If you answered no to all three questions above, please continue with the questions below.

2.10c **Did the father pass away because of an illness?**

Yes No

2.11 **Was the illness due to . . .**

a) **heart disease?**	Yes	No
b) **stroke?**	Yes	No
c) **hypertension?**	Yes	No
d) **diabetes?**	Yes	No
e) **pulmonary disease?**	Yes	No
f) **asthma?**	Yes	No
g) **HIV/AIDS?**	Yes	No

h) **other illness? (***write down illness***):** _____

2.12a **Did the illness include weight loss? This is moderate or severe weight loss with no other symptoms of malnutrition.**

Yes No

2.12b **Did the illness include wasting? This is moderate or severe weight loss with at least four of the following symptoms: paleness, changing hair colour, swelling of legs, burning sensations of the feet, dry scaly skin.**

Yes No

2.12c **Did the illness include acute jaundice? This is the yellowing of the whites of the eyes during the disease that led to death with fever and/or itching but without history of alcohol abuse.**

Yes No

4.12d **Did the illness include herpes zoster? This is shingles or a rash made up of painful red dots, often running in a line on the body.**

Yes No

2.12e **Did the illness include blisters or sores?**

Yes No

2.12f **Did the illness include two or three of the following: ulcers in the mouth, difficulty swallowing, white patching inside the mouth and tongue?**

Yes No

2.12g **Did the illness include a respiratory tract illness? This is where the person had trouble breathing, a cough lasting 3 to 27 days with fever but not recent tuberculosis, weight loss, or wasting.**

Yes No

2.12h **Did the illness include recent TB, where the person suffered from TB in the last five years of their life?**

Yes No

2.12i **Did the illness include acute diarrhoea where they had loose stools lasting 3 to 27 days?**

Yes No

Mother's Cause of Death

2.13a **Did the mother pass away because of old age?**

Yes No

2.13b **Did the mother pass away because of suicide?**

Yes No

Directions: If you answered no to all three questions above, please continue with the questions below.

2.13c **Did the mother pass away because of an illness?**

Yes No

2.14 **Was the illness due to . . .**

a) **heart disease?**	Yes	No
b) **stroke?**	Yes	No
c) **hypertension?**	Yes	No
d) **diabetes?**	Yes	No
e) **pulmonary disease?**	Yes	No
f) **asthma?**	Yes	No
g) **HIV/AIDS?**	Yes	No

h) **other illness? (***write down illness***):** _____

2.15a **Did the illness include weight loss? This is moderate or severe weight loss with no other symptoms of malnutrition.**

Yes No

2.15b **Did the illness include wasting? This is moderate or severe weight loss with at least four of the following symptoms: paleness, changing hair colour, swelling of legs, burning sensations of the feet, dry scaly skin.**

Yes No

2.15c **Did the illness include acute jaundice? This is the yellowing of the whites of the eyes during the disease that led to death with fever and/or itching but without history of alcohol abuse.**

Yes No

4.15d **Did the illness include herpes zoster? This is shingles or a rash made up of painful red dots, often running in a line on the body.**

Yes No

2.15e **Did the illness include blisters or sores?**

Yes No

2.15f **Did the illness include oral candidiasis? This is if the person has two or three of the following: ulcers in the mouth, difficulty swallowing, white patching inside the mouth and tongue?**

Yes No

2.15g **Did the illness include a respiratory tract illness? This is where the person had trouble breathing, a cough lasting 3 to 27 days with fever but not recent tuberculosis, weight loss, or wasting.**

Yes No

2.15h **Did the illness included vaginal tumors with our without bleeding?**

Yes No

2.15i **Did the illness include recent TB, where the person suffered from TB in the last five years of their life?**

Yes No

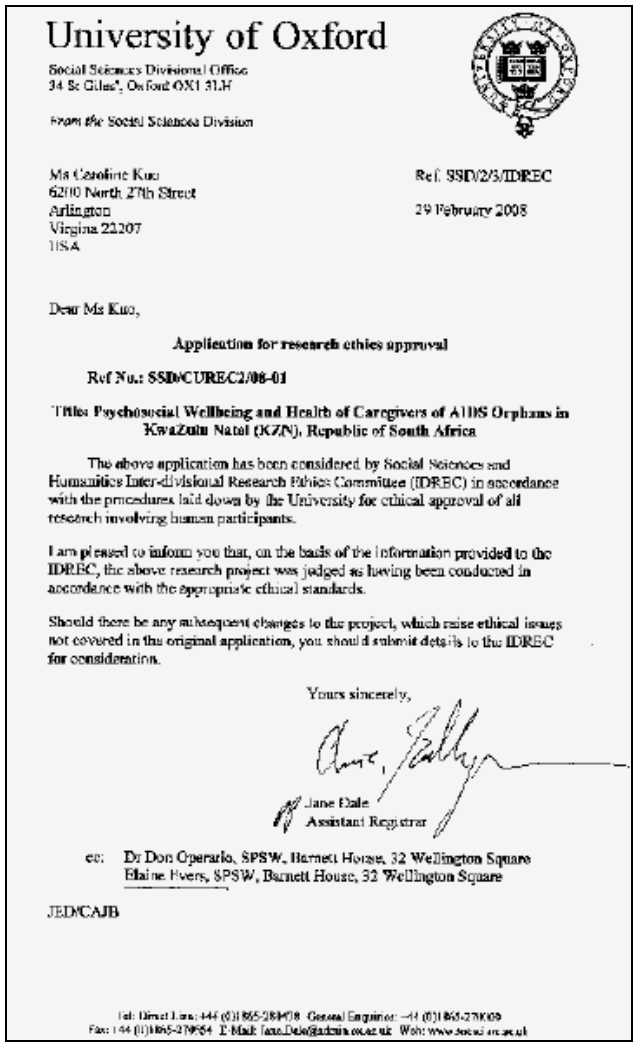
2.15j **Did the illness include acute diarrhoea where they had loose stools lasting 3 to 27 days?**

Yes No

Thank you for sharing this very private information with us! Please remember, we will keep this information confidential. The only person who looks at this paper is the director of the project. To help us protect your information, please put your answers in a sealed envelope before you hand it to the interviewer.

APPENDIX 2: PILOT CERTIFICATES OF APPRECIATION

APPENDIX 3: ETHICAL CLEARANCE LETTERS



University of Oxford

Social Sciences Divisional Office
34 St Giles', Oxford OX1 3LH

From the Social Sciences Division

Ms Caroline Kuo
6200 North 27th Street
Arlington
Virginia 22207
USA

Ref: SSD/2/3/IDREC

29 February 2008

Dear Ms Kuo,

Application for research ethics approval

Ref No.: SSD/CUREC2/08-01

Title: Psychosocial Wellbeing and Health of Caregivers of AIDS Orphans in KwaZulu Natal (KZN), Republic of South Africa

The above application has been considered by Social Sciences and Humanities Inter-divisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the above research project was judged as having been conducted in accordance with the appropriate ethical standards.

Should there be any subsequent changes to the project, which raise ethical issues not covered in the original application, you should submit details to the IDREC for consideration.

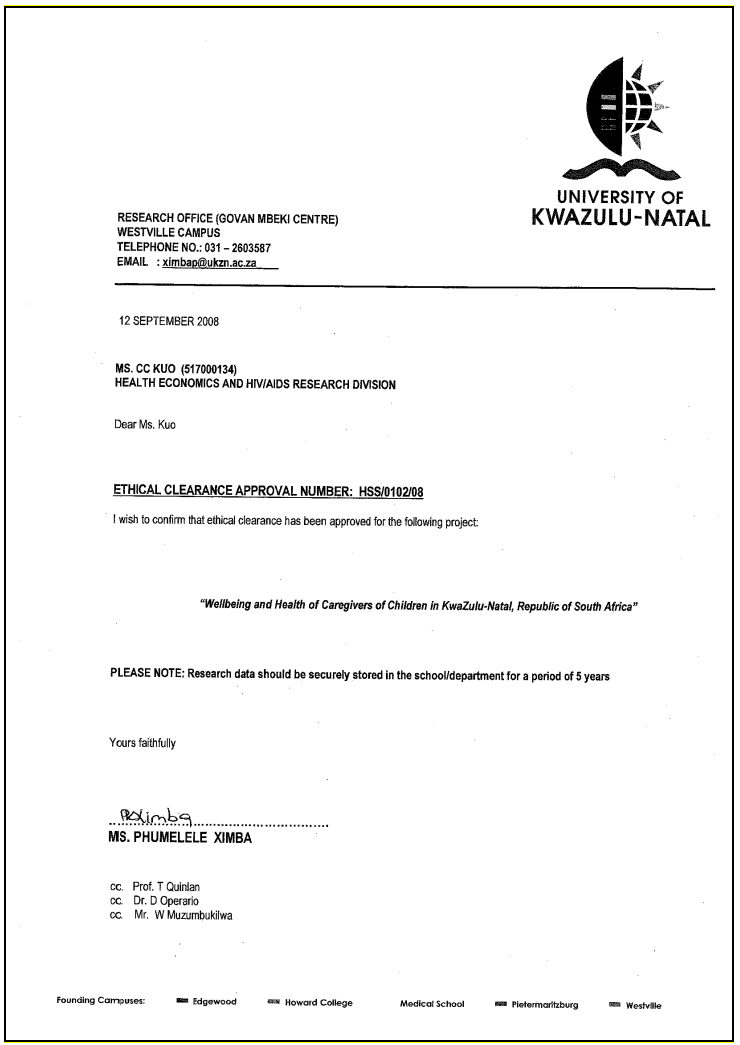
Yours sincerely,

Jane Dale
Assistant Registrar

cc: Dr Don Operario, SPSW, Barnett House, 32 Wellington Square
Elaine Byers, SPSW, Barnett House, 32 Wellington Square

JED/CAJB

Tel: Direct Line: +44 (0)1865-284708 General Enquiries: +44 (0)1865-270309
Fax: +44 (0)1865-270954 E-Mail: [illegible] Web: [illegible]



UNIVERSITY OF KWAZULU-NATAL

RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL : ximbap@ukzn.ac.za

12 SEPTEMBER 2008

MS. CC KUO (517000134)
HEALTH ECONOMICS AND HIV/AIDS RESEARCH DIVISION

Dear Ms. Kuo

ETHICAL CLEARANCE APPROVAL NUMBER: HSS/0102/08

I wish to confirm that ethical clearance has been approved for the following project:

"Wellbeing and Health of Caregivers of Children in KwaZulu-Natal, Republic of South Africa"

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Yours faithfully

PXimba
MS. PHUMELELE XIMBA

cc. Prof. T Quinlan
cc. Dr. D Operario
cc. Mr. W Muzumbukilwa

Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

APPENDIX 4: EXAMPLE OF HEALTH REFERRAL LETTERS

This letter is private and confidential and for the use of medical personnel assisting in the direct care of the individual whose medical details are in this letter.

Health Economics and HIV/AIDS Research Division

March 6, 2009

Mrs. Dudu Sishange
Head Sister
Umlazi, G Section Clinic
G 739 Inyala Street
P.O. Box Umlazi
4031

Dear Mrs. Sishange,

Our research team from the University of Oxford in collaboration with HEARD, University of KwaZulu Natal conducted a survey on the health of adults caring for children in Umlazi F and G Sections. In the course of our survey, we asked child carers about their health including questions on anxiety, depression, stress following a traumatic event, alcohol and drug use. We are writing you because we feel that the individual that we spoke to may be at risk for all or some of these health issues.

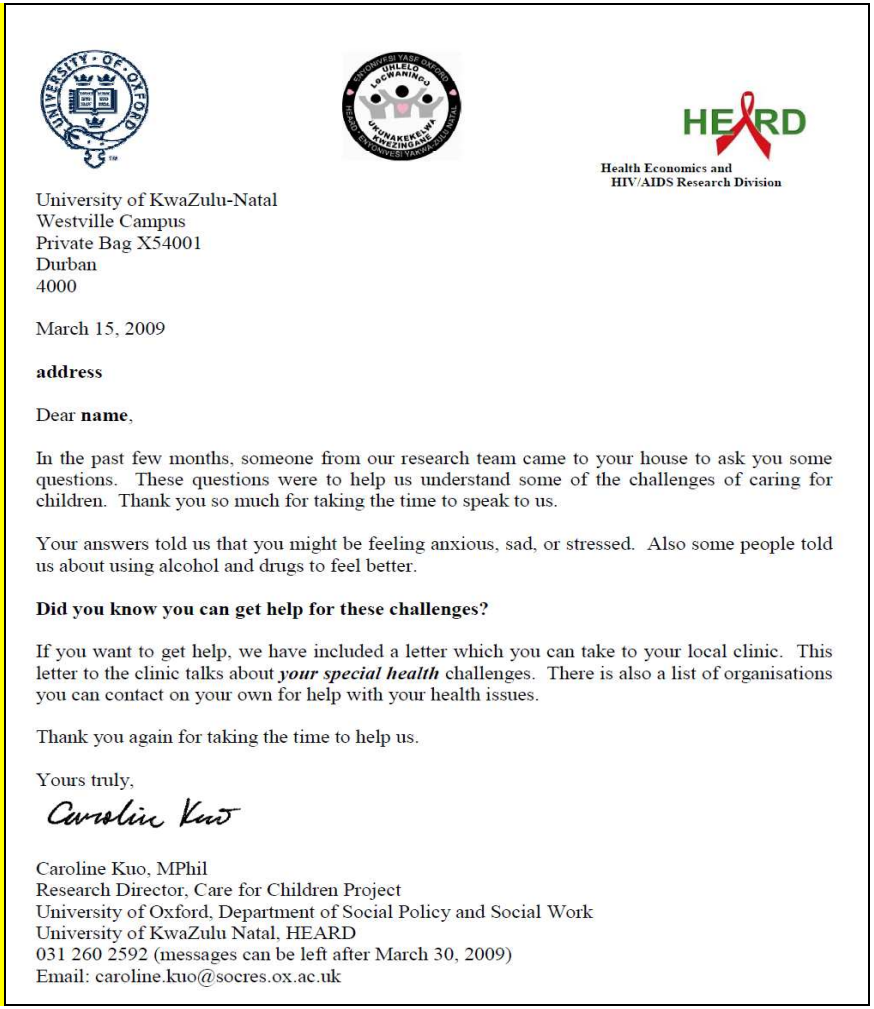
Although this individual's participation in the survey and the information they provided about their health is highly confidential, they have decided to disclose their information to you in order to gain your assistance in addressing their health issues. We have spoken to both you and Mrs. Lindiwe Made, Supervisor of G Clinic regarding this survey; both of you have agreed to accept referrals to G Clinic, and if necessary, make mental health referrals to the Department of Psychiatry at Prince Mshiyeni Memorial Hospital. Dr. S. Mashaphu, head of the Department of Psychiatry at the hospital is aware of possible referrals from your clinic in relation to this study. We thank you for your assistance. The individual has received a letter explaining that we are concerned about their health and they can discuss this with you further. Their answers to our survey suggest that they may be suffering from **moderate levels of anxiety, depression, and alcohol dependence**.

Please do not hesitate to contact me if you require any further details, or wish to discuss this in more detail. We thank you for your support in providing assistance to this individual.

Yours truly,

Caroline Kuo, MPhil
Research Director, Care for Children Project
University of Oxford, Department of Social Policy and Social Work
University of KwaZulu Natal, HEARD
031 260 2592 (messages can be left after March 30, 2009)
Email: caroline.kuo@socres.ox.ac.uk

University of KwaZulu-Natal, Westville Campus, Private Bag X54001, Durban, 4000



Health Economics and HIV/AIDS Research Division

University of KwaZulu-Natal
Westville Campus
Private Bag X54001
Durban
4000

March 15, 2009

address

Dear **name**,

In the past few months, someone from our research team came to your house to ask you some questions. These questions were to help us understand some of the challenges of caring for children. Thank you so much for taking the time to speak to us.

Your answers told us that you might be feeling anxious, sad, or stressed. Also some people told us about using alcohol and drugs to feel better.

Did you know you can get help for these challenges?

If you want to get help, we have included a letter which you can take to your local clinic. This letter to the clinic talks about ***your special health*** challenges. There is also a list of organisations you can contact on your own for help with your health issues.

Thank you again for taking the time to help us.

Yours truly,

Caroline Kuo, MPhil
Research Director, Care for Children Project
University of Oxford, Department of Social Policy and Social Work
University of KwaZulu Natal, HEARD
031 260 2592 (messages can be left after March 30, 2009)
Email: caroline.kuo@socres.ox.ac.uk

APPENDIX 5: GRANT AMOUNTS AND ELIGIBILITY REQUIREMENTS

Table of Grant Amounts and Eligibility Requirements

Grant Type	Amount Per Month (Rand)	Eligibility Requirements
Old Age Pension	1,010	• South African/permanent resident and living in country at time of application • If male, 65 year or older; if female, 60 years or older • Spouse must meet requirements of the means test • Must not be maintained or cared for by a State institution • Must submit at 13 digit bar coded identity document
Disability Grant	1,010	• South African citizen/permanent resident and living in country at time of application • If male, 18-64 years; if female, 18-59 years • Must submit a medical/assessment report confirming disability • Spouse must meet requirements of the means test • Must not be cared for by a State institution • Must not be in receipt of another social grant (for the applicant) • Must submit a 13 digit bar coded identity document
Grant in Aid	240	• Person who requires full-time attendance by another person because of physical or mental disabilities • Not cared for in an institution that receives a subsidy from the State for the care or housing of such beneficiaries • Receives social grant
Social Relief Grant	Food parcel or voucher	• 13-digit bar-coded identity document and you children's birth certificates. • Need of emergency assistance because: you are waiting for the children's grants to be processed; a crisis or disaster has occurred; you do not qualify for a grant, and you are in a desperate situation ; you are unable to work because you are medically unfit; you are unable to get maintenance from the other parent of the child or children; the breadwinner in the family has died; the breadwinner has been sent to prison for a short time (less than six months); you have been affected by a disaster, but the area or community in which you live has not been declared a disaster area
Government Housing Subsidy	In kind transfer of home	• Must be married or constantly be living together with any other person. A single person with proven financial dependants (such as children or family members) may also apply. • Citizen of South Africa or permanent resident • Gross monthly household income must not exceed R3 500 • Not yet benefited from government funding unless you qualify for a Consolidation Subsidy, are disabled, are a first time property owner
Care Dependency Grant	1,010	• Must be a South African citizen (except for foster parents who have foster children who qualify for the care dependency grant) • The applicant and child must be resident in South Africa • Child must be between 1-18 years of age • Must submit medical/assessment report confirming disability • Applicant, spouse, and child must meet the requirements of the means test (except for foster parents) • The care dependent child/children must be permanently cared for by a State institution • Applicant must submit a 13 digit bar-coded identity document • The child must have a 13 digit bar-coded birth certificate

Child Support Grant	240	• The child and primary caregiver must be South African citizens • The child and primary caregiver must be resident in South Africa • Applicant must be the primary caregiver of the child concerned • The child must be under 14 years of age • The applicant and Spouse must meet the requirements of the means test • The caregiver must have a 13 digit bar-coded identity document • The child must have a 13 digit bar-coded identity document • The applicant cannot apply for this grant for more than six non-biological children
Foster Care Grant	680	• The applicant and child must be a resident of South Africa at the time of application • The applicant must have a 13 digit bar-coded identity document • Court order must indicate that the child has foster care status • The child must have valid South African 13 digit bar-coded identity document • Foster child must pass the means test

Source: South African Social Service Administration (Administration 2008)