Health and responsibility:
The relationship between parental illness and children's work in South Africa

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Abstract

South Africa faces a high disease burden and a limited public capacity to provide care to the ill. Research from the UK and sub-Saharan Africa suggests the burden often falls to children, who also take over domestic responsibilities necessary for household survival. To date, there is limited research exploring the relationship between parental illness and children' responsibilities, or the moderating effect of socio-demographic variables.

The thesis is comprised of three research phases. The first is a literature review to summarise existing research and identify substantial gaps, which included limited amounts of quantitative evidence on this topic and a lack of a tool to assess child responsibility that had both been adapted to the South African context and included caring responsibilities. The second research phase consists of an exploratory study of n = 349 children living with ill adults in urban and rural communities in the Western Cape province of South Africa to investigate their range of responsibility, which included caring for an ill parent, household chores, childcare, and income-generation. The resulting data were used to create the Child Responsibility Measure, which assesses the range and time burden of responsibilities among South African children.

The third research phase is a cross-sectional quantitative survey of n = 2,476 pairs of children and parents from urban and rural communities in KwaZulu-Natal province, South Africa. Resulting data on parental health, socio-demographics, and child responsibilities were analysed with multiple regressions to determine drivers of children's responsibility. Among the findings were

that parental illnesses increase the likelihood children provide care and have larger responsibility workloads, and girls are more likely to take on all types of responsibility excluding income-generating activities, which were more common in boys. Additionally, while urban children were more likely to provide personal care, rural children had greater responsibility workloads.

Note on the candidate's research role

All of the data collection described in this thesis was conducted under the umbrella of the Young Carers Project (www.youngcarers.org.za). The project is a collaboration between international universities including the University of Oxford, the Health, Economics, and HIV/AIDS Research Division (HEARD) at the University of KwaZulu-Natal in Durban (www.heard.org.za), and Brown University in Providence, Rhode Island; several national South African Departments including Social Development, Education, Health, Agriculture, and Forestry and Fisheries; a home based-care organisation, Tholulwazi Uzivikele in Manguzi, South Africa (www.tuproject.org), and Cape Town Child Welfare.

The candidate conducted all aspects of the literature review (*Chapter 2*).

The first of two empirical studies described in this thesis, the exploratory study (*Chapter 3*), was conceptualised by the candidate and his supervisor, Dr Lucie Cluver. The candidate also designed the questionnaire based on a journal-style workbook used in Evans and Becker (2007, 2009), which itself was adapted from one in Healthlink Worldwide (2006). Data collection was performed by interviewers who were recruited via Dr Cluver based on her previous work experience with them. The candidate determined sites for data collection, trained research staff, supervised them in the field, monitored data quality, entered questionnaire data into an electronic database, and analysed it. The exploratory study received its funding from the John Fell Fund as part of the wider Young Carers Project South Africa.

The second empirical study, a quantitative cross-sectional survey (*Chapters 4*, *5*, and *6*), was collaboratively conceptualised between researchers at Oxford, HEARD, and Brown University including Drs Cluver and Caroline Kuo (who served as Primary Investigators for the quantitative survey), Profs Frances Gardner and Don Operario, Marisa Casale, and the candidate. This team created the questionnaires, with the carer component being based on Dr Kuo's materials from her doctoral thesis study (Kuo, 2010). Ms Kerry Mauchline designed the questionnaires' layout. The candidate created the Child Responsibility Measure used in this study based on the findings of his literature review and exploratory study. Field and office staff candidates were recruited via Human Resources at HEARD in the urban site and Tholulwazi Uzivikele in the rural site, who were then screened and interviewed by Ms Casale and the candidate. Ms Casale and the candidate served as project managers for the duration of data collection, and were later joined by Ms Lebo Sello during rural data collection. Ms Casale, Ms Sello, and the candidate trained research staff, supervised them in the field, monitored data quality, and supervised data entry and office staff teams. Ms Casale, Dr Kuo, and the candidate cleaned the resulting databases. The candidate later trained Ms Robyn Cox and Mr Jamie McLaren Lachman to assist with database cleaning. The candidate conducted all data analyses presented in this thesis. The Health, Economics, and HIV/AIDS Research Division of University of KwaZulu-Natal funded the quantitative survey.

Key terms

Deprivation:	Lacking 'the types of diet, clothing, housing, household facilities and fuel and environmental, educational, working, and social conditions, activities and facilities which are customary, or at least widely encouraged and approved, in the societies to which they belong,' (Townsend, 1987, pp. 125-126).
Enumerator area:	Sub-district used for participant stratification in the urban cohort of the cross-sectional survey. A workload-defined boundary for census enumerators.
Health deprivation:	Measure of inequality between communities at Enumeration Area and Ward level. Used to select field sites in the urban cohort of the cross-sectional survey. Indicated by premature mortality (Noble et al., 2006).
Home community-based care:	Provision of health and intimate care at an unwell person's home rather than in a hospital setting, either by volunteers, trained carers, family members or young carers.

Household:	The place in which someone sleeps for at least four nights a week over the course four weeks prior to interview.
Isigodi:	Sub-district used for participant stratification in the rural cohort of the cross-sectional survey. A traditional geo-cultural (as opposed to geo-spatial) boundary.
isiXhosa:	Language of the Xhosa ethnic group.
isiZulu:	Language of the Zulu ethnic group.
Orphan:	Child under 18 years of age who has lost one or both parents (UNAIDS, UNICEF, & US Bureau of the Census, 2004).
Parent:	Person with primary responsibility for a child. In this study, 'parent' refers to biological parents, grandparents, relatives, and foster parents who are at least 18 years of age.
Parentification:	Process by which child takes on parenting role, particularly emotional components, due to reduced adult presence or incapacity.
Responsibility:	Any activity done for the benefit of another person or persons.

Unwell:	Being in a state of illness or disability over the two weeks prior to interview.
Xhosa:	Black African group with large populations in the Western and Eastern Cape provinces of South Africa. Frequently used in lieu of isiXhosa as the name of the language of this ethnic group.
Young carer:	Child under the age of 18 years who takes on responsibilities as the result of another person's illness or disability.
Zulu:	Black African group with large populations in the KwaZulu-Natal province of South Africa. Frequently used in lieu of isiZulu as the name of the language of this ethnic group.

Chapter 1: Introduction

Familial illness can disrupt household dynamics by creating a need for care, reducing labour capacity, and catalysing or exacerbating existing poverty. To alleviate the negative impact of illness, children sometimes take on 'adult' responsibilities to alleviate the resulting burdens (Becker, 2000; Becker, Aldridge, & Dearden, 1998; Dearden & Becker, 2004). Children's responsibilities have been found to include caring for an ill person by helping with medication, providing emotional support, or providing intimate care by washing or toileting the ill person, in addition to increases in household chores (Dearden & Becker, 2004; Warren, 2007).

While child caring and responsibility due to familial illness is well-researched in the United Kingdom, and to a lesser extent Australia and the United States, it has been virtually ignored in sub-Saharan Africa (Becker, 2007; Skovdal, 2009b). Numerous indicators suggest that children in South Africa face more household illness and have fewer resources to alleviate the burden than those in the world's more developed regions. This chapter describes the South African context including disease burden, healthcare, domestic life, and cultural ideas regarding the responsibilities of children. *Section 1* explores the relationship between parental illness and child responsibility, while *Section 2* discusses South African contextual factors including general health, healthcare, and domestic life. *Section 3* explores differences between cultural conceptions of childhood and how they may affect the nature and workload of children's responsibilities. *Section 4* describes the thesis aims and research questions, and *Section 5* concludes the chapter with a summary of the research phases comprising the bulk of the thesis.

1 Caring and responsibility in children

Research in the United Kingdom has documented that children with ill family members take on additional responsibilities to alleviate household burden. In a national survey of *n* = 6,178 young carers, Dearden and Becker (2004) found children provided care to ill people, ranging from intimate care (washing, dressing, and toileting their ill family member) to medical care (giving medications and changing soiled dressings). Around half of the healthcare and domestic needs resulted from a physical health problem, 29% (*n* not given) were due to a mental health disorder, 17% from a learning disability, and 3% from sensory impairment. Children most commonly cared for their mothers, who accounted for 59% (*n* not given) of familial care recipients; children also reported caring for fathers (16%), siblings (33%), and grandparents (4%). A time burden analysis of the third of the sample for which the data were available (35%; *n* = 2,149) found half the children (50%; *n* = 1,080) spent 11 hours or more caring per week, while 6% (*n* = 162) spent 30 or more. Nearly two-thirds of the sample (64%, *n* not given) had been providing care for three years or more. The Office for National Statistics (2003) estimates that in 2001 there were 175,000 children in the UK providing some sort of unpaid care.

In addition to caring, children's responsibilities include household chores that consist of domestic maintenance tasks like cooking family meals, cleaning the house, washing clothes, ironing, and shopping for food (Dearden & Becker, 2004; Warren, 2007). In a quantitative survey of *n* = 390 children aged 9 to 18 years, Warren (2007) found that children identified as 'young carers' had greater household chore workloads, both in terms of time and intensity. For instance, children who were not providing personal care most often completed household

chores to extent that they personally benefitted, such as cleaning their own room or preparing a meal for themselves. In comparison, children identified as 'young carers' were cooking for the entire family and cleaning the whole household.

Within sub-Saharan Africa there has been very little research or policy focused on children caring for the ill as a specific group affected by HIV/AIDS, non-communicable diseases, or other illnesses and disabilities. Becker (2007) identifies 350 projects for young carers in the UK in addition to unique legal rights and a well-developed research base, compared to 'embryonic' development of research and policy in the subcontinent, furthermore noting that much of the literature on sub-Saharan Africa originates with UK-based researchers. Skovdal (2009b) identifies only nine studies with data collected in sub-Saharan Africa, including six articles from peer-reviewed journals (Bauman et al., 2006; Martin, 2006; Robson, 2000, 2001, 2004; Robson, Ansell, Huber, Gould, & Van Blerk, 2006), two book chapters (Bauman & Germann, 2005; Robson & Ansell, 2000), and a book (Evans & Becker, 2009). Two of the pieces are not considered 'research' in the literature review of this thesis (*Chapter 2*) because they report solely on the ethical difficulties of conducting research with 'young carers' (Robson, 2001) or do not present any new data from studies (Bauman & Germann, 2005).

1.1 'Young carers' and 'parentification'

In the literature, children with caring responsibilities are referred to as 'young carers,' while taking on a parenting role is referred to as 'parentification.' For a number of reasons that are elucidated in this section, neither description is used in this thesis unless referring to descriptions of participants in other research.

According to Becker (2000), young carers are defined as 'children and young persons under 18 who provide or intend to provide care, assistance, or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult,' (p. 378). The term 'young carer' emphasises personal care responsibilities such as bathing and toileting (Morrow & Richards, 1996; Robson, 2000), and a child who shoulders burdens by him or herself. As noted in the previous section, children who care for their ill parents often spend more time on other responsibilities and their chores are more in-depth. Using the 'young carer' label may thus exclude what some researchers (e.g., Bray, 2009) consider to be a substantial component of the responsibility burden resulting from familial illness. Second, population data indicate the nuclear family household is far less common in South Africa (56%) than in the UK (86%), and that the extended family household is 13 times more common in South Africa (13% versus 1%) (Ziehl, 2005). Some existing research suggests that children often provide assistance to adult carers (Harris, 2008; Harris & Stuart, 2006; Lindsey, Hirschfeld, Tlou, & Ncube, 2003), or that children work together to meet the needs resulting from household illness (Skovdal, Ogutu, Aoro, & Campbell, 2009). Conversely, single-parent households are twice as common in South Africa (22%) as they are in the UK (10%) (Ziehl, 2005), indicating greater proportions of households where there are only children to address household need.

Mika, Bergner, and Baum (1987) define parentification as 'the familial interaction pattern in which children and adolescents are assigned roles and responsibilities normally in the province of adults in a given culture,' (p. 271). J. A. Stein, Riedel, and Rotheram-Borus (1999) write that parentification has 'children or

adolescents assuming adult roles before they are emotionally or developmentally ready to manage those roles successfully,' (p. 193). Parentification, while acknowledging children's instrumental tasks, differs from young carers in emphasis, focusing instead on children taking on the emotional expressive role of a parent (Jurkovic, Jessee, & Goglia, 1991; Tompkins, 2007).

The definitions for both 'young carer' and 'parentification' are problematic because of the emphasis on 'adult' responsibilities and roles, which depend on strong dichotomisations between 'children' and 'adults.' Such strong categorisations in terms of capacity and appropriateness are prominent in Western nations, though only recently, and are not the norm in many parts of sub-Saharan Africa (see *Section 3* of this chapter for a more detailed discussion). Another problematic aspect of these labels is the top-down nature of their application, identifying children based on a limited set of responsibilities or familial interactions; while the impact of familial illness may be apparent for children who provide care to an ill person or take on the role of surrogate parent, it is less certain for children whose labours are enhanced in subtler ways, particularly with less obvious responsibilities like housework.

Rather than looking at children with specific types of responsibilities like personal care and exaggerated time burdens, this thesis seeks to understand how parental illness and moderating socio-demographic factors affect the extent and burden of children's responsibilities. As will be shown in the next chapter, the limited existing research from sub-Saharan Africa does not provide sufficient data to differentiate and categorise children as 'young carers' or 'parentified' based on their living circumstances and the extent of their responsibilities. Finally, it

must be noted that even if such criteria are devised, the application of either label may be problematic due to HIV/AIDS-related stigma, fostering community resentment against children and families receiving support, and simplifying the myriad impacts of familial illness on children (Evans & Becker, 2009).

1.2 The impact of responsibility

Despite calls for research into the impact of responsibilities on children in sub-Saharan Africa (Foster & Williamson, 2000), there have only been a handful of studies devoted to this topic (Skovdal, 2009b). With this limited research background, data from adult carers in sub-Saharan Africa and children from Western and Chinese contexts are presented to highlight possible outcomes for children in South Africa.

The limited quantitative evidence indicates negative consequences for children who take on caring responsibilities and large domestic responsibility time burdens. One of these studies, Gwandure (2007), found that South African children caring for AIDS-unwell parents exhibited greater mental distress and poorer cognitive functioning compared to similar non-caring children (n = 60). In a meta-analysis of young carer studies in Western settings, Hooper, DeCoster, White, and Voltz (2011) found a small but significant correlation between parentification and psychopathology in adulthood. Robson et al. (2006) describe caring as 'traumatic' for children (p. 104), referring to the distress children exhibited while describing their experiences in Robson (2001). However, in creating the validated Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for British young carers, Joseph, Becker, Becker, and Regel (2009) found a more complex impact of children's responsibilities. For instance, girl young car-

ers generally reported negative outcomes (exhibiting both positive and negative outcomes with provision of emotional care), while boys generally reported positive outcomes (though provision of personal care had a significantly negative impact).

A number of physical risks are suggested to be associated with providing care as well. For one, there is a risk of HIV or tuberculosis transmission when providing care, which is greater among children due to their limited knowledge regarding safety precautions in providing care and their often being unaware of a care recipient's HIV-status (Akintola, 2005, 2006; Kang'ethe, 2010; Robson et al., 2006). A recent quantitative study (partially using data collected in the third research phase comprising this thesis) found that children who were exposed to bodily fluids while providing care had three times greater odds of having tuberculosis than other children (OR = 3.12; 95% CI = 1.96-4.95) (Cluver, Orkin, Moshabela, Kuo, & Boyes, 2013). Several researchers note physical risks to home-based care in adults in sub-Saharan Africa, including the heavy and demanding nature of the work, made more difficult by lack of proper care materials (Akintola, 2004, 2006; Kang'ethe, 2010; Thomas, 2006). For female carers, especially girls, there is an elevated risk of sexual abuse and exposure to HIV from the care recipient (Akintola, 2004, 2006; Lindsey et al., 2003).

Excessive domestic chores have also been linked to negative outcomes in children. In a quantitative study of HIV/AIDS-affected (orphaned and living with an ill parent) and unaffected children in China (*n* =1,449), Yu et al. (2012) found that HIV/AIDS-affected children had greater responsibility time burdens, and that greater workloads were associated with depressive symptoms. A number of

other studies, mostly qualitative, have noted that large responsibility time burdens negatively affect children's school attendance and performance and their ability to socialise with friends (Barnard, 2002; Bray, 2003; Evans, 2010b, 2010c; Evans & Becker, 2009; Harms, Jack, Ssebunnya, & Kizza, 2010; Lindsey et al., 2003; Martin, 2006; Robson, 2000; Robson et al., 2006; Skovdal, 2010; Skovdal et al., 2009; Thomas, 2006; Wood, Chase, & Aggleton, 2006).

Some researchers warn against the tendency to problematize children's caring roles, suggesting such arrangements are an effective and culturally-appropriate means of coping with familial illness (Olsen, 1996, 2000; Skovdal, 2009b; Skovdal et al., 2009), and that unsubstantiated claims of negative outcomes can become accepted as scholarly 'truth' without further examination (Bray, 2009). Others suggest that caring responsibilities can have positive impacts on children, including increased maturity and ability to cope as a result of skills acquired (Bray, 2009; Evans & Becker, 2007, 2009). Additionally, with the backing of supportive households and communities, children sometimes report a feeling of satisfaction from meeting their familial obligations and a means of deriving recognition from their communities (Skovdal, 2009a, 2009b; Skovdal & Andreouli, 2011; Skovdal & Ogutu, 2009; Skovdal et al., 2009). On the other hand, Robson et al. (2006) caution that 'for some young people, at least, experiences may be part of strategies for basic psychological survival,' (p. 105), while Bray and Brandt (2007) warn that short-term benefits of caring may mask its long-term negative impacts.

2 The South African context

This section explores the context in which this research takes place. It identifies and describes several aspects of South African health, demographics, public services, and culture that are suggested to increase the reliance on children to provide care to the ill and maintain the home.

2.1 Disease and burden in South Africa

South Africa is faced with what has been described as a quadruple disease burden. Group I consists of communicable diseases, maternal and perinatal conditions, and nutritional deficiencies, Group II non-communicable diseases, and Group III injuries. The last Group (IV) is HIV/AIDS, which is considered separately from other communicable diseases due to its outsize prevalence and burden within South Africa (Bradshaw et al., 2003; Norman, Bradshaw, Schneider, Pieterese, & Groenewald, 2006). With an estimated 17.8% prevalence in people between 15-49 years of age, South Africa is home to 5.6 million people living with HIV/AIDS, the largest such population in the world (UNAIDS, 2010). It is also South Africa's leading cause of disability-adjusted life years, or years of life lost to illness, disability, or death (Bradshaw et al., 2003; Bradshaw, Norman, & Schneider, 2007).

Within the context of the strain caused by HIV/AIDS, there are additional burdens from other communicable and non-communicable diseases, and violence and injuries, which account for a substantial amount of disability-adjusted life years (Bradshaw et al., 2003; WHO, 2008). Though life expectancy has dropped overall within South Africa, the number of adults over sixty has increased along with greater burden from non-communicable diseases like cardiovascular illness, diabetes, cancer, and asthma (Mayosi et al., 2009; Tollman et al., 2008;

WHO, 2009). Part of this is attributable to changes in lifestyle, especially increases in wealth and cardiovascular disease, while smoking, exposure to fumes from cheap cooking and heating fuels, alcohol dependence, and poorer treatment exacerbate health problems in impoverished South African communities (M. Schneider, Bradshaw, Steyn, Norman, & Laubscher, 2009). Non-communicable diseases account for the majority of ambulatory primary care clinic visits (Mash et al., 2012).

According to Statistics South Africa (2007), disabilities are:

> …A physical or mental handicap which lasted for six months or more, or is expected to last at least six months, which prevents the person from carrying out daily activities independently, or from participating fully in education, economic, or social activities. (p. 35)

Using this definition, an estimated 1.9 million South Africans, or 4.0% of the population, suffer from some type of disability, with 6.4% of those suffering from multiple disabilities. The most frequently cited disabilities were physical (40.5%), emotional (19.5%), and visual (13.0%). Others included audio (9.4%), intellectual (6.7%), and verbal (4.8%) (Statistics South Africa, 2007).

Recently, violence has become recognised as a public health problem in South Africa (Norman et al., 2007). Fuelled by poverty and inequality, perceptions about masculinity, cycles of childhood violence, alcohol and drugs, gun culture, and a history of self-defence and community enforcement of safety, some estimate that interpersonal violence is the second leading cause of years of life lost to illness, disability, or death (Norman et al., 2007; Seedat, Van Niekerk, Jewkes, Shuffla, & Ratele, 2009). Other injuries unrelated to violence, primarily resulting from traffic accidents to both vehicle passengers and pedestrians but also includ-

ing burns and falls, are another significant sources of years lost (Seedat et al., 2009).

South Africa is host to numerous structural factors associated with vulnerability to mental health disorders, including poverty, rapid social change, risk of violence and physical injury, and inaccessibility of mental healthcare services (Patel & Kleinman, 2003). Lifetime prevalence of mental health disorders in South Africa is 30.3%, with anxiety the most prevalent disorder at 15.8% (Herman et al., 2009; D. J. Stein et al., 2008). Little research has been conducted on mental health disorders in sub-Saharan Africa, and the majority of what mental health research there is originates in South Africa (Razzouk et al., 2010). A small number of studies collecting data in Nigeria, where 12-month mental health disorder prevalence ranged from 4.7% to 5.8% (Demyttenaere et al., 2004; Gureje, Lasebikan, Kola, & Makanjuola, 2006), suggest greater prevalence in South Africa.

Mental health disorders are a substantial source of illness in South Africa; unipolar depression was second only to HIV/AIDS in terms of years of life lost to illness, disability, or death (Norman et al., 2006). Alcohol abuse is another large source of burden, resulting in interpersonal violence, alcohol use disorders, and road traffic injuries; in total, alcohol use is estimated to account for 7% of years lost (M. Schneider, Norman, Parry, Bradshaw, & Plüddemann, 2007).

Household illness and parental death is a relatively common phenomenon within impoverished South African households. In a survey of Soweto, Gray et al. (2006) found that 44% of households contained at least one ill adult. Household illness often results in considerable financial burdens and/or cost barriers to treatment

(Goudge, Gilson, Russell, Gumede, & Mills, 2009). Household death, especially that due to AIDS, is also associated with a strain on household resources due to the loss of income and funeral costs (Collins & Leibbrandt, 2007). Compared to median black African income, funerals cost between seven months' and one year's salary, and while one-quarter to 39% of households have insurance to help defray some of the costs, another one-quarter need to borrow money to cover expenses (Case, Garrib, Menendez, & Olgiati, 2008; Collins & Leibbrandt, 2007).

Leading causes of death in South Africa are HIV/AIDS, heart disease, stroke, tuberculosis, and interpersonal violence (Norman et al., 2007). Around 15% of all deaths are attributable to non-natural causes (Statistics South Africa, 2007). In rural north-eastern South Africa, household adult death within the previous two years was associated with reduced food security (Twine & Hunter, 2008) while high funeral costs reduced per person household spending and lowered rates of children's school enrolment (Case & Menendez, 2009).

2.1.1 Healthcare in South Africa

Healthcare in South Africa is provided through a mix of private and public sector facilities. Private healthcare is accessed mainly through health insurance, known in South Africa as medical schemes. Accounting for 59% of healthcare spending in South Africa (McIntyre et al., 2007), private healthcare serves only around 16% of the population (Day & Gray, 2007). Most of those who have access to private healthcare through medical schemes are wealthier and are in formal sector employment or the dependent of one (Borghi et al., 2009).

Some 84% of South Africans rely primarily on nearly fully tax-funded public healthcare (Day & Gray, 2007; McIntyre et al., 2007). The post-Apartheid public healthcare system was developed in line with the Declaration of Alma-Ata (WHO, 1978) to address extreme inequalities in health outcomes that had developed under the colonial and Apartheid eras (Benatar, 2004; Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). The public sector primarily serves black Africans; when last ill, 71.9% of black Africans consulted a public healthcare facility, compared to 52.8% of coloured, 49.4% of Indian, and 16.1% of white South Africans (Statistics South Africa, 2011). Primary health care is provided by district health systems, which increase access to poorer communities through clinics (Benatar, 2004; Coovadia et al., 2009).

The public sector is beset with a number of problems in administering healthcare, including human resource and management deficiencies and the migration of many public sector workers to private facilities or abroad (Coovadia et al., 2009; Day & Gray, 2007). Since the creation of the district health systems, funding allocations have been inversely correlated with disease burden and poorer healthcare capacity (Stuckler, Basu, & McKee, 2011). While 71% of households are less than two kilometres away from a clinic, 18.5% of tribal and 51.2% of formal rural residents must travel 10 kilometres or more (Statistics South Africa, 2011). One-quarter of South Africans were unable to access treatment the last time they were physically ill (Lalloo, Smith, Myburgh, & Solanki, 2004). A household survey of healthcare delivery in South Africa found that when controlling for race, gender, age, and area type, only socio-economic status was predictive of access (Lalloo et al., 2004).

Despite official guidance of 'progressive' (Burns, 2011, p. 100) national mental health legislation ("Mental Health Care Act 17 of 2002," 2002), policy has been poorly disseminated and implemented throughout South Africa (Draper et al., 2009). Only around one-quarter of South Africans meeting DSM-IV criteria for a mental health disorder receive treatment (Williams et al., 2008). This is partially a reflection of the scarcity of public mental healthcare resources in South Arica, a factor noted to reduce focus on the burden of mental health disorders in sub-Saharan Africa (Gureje & Alem, 2000) and other developing nations (Alarcón & Aguilar-Gaxiola, 2000). In South Africa, this is exemplified by substantial funding disparities between general and psychiatric hospitals, poor care facilities, a shortage of mental health practitioners, and underdeveloped community mental health services, resulting in an inability to meet demand and treat or rehabilitate those with serious conditions (Burns, 2010, 2011).

In addition to biomedical or 'Western' medicine, an estimated 80% of people in sub-Saharan African use the services of traditional health practitioners and remedies (WHO, 2002), which the World Health Organization defines as:

> …Diverse health practices, approaches, knowledge and beliefs incorporating plant, animal and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being, as well as to treat, diagnose or prevent illness. (WHO, 2002, p. 7)

Traditional medicine is rooted in a belief of spiritual or supernatural causes of illness, though traditional health practitioners treat health problems from the spiritual to chronic illness like HIV/AIDS (Kale, 1995; Peltzer & Mngqundaniso, 2008).

Traditional health practitioners generally take on two roles: inyanga, or herbalist, and sangoma, or diviner (Kale, 1995; Walwyn & Maitshotlo, 2010). While there are claims of traditional medicine's effectiveness, particularly concerning pain relief, the most recent literature suggests no clinical evidence of efficacy (Richter, 2003). Additionally, traditional medicine can be an obstacle to successful treatment, particularly with HIV/AIDS. For one, traditional medicine remains largely unregulated in South Africa, with most legislation concerning the recognition and categorisation of different types of traditional health practitioners rather than its practice (Moagi, 2009; Richter, 2003; Street, Stirk, & Van Staden, 2008; Walwyn & Maitshotlo, 2010). The problems manifest themselves with the varying quality in remedies, which if not stored properly can grow moulds that present danger to people with compromised immune systems (S. Govender, Plessis-Stoman, Downing, & Van de Venter, 2006; Street et al., 2008), contamination of products with pesticides, wastes, or heavy metals, and the misidentification of plants that leads to poisoning (Stewart, Steenkamp, & Zuckerman, 1998; Street et al., 2008).

The mixture of plants and herbs with active elements carries an inherent risk of interaction with biomedical treatments (Ernst, 2000). Hypoxidaceae and Fabaceae, two popular plants in traditional medicine for HIV/AIDS-treatment, not only have no evidence of efficacy but can negatively interact with antiretroviral therapy (ART), putting patients at risk for treatment failure, drug resistance, or even toxicity (Mills, Cooper, Seely, & Kanfer, 2005; Mills, Foster, et al., 2005; Street et al., 2008). Research suggests that half of South African HIV/AIDS patients use a combination of traditional medicine and ART (Walwyn & Maitshotlo,

2010), and that reduced ART adherence (< 95%) is associated with traditional medicine utilisation (Namuddu et al., 2011). In other cases, traditional remedies may be used in lieu of ART; while some patients switch to traditional medicine because of the negative side effects of ART (Peltzer & Mngqundaniso, 2008), recent surveys have found that substantial numbers of traditional health practitioners exhibit poor working knowledge of HIV/AIDS (50%), claim to have an AIDS 'cure' (20%), or believe that traditional medicine should be used exclusively to treat HIV/AIDS (39%) (Walwyn & Maitshotlo, 2010). Within the context of biomedical healthcare, some see opportunities to work with traditional healers to increase access to ART and other essential treatments (De Jager, Prinsloo, & Joubert, 2010; Kale, 1995; Richter, 2003), though others view traditional medicine and its lack of adherence to WHO minimum standards of HIV/AIDS treatment as an obstacle to proper HIV/AIDS care (Walwyn & Maitshotlo, 2010).

2.1.2 Antiretroviral therapy

Presently, antiretroviral therapy (ART) is recognised as the best means of treating HIV/AIDS in terms of both controlling viral load and reducing mortality (e.g., Detels et al., 1998; Hogg et al., 1998; Hogg et al., 1997; Mocroft et al., 1998). By the end of 2010, 55% of those requiring ART in South Africa were receiving it, a 43% increase from 2009 (WHO, 2011). One of the obstacles to better provision is government policy that favours drug conservation over maximum viral suppression (DOH, 2010; Emery et al., 2008; Walensky et al., 2009). While the WHO (2010) recommends that ART begin at CD4 counts ≤ 350 cells/mm^3, the South African Department of Health (DOH, 2010) eligibility criteria is ≤ 200 cells/mm^3 unless the person is pregnant or has tuberculosis, where the minimum is raised to ≤ 350 cells/mm^3, or any CD4 count if exhibiting WHO Stage IV AIDS or

MDR/XDR-tuberculosis. Though drug conservation and rationing is a realistic and pragmatic strategy within resource-deprived settings (Bennet & Chanfreau, 2005) and allows for the prioritisation of the most unwell individuals (Walensky et al., 2009), the higher threshold increases the risk of opportunistic illnesses and poor health outcomes in AIDS-ill individuals (Emery et al., 2008; Lawn, Myer, Orrell, Bekker, & Wood, 2005).

High ART adherence (≥ 95%) is strongly associated with positive health outcomes in people living with AIDS (Bangsberg et al., 2000; Paterson et al., 2000). Depending on measurement tools, patient adherence in South Africa is reported to be between 70.8% and 82.9% (Peltzer, Preez, Ramlagan, & Anderson, 2010). Obstacles to adherence include poorer education, reduced partner support, and being busy or forgetful (El-Khatib et al., 2011). Adherence was almost three times greater in urban populations (Peltzer et al., 2010).

2.1.3 Home- and community-based care

The combined impact of quadruple disease burden has shifted much of the responsibility for care from the public healthcare sector to households and communities via two pathways. First, the public healthcare sector has struggled to cope with the increased demand for care, where 25.7% of primary health care clinics and 46.2% public hospital patients are HIV-positive (Shisana et al., 2003). AIDS-ill patients in South Africa demand particular care: 16% are unable to control their bowels and bladder, 17% require assistance toileting or getting in or out of bed, 19% require assistance with bathing, around 10% with eating, and around 20% with ambulation (Steinberg, Johnson, Schierhout, & Ndegwa, 2002).

Second, HIV/AIDS has reduced the capacity of the public healthcare sector to meet demands for care. Analysis of Demographic Health Survey data from sub-Saharan Africa found increases in HIV-prevalence were associated with decreases in non-HIV/AIDS related health services (Case & Paxson, 2009). In South Africa, healthcare workers often miss work due to work stress from patient load and working conditions, and their own personal illness; HIV-prevalence among healthcare workers is similar to the general population at 15.7%, increasing to 20% among those under 35 years of age (Shisana, Hall, Maluleke, Chauveau, & Schwabe, 2004; Shisana et al., 2003). HIV/AIDS-illness can be more problematic among healthcare workers due to the combination of supressed immune systems and high exposure to tuberculosis and other infectious diseases. One strategy that has been implement in response is 'task shifting,' or 'the delegation of medical and health service duties from higher to lower cadres or new cadres,' (Zachariah et al., 2008, p. 550). A systematic review of task shifting identified several benefits of this strategy including streamlining services to increase HIV treatment and care in high burden, low resource African settings (Callaghan, Ford, & Schneider, 2010). However, given that task shifting relies on lower-level staff performing higher-level functions, it presents challenges to continued success, including higher HIV-prevalence among non-professional healthcare staff (20% versus 13.7%) (Shisana et al., 2004), and difficulties in sustainable treatment quality and safety (Zachariah et al., 2008).

In response to the overwhelming demand for care and the diminishing capacity to provide it, the South African government has promoted home- and community-based care as an alternative to public healthcare options (DOH, 2001). The

guidelines stress that 'no single entity is able to meet the total requirements and challenges of home-based care,' and that 'a collaborative effort is fundamental to success,' referring to the responsibilities of communities and the formal healthcare sector (p. 1). However, Akintola (2004, 2006) writes that most of the responsibility has fallen to the ill person's family and community, a source of considerable burden for these care providers (Nnko et al., 2000; Steinberg et al., 2002); home-based care for AIDS-ill patients require a median of five hours per day (Bachmann & Booysen, 2003). Additionally, as HIV/AIDS in sub-Saharan Africa has mostly affected working and parenting age adults (Blacker, 2004; Heuveline, 2004; Kahn, Garenne, Collinson, & Tollman, 2007; Oramasionwu, Daniels, Labreche, & Frei, 2011; Porter & Zaba, 2004), households and extended kin networks struggle to provide care. Oftentimes the home community-based care responsibilities fall to female relatives of the ill person (Akintola, 2006; Lindsey et al., 2003; Nnko et al., 2000; Steinberg et al., 2002; Uys, 2002).

In response to the increased demand for care during the early part of the HIV/AIDS-epidemic in sub-Saharan Africa, home- and community-based care organisations began to develop to meet the need (Akintola, 2004, 2006; Russel & Schneider, 2000). Home community-based carers are mostly comprised of volunteers and provide services, including palliative and emotional care and assistance with ART for the extremely ill (Akintola, 2004, 2005; H. Schneider, Hlophe, & Van Rensburg, 2008; Uys, 2002). The development of home community-based care organisations has been organic and incremental (H. Schneider et al., 2008), though remains largely unavailable due to limited resources and funding, difficulties with transportation, lack of volunteers, burnout, and inadequate training

(Mohammad & Gikonyo, 2005; Russel & Schneider, 2000; Steinberg et al., 2002; Uys, 2002).

2.2 Domestic life in South Africa

South Africa is characterised by high levels of inequality. According to the US Central Intelligence Agency (https://www.cia.gov/library/publications/the-world-factbook/rankorder/2172rank.html), South Africa's Gini index score of 65.0, where 0 is perfect income equality and 100 is maximum inequality, is the second highest in the world (only Namibia, with a similar recent history as a colony of Apartheid-era South Africa, scores higher with a Gini index of 70.7). Much of the inequality is associated with the residual impacts of the Apartheid, reflected in substantial economic differences between the main ethnic groups. On average, black Africans households' annual household consumption expenditure is below ZAR 45,000, a third that of Indian and a fifth of white households. White South Africans also spent eight times the amount black Africans spent on housing expenditures (ZAR 68,382 compared to ZAR 8,495) (Statistics South Africa, 2011).

Impoverished homes in South Africa require more labour to maintain, especially in informal urban settlements and rural (mostly ex-homelands) settings, partially due to a lack of services including electricity and piped water, dependence on subsistence agriculture, more livestock and pets to care for, and poorer quality homes requiring continual repair (Bray, 2003; Budlender, Chobokoane, & Mpetsheni, 2001; Statistics South Africa, 2001b). Furthermore, lack of electricity results in reliance on alternative fuels including gas, paraffin, wood, or dung for cooking, heating, and lighting fuel, requiring more labour to maintain and pre-

senting increased health and safety risks. Seventy per cent of informal urban dwellings rely on gas or paraffin for cooking, while nearly half (47%) of rural households use wood or dung (Budlender et al., 2001). Similar issues relate to the availability of water. The majority of formal homes have access to water within the dwelling (68%), compared to only 8% of informal and 3% of rural households. The remainder rely on on-site water taps or collect their water from an off-site community tap (Budlender et al., 2001). With a lack of public utilities and social services, many households in sub-Saharan Africa rely on children to collect firewood and fetch water (Laird, 2005). On average, collecting fuel sources and water requires an hour of a child's time, and even longer among children in rural areas (Rama & Richter, 2007). Other differences in responsibility demands may be determined by a household's building material; respondents in Bray (2003) note that linoleum floors in an informal shack are easier to clean and sweep than mud in a traditional hut.

Though education is mandatory for children up to 15 years of age or completion of primary education (ninth grade in South Africa), children often do not meet these minimum standards. In a recent survey of young South Africans, one quarter (23.3%) of respondents between 16 and 24 years had not completed compulsory education (Operario, Cluver, Rees, MacPhail, & Pettifor, 2008). Obstacles to school attendance included orphanhood and poverty (ibid), while ability among black African students was a less strong of predictor of school progression than for other children of other ethnic groups (Lam, Ardington, & Leibbrandt, 2008).

3 Conceptions of childhood

The Western concept of 'childhood' was fostered in the Enlightenment and became commonplace during the Industrial Revolution, when skills and education took precedence over unskilled labour (Coleman, 1990; Edwards, 1996). The view of children transformed from commodities for household functioning and survival to becoming economically 'worthless' yet emotionally 'priceless,' (Zelizer, 1994). The modern view in the West holds childhood to be a protected time for play and education in preparation for adulthood, generally free of responsibility (Laird, 2005; Robson, 2004). In contrast, many areas of sub-Saharan Africa rely on reciprocity between family and community members for survival, where the emphasis lies on sustaining the household as opposed to children's rights (Laird, 2005; Van Blerk & Ansell, 2002), and children are often seen as assets that can be the difference in coping with environmental, economic, or health stressors. This has been especially true of the era of the HIV/AIDS-epidemic, with its detrimental impact on household needs and capacity (Abebe, 2007; Laird, 2005; Van Blerk & Ansell, 2002).

Differences between Western and 'traditional' sub-Saharan African views of childhood are illuminated in comparison of passages in the *UN Convention on the Rights of the Child* (UN, 1989) and the African Union's *African Charter on the Rights of the Child* (Organization of African Unity, 1990). Article 31 in the latter describes the responsibilities of the child, stating:

> Every child shall have responsibilities towards his family and society…The child, subject to his age and ability…shall have the duty to work for the cohesion of the family, to respect his parents, superiors, and elders at all times and to assist them in case of need.

Though the UN document contains no description of children's responsibilities (Laird, 2005), it does state that families and education have the duty to prepare them for responsibilities in adulthood (UN, 1989, Preamble and Article 29), suggesting that children's economic value exists only in their potential as adults.

Edwards (1996) warns that sentimentality regarding childhood in Western nations and the large multinational organisations they dominate (e.g., the UN) is an obstacle to appropriate responses to social problems concerning children. Interestingly, while the same article calls for an increased role for children's self-determination regarding interventions on their behalf, much of the research originating in sub-Saharan Africa suggests that children's families and heads of household determine whether and how much responsibility a child will have in order to cope with household need (Robson, 2000, 2004; Van Blerk & Ansell, 2007). Research in South Africa suggests that children and adolescents are subordinate to their parents in terms of power and decision making when households are coping with the impact of illness (Ansell & Van Blerk, 2004; Robson et al., 2006).

The notion of children providing care for ill adults is firmly in opposition to Western concepts of childhood (Evans & Becker, 2009; Robson, 2004; Skovdal, 2009b). For instance, Becker (2000) describes the type of responsibilities young carers take on as those 'which would normally be associated with an adult,' (p. 378). In the UK, AIDS-ill African migrant parents report difficulty in reconciling the much more demanding expectations of children from their own beliefs with those of their adopted country, often finding that children behave based on the hegemonic (i.e., Western) culture (Evans, 2011).

The distinct notions of childhood should not be taken as homogenous within their geographic or cultural geography, however. Research from within sub-Saharan Africa suggests that perceptions and expectations of children are changing due to current needs and the permeation of Western values. Skovdal (2009a) summarises the catalysts of this change, writing:

> Although Luo [a tribal group in Kenya] children have traditionally been helping out with productive and reproductive activities in their homes, disease, poverty and globalisation of values has stretched communitarian ideals and weakened traditional coping methods. (p. 8)

Robson (2004) and Skovdal (2009a, 2009b) describe conflicting viewpoints expressed among children, parents, and key informants in their studies in Zimbabwe and Kenya. The emergence of 'Western' notions of childhood is attributed to exposure through the internet, radio, and television, and also the prominence of Western values in international AIDS organisations and programmes (Edwards, 1996; Laird, 2005; Robson, 2000; Skovdal, 2009a, 2009b). Other changes appear to reflect the strains of poverty and disease, which limit household's options for responding to disease, and require beliefs to evolve to match reality. Skovdal and Andreouli (2011) write:

> The representation of children as active participants in the household economy is a reflection of the dynamic interplay between their material needs and normative expectations. Because of the endemic poverty that characterises the area, many households remain dependent on children's contribution to sustain household livelihoods. (p. 621)

3.1 The 'Generational Bargain' in South Africa

In the 'generational bargain,' Collard (2001) posits that there are three generations of resource acquisition and disbursal: young, working, and old. The working generation controls the majority of resources and allocation, and provides

the majority of care to the young and old generations. The bargain relies on self-interest and perpetuity: the working generation cares for the old in return for the care they received when young, and care for the young in the hopes of receiving care when older (ibid).

In sub-Saharan Africa, the bargain has been breaking down as a result of demographic changes and increases in healthcare needs due to the HIV/AIDS-epidemic. Fewer adults are available to cope with the care needs following familial illness and death (Van Blerk & Ansell, 2007); as HIV/AIDS mostly affects people of working and parenting age, the burden of care shifts to the young and old generations. Older grandparents often provide care for the young generation, leaving the older population in a perpetual state of parenting. The young, on the other hand, become considered 'assets,' expected to contribute to the household to a larger degree than they otherwise would. In a role-reversal, the young provide replace the working to care for the older generation (Abebe, 2007).

Some younger (i.e., not grandparents or otherwise elderly) adoptive families resort to immediate returns on the generational bargain in order to cope with the additional burden of caring for orphaned children (Van Blerk & Ansell, 2007). While beneficial in the short term, the compromises made can sacrifice children's education, reducing the future potential of the young generation to earn money and provide care when they age into the working generation (Collard, 2001; Van Blerk & Ansell, 2007).

4 Thesis aims and research questions

The aim of the thesis is to produce data on the impact of parental illness on children's responsibilities in deprived South African communities. To achieve this goal, the thesis is guided by research questions that were developed to address knowledge gaps identified in the literature review (described in more detail in *Chapter 2*, *Sections 3.4* and *4*). The research questions fall into three categories, described below:

Nature of children's responsibilities

- What types of responsibilities do children in South Africa engage in?

Predictors of children caring for their parents

- Does parental illness predict children's engagement in intimate or medical care?
- What other factors predict children's engagement in intimate or medical care?

Predictors of children's responsibility workload

- Does parental illness predict greater responsibility workloads in children?
- What other factors predict greater responsibility workloads in children?

5 Thesis organisation

This thesis is composed of three separate research phases, with each successive phase building upon the findings of the previous. The phases are a literature review, an exploratory study, and a quantitative, cross-sectional survey, which are presented across the next six chapters. Each phase is presented alongside a summary in *Figure 1.1*.

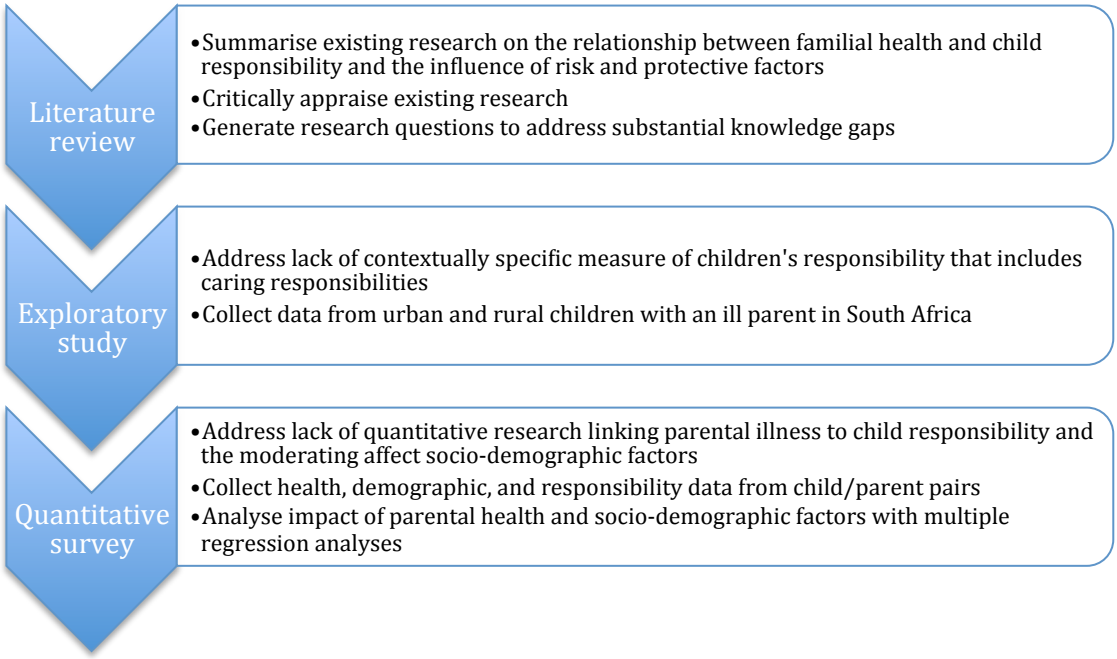


Figure 1.1. **Thesis research phases**

The literature review reports on any literature presenting new and original data from sub-Saharan Africa on the relationship between familial health and children's caring roles or responsibilities. The review summarises existing knowledge on this relationship, including the range and types of children's responsibilities, time burdens, and associated socio-demographic factors. The findings were used to create a hypothesised ecological systems model of the interaction between familial health and child responsibility. The existing literature was critically appraised, highlighting research gaps that were used to create research questions guiding the remaining two phases of the thesis. Literature review search strategy, findings, and research questions are presented in *Chapter 2*.

The second research phase is the exploratory study, which was designed to address the lack of a contextually appropriate measure of children's responsibilities. The exploratory study addressed this gap by generating contextually appropriate items for a tool to be used in quantitative data collection and analysis in

the third research phase. The exploratory study consisted of a semi-structured questionnaire administered to *n* = 349 children between 10 and 18 years in urban and rural settings of the Western Cape province who were living with an ill adult. The resulting items were used in conjunction with the findings of the literature review on the range of children's responsibilities to create a Child Responsibility Measure. The methodology, analysis strategy, and results of this study are discussed in *Chapter 3*, and the Child Responsibility Measure design is described in *Chapter 4*, *Section 4.3*.

The final research phase is the quantitative, cross-sectional survey, which addressed the research gap of a lack of quantitative studies focusing on the relationship between parental illness and child responsibility in sub-Saharan Africa using large and representative samples. This study collected data from *n* = 2,476 child/parent pairs across an urban and rural site in KwaZulu-Natal province with standardised measures of demographics, health, and socioeconomic factors. Child responsibility range and time burden is assessed using the Child Responsibility Measure, which was created using items generated in the literature review and exploratory study. Research ethics, study sites, sampling techniques, questionnaire design, research staff, analysis strategy, and methodological strengths and limitations are presented in *Chapter 4*.

Resulting data were analysed for descriptive statistics and assessed for bivariate associations, both of which are presented in *Chapter 5*. Bivariate associations were used to identify socio-demographic factors that potentially moderate the impact of parental illness on child responsibility. Theoretically and statistically relevant factors were incorporated into multiple regression models to determine

the drivers of child responsibility. The results of multiple regression analyses are presented in *Chapter 6*.

The cumulative findings of all three phases are discussed within the context of existing literature in *Chapter 7*. The studies' strengths and limitations, implications for policy and practice, and directions for future research follow, ending with a thesis conclusion.

The thesis is formatted according to American Psychological Association style, including citations, table formats, quotes, and captions.

Chapter 2: Literature review

The literature review summarises existing research on the relationship between familial illness and child responsibility in sub-Saharan Africa, focusing on the range, nature, and time burden of children's responsibilities, the impact of parental illness, the moderating effect of socio-demographic factors, and the quality of existing research.

Section 1 presents the aims of the literature review. Search and review methods are described in *Section 2*. Results, including a summary of findings and identification of research gaps, are presented in *Section 3*, with research questions derived from the review in *Section 4*. The impact of familial illness and the moderating effect of socio-demographic factors are organised into a conceptual framework in *Section 5*. The review is summarised in *Section 6*.

1 Literature review aims

Existing research on young carers in sub-Saharan Africa is described as 'emerging,' with an 'embryonic awareness of young carers as a distinct social groups within the "vulnerable children" population' (Becker, 2007, p. 42). Given the limited research on this subject, the literature review was guided by four aims:

1) Summarise empirical findings and trends across existing studies with an emphasis on exploring the relationship between familial illness and children's responsibilities, the time burden of these responsibilities, and the effect of socio-demographic factors.
2) Describe and assess the methodological quality of resulting studies and identify gaps in the literature.
3) Produce research questions to guide the remainder of this thesis.
4) Create a hypothesised conceptual framework illustrating the interaction of parental illness, socio-demographic factors, and children's responsibility.

2 Methods

The literature review examined published and unpublished studies presenting new and original data on the relationship between familial illness and children's responsibilities in sub-Saharan Africa. Relevant literature was identified via three strategies: database searches, hand searches of references, and personal contacts with researchers and authors.

The literature review itself is a narrative review, which 'discusses and summarises the literature on a particular topic, without generating any pooled summary figures through meta-analysis,' according to the NHS (http://www.nhs.uk/news/Pages/Newsglossary.aspx). A narrative review format was selected because 'this type of review usually gives a comprehensive overview of a topic, rather than addressing a specific question,' (ibid). It is this last aspect of a narrative review that made it the best fit for the needs of this thesis.

2.1 Criteria for considering records in the review

2.1.1 Types of studies

Empirical qualitative and quantitative studies and literature reviews were eligible for inclusion in this review. Studies needed to present new data or analyses on the relationship between familial illness and child responsibility. A responsibility was defined as any activity performed by a child for the benefit of another person. All or part of the reported data must have been collected in sub-Saharan Africa. Editorials, commentaries, and theoretical and conceptual reports were not included if they did not meet the above criteria.

2.1.2 Types of participants

Studies were included if data had been collected from or about children up to 18 years of age. Some or all of the data must have been collected from participants originating from and recruited in sub-Saharan Africa. In studies presenting data from individuals both within and outside of this demographic, some or all data from eligible participants must have been explicitly stated as coming from a relevant individual.

2.2 Search methods for identification of studies

Studies were included if they described children's responsibilities due to another person's health. This included tabulations, lists, and passing references to responsibilities in descriptions or quotes. Studies on child- and youth-headed households were considered relevant if the article included data on children living with unwell family members.

Eight databases were searched ending September 2012:

- OVID
  - Embase (1980-2012)
  - GeoRef (1980-2012)
  - Global Health (1973-2012)
  - Ovid MEDLINE (1980-2012)
  - PsycINFO (1967-2012)
- Google Scholar (1980-present; limits: Biology, Life Sciences, and Environment Science; Medicine, Pharmacology, and Veterinary Science; Social Science, Arts, and Humanities)
- Grey literature
  - Open Grey (www.opengrey.eu)
  - World Health Organization

Abstracts were screened for conceptual and methodological relevance and full text was retrieved if possible. The search was designed to include all relevant literature published from the beginning of the AIDS epidemic in sub-Saharan Africa

in the 1980s. Additional efforts included cross-referencing of related reviews and studies and personal communication with study authors.

2.2.1 Keyword search terms

The following search terms were used to identify relevant studies, truncated where possible. Terms such as "child work," "child labour," and other similar phrases were considered too sensitive that would have resulted in large numbers of irrelevant studies. Specific country and place names were not included as search terms as they may not be specified in searchable headings and consist of enough variety to exclude potentially relevant studies (e.g., a study identified only as taking place in Cape Town but not specified as South Africa).

Search terms included were:

> ("young care*" OR "child care*" OR "parentification" OR "family care*" OR "home care*" OR "child-headed household*" OR "child headed house-hold*" OR "youth-headed household*" OR "youth headed household*" OR "home-based care*" OR "home based care*" OR "AIDS-affected child*" OR "AIDS affected child" OR "AIDS-affected adolescent*" OR "AIDS affected adolescent" OR "inter-generational contract" OR "inter generational con-tract" OR "generational bargain") AND "Africa"

2.3 Analysis

Record abstracts were examined for relevance according to pre-specified inclusion criteria. Full text of studies potentially meeting eligibility criteria were obtained and examined further.

Each study was analysed for relevant content and quality. Relevant content included the nature of children's responsibilities in terms of type and time burden as they related to familial illness and what factors influenced this interaction. Data were coded and placed in Excel tables for organisation and later synthesis.

Quality was assessed using tools for methodological appraisal including *10 Questions to help you make sense of Qualitative Research* (Critical Appraisal Skills Programme, 2001) and the *Critical Review Form – Quantitative Studies* (Law et al., 1998).

3 Results

3.1 Description of studies

Results of the search including number of records identified, retrieved, and evaluated for eligibility are summarised in the flowchart in *Figure 2.1*. While many records failed to meet multiple aspects eligibility criteria, each has been categorised based on the first identified reason.

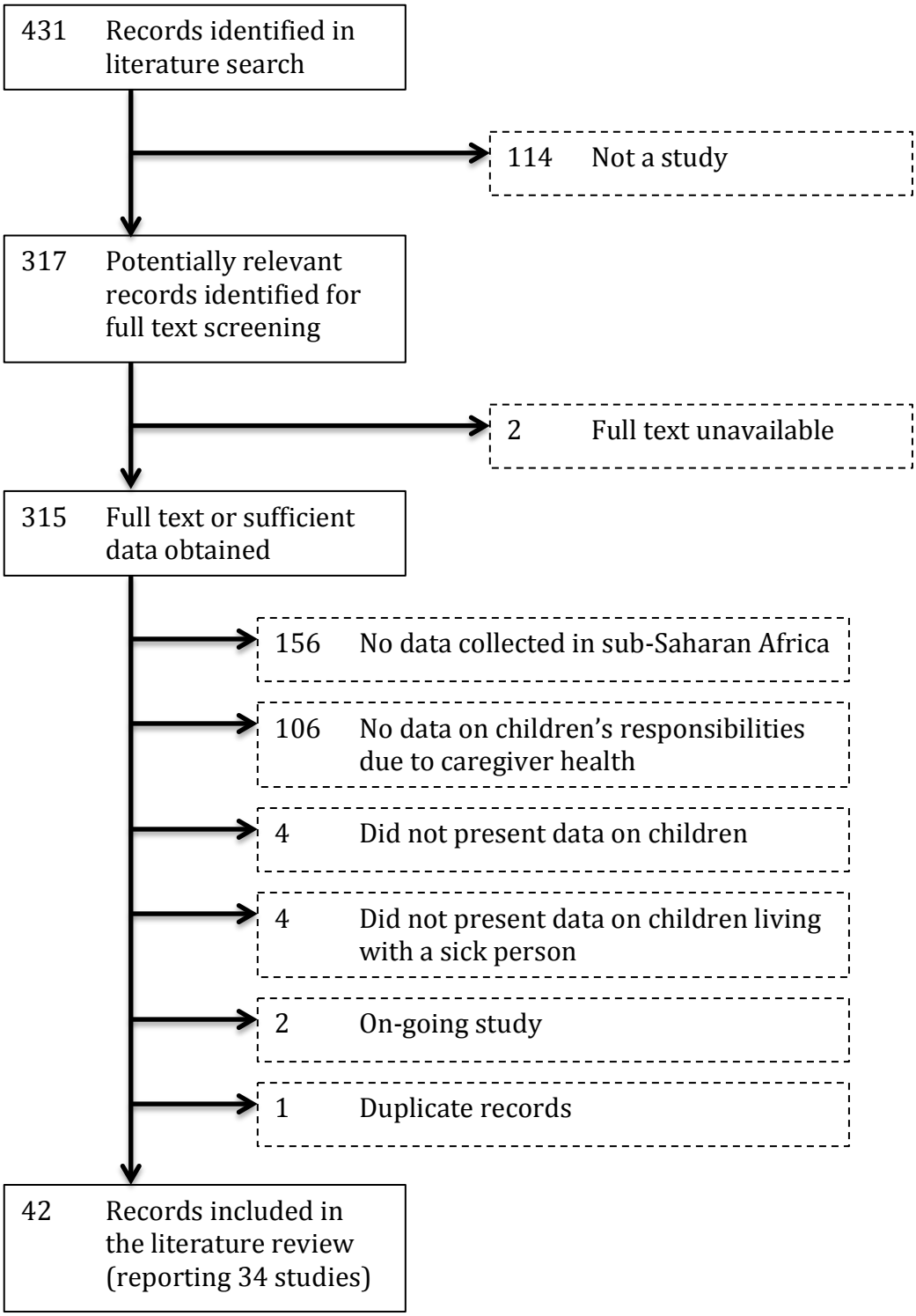


Figure 2.1: **Flow diagram of included and excluded records in the literature search**

In total, 42 articles presented data on the interaction between familial illness and child responsibilities that had been collected in sub-Saharan Africa. Among the articles were a literature review examining the responsibilities of children living with unwell parents in four sub-Saharan African countries: Angola, Nigeria,

Uganda, and Zimbabwe (Bray, 2009) and a meta-synthesis of qualitative studies on young carers (Rose & Cohen, 2010) that included two articles identified in the review (Martin, 2006; Robson, 2004). The former literature review notes there are very few studies on the relationship between parental illness and child responsibility in sub-Saharan Africa, and that most data were extracted from studies on child wellbeing in the context of HIV/AIDS. One unpublished Masters dissertation was identified via this review (Barnard, 2002), which was unable to be located nor the author contacted. The findings of this dissertation were derived from the literature review noted above (Bray, 2009).

All studies were conducted in east or southern Africa. Eleven collected data in South Africa, in which a plurality of the total studies collected data (*Table 2.1*).

Table 2.1
Sub-Saharan African Countries Where Data Were Collected (Alphabetical Order by Country)[1]

Country	Studies per country[2]	Study author(s) and year[3]
Botswana	2	• Lindsey et al. (2003) • Kang'ethe (2010)
Ethiopia	1	• Abebe (2007); Abebe and Skovdal (2010)
Kenya	2	• Skovdal (2009a, 2009b); Skovdal and Ogutu (2009); Skovdal et al. (2009); Abebe and Skovdal (2010); Skovdal and Andreouli (2011) • Skovdal (2010)
Lesotho	2	• Robson et al. (2006) • Van Blerk and Ansell (2007)
Malawi	2	• Chimwaza and Watkins (2004) • Van Blerk and Ansell (2007)
Namibia	2	• Thomas (2006) • Ruiz-Casares (2009)
South Africa	11	• Barnard (2002) • Steinberg et al. (2002) • Bray (2003) • Akintola (2004, 2006) • Harris and Stuart (2006); Harris (2008) • Lamming (2006) • Bray and Brandt (2007) • Moffett (2007) • Korevaar (2009) • Mogotlane, Chauke, Van Rensburg, Human, and Kganakga (2010) • McArdle (2011)
Tanzania	3	• Robson et al. (2006) • Evans and Becker (2007, 2009); • Evans (2010b, 2010c)
Uganda	4	• Akintola (2004) • Withell (2009) • Evans (2010b, 2010c) • Harms et al. (2010)
Zimbabwe	5	• Robson and Ansell (2000) • Robson (2000, 2004); Robson et al. (2006) • Bauman et al. (2006) • Martin (2006) • Wood et al. (2006)

[1] The literature review has been updated since the initial search conducted in 2008; it now includes articles published between the initial search and the final version of this thesis
[2] Studies reported in more than one article are counted as one study
[3] Several studies included data from multiple countries and were thus counted multiple times

3.2 Study methodologies

Four articles present data collected with cross-sectional surveys. No study collected longitudinal data. Steinberg et al. (2002), Bauman et al. (2006), and Mogotlane et al. (2010) collected and analysed original quantitative data; Robson et al. (2006) conducted secondary analysis of survey data from two other studies reported in Gould and Huber (2003) and Van Blerk and Ansell (2002). One qualitative study collected data from a control group for comparison, though the re-

search aim was to explore child-headed households rather than child responsibility due to parental illness (Moffett, 2007). The remaining studies relied on qualitative methods including unstructured or semi-structured interviews (*n* = 26), focus groups (*n* = 10), case studies (*n* = 4), secondary analysis of survey data (*n* = 4), or a combination of methods (*n* = 13).

Table 2.2
Sample Sizes and Recruitment Methods (Chronological Order, Date Published)

Study author(s) and year	Study methods					
	Semi-structured or un-structured interviews	Focus groups	Case studies	Secondary analysis of survey or clinical data	Cross-sectional survey	Longitudinal survey
Robson and Ansell (2000)	X					
Robson (2000, 2004)	X					
Barnard (2002)	*Full text not available, data drawn from Bray (2009)*					
Steinberg et al. (2002)	X				X	
Bray (2003)	X			X		
Lindsey et al. (2003)	X					
Akintola (2004, 2006)	X					
Chimwaza and Watkins (2004)	X					
Bauman et al. (2006)					X	
Harris and Stuart (2006); Harris (2008)	X					
Lamming (2006)			X			
Martin (2006)	X	X		X		
Robson et al. (2006)	X	X		X	X	
Thomas (2006)	X					
Wood et al. (2006)	X		X			
Abebe (2007); Abebe and Skovdal (2010)	X	X				
Bray and Brandt (2007)	X	X		X		
Evans and Becker (2007, 2009)	X					
Moffett (2007)	X					
Van Blerk and Ansell (2007)	X	X				
Korevaar (2009)	X					
Ruiz-Casares (2009)	X					
Skovdal (2009a, 2009b); Skovdal and Ogutu (2009); Skovdal et al. (2009); Abebe and Skovdal (2010); Skovdal and Andreouli (2011)	X	X	X			
Withell (2009)	X					
Evans (2010b, 2010c)	X	X				
Harms et al. (2010)	X					
Kang'ethe (2010)	X	X				
Mogotlane et al. (2010)		X			X	
Skovdal (2010)	X	X	X			
McArdle (2011)	X					

Note: **Articles reporting from the same study are grouped together.**

Every study in the literature review excluding Korevaar (2009) and Kang'ethe (2010) included child respondents between 0 and 17 years of age. Korevaar (2009) instead collected data regarding children from NGO workers who worked with them rather than the children themselves, arguing that the nature of the research was too sensitive for children. Kang'ethe (2010) collected data from adult

home community-based carers who provided information about child carers. Several studies collected data from adults, including adults (18+) providing care (*n* = 16), parents (*n* = 11), and key informants such as NGO workers and government officials (*n* = 10). Respondent types are summarised in *Table 2.3*.

Table 2.3
Number and Type of Study Participants (Chronological Order, Date Published)

Study author(s) and year	Respondent type by number			
	Children (0-17)	**Adults providing care (18+)**	**Parents or care recipient (18+)**	**Key informants (NGO workers, government officials, etc.)**
Robson and Ansell (2000)	9			
Robson (2000, 2004)	9			9
Barnard (2002)	25			
Steinberg et al. (2002)	*Household survey* (*n* = 771)			
Bray (2003)	~5,000		16	
Lindsey et al. (2003)	2	33	*Not stated*	
Akintola (2004, 2006)	1	40		10
Chimwaza and Watkins (2004)	1	14		
Bauman et al. (2006)	50		50	
Harris and Stuart (2006); Harris (2008)	4 (up to age 19)			
Lamming (2006)	1			
Martin (2006)	13, plus 6 focus groups of ~14 children each			
Robson et al. (2006)	~100 (Lesotho) 270 (Tanzania)			
Thomas (2006)		7	7	
Wood et al. (2006)	56 (up to age 22)		41	
Abebe (2007); Abebe and Skovdal (2010)	53			
Bray and Brandt (2007)	*Not stated* (up to age 23)			*Not stated*
Evans and Becker (2007, 2009)	15	7	21	13
Moffett (2007)	22 (up to age 19)			
Van Blerk and Ansell (2007)	~200	*Not stated*	*Not stated*	
Korevaar (2009)				4
Ruiz-Casares (2009)	33 (up to age 21)			
Skovdal (2009a, 2009b); Skovdal and Ogutu (2009); Skovdal et al. (2009); Abebe and Skovdal (2010); Skovdal and Andreouli (2011)	48			41
Withell (2009)	10			
Evans (2010b, 2010c)	62 (up to age 23)			59
Harms et al. (2010)	13			
Kang'ethe (2010)		82		5
Mogotlane et al. (2010)	*Child-headed household survey* (n = 1,528)			*Not stated*
Skovdal (2010)	69		36	
McArdle (2011)	4 households			*Not stated*

Note: **Articles reporting from the same study are grouped together.**
***Several studies recruited from sites outside sub-Saharan Africa; the numbers indicated here refer only to relevant participants.**

3.3 Study contents

Study data were organised into three content areas: types of responsibility, time devoted to responsibilities, and factors influencing child's amount of responsibility (*Table 2.4*). Though the contents may not have been the focus of the article, any part presenting data relevant to one of the three areas was classified as containing content on the subject.

Table 2.4
Study Contents (Chronological Order, Date Published)

Study author(s) and year	Study Contents		
	Types of responsibility	Responsibility time burden	Factors influencing amount of responsibility
Robson and Ansell (2000)	X		X
Robson (2000, 2004)	X		X
Barnard (2002)			X
Steinberg et al. (2002)	X		X
Bray (2003)	X	X	X
Lindsey et al. (2003)	X		
Akintola (2004, 2006)	X		X
Chimwaza and Watkins (2004)	X		
Bauman et al. (2006)	X	X	X
Harris and Stuart (2006); Harris (2008)	X		
Lamming (2006)			
Martin (2006)	X		X
Robson et al. (2006)	X		X
Thomas (2006)			X
Wood et al. (2006)	X		X
Abebe (2007); Abebe and Skovdal (2010)	X		X
Bray and Brandt (2007)			X
Evans and Becker (2007, 2009)	X		X
Moffett (2007)	X		X
Van Blerk and Ansell (2007)	X		X
Korevaar (2009)	X		X
Ruiz-Casares (2009)	X		X
Skovdal (2009a, 2009b); Skovdal and Ogutu (2009); Skovdal et al. (2009); Abebe and Skovdal (2010); Skovdal and Andreouli (2011)	X	X	X
Withell (2009)	X		X
Evans (2010b, 2010c)	X		X
Harms et al. (2010)	X		X
Kang'ethe (2010)	X		
Mogotlane et al. (2010)	X		X
Skovdal (2010)	X		X
McArdle (2011)	X		X

Note: **Only contents relevant to this thesis are included. Articles reporting the same study are grouped together.**

3.3.1 Children's responsibilities

Type of responsibilities

For the purposes of the literature review, an activity is only classified as a 'responsibility' if it was:

1) Specified either by the author or participant in a quote.
2) Involved physical engagement.
3) Performed for the benefit of a person other than or in addition to the child him or herself.

The reason for the distinction was a tendency noted in Bray (2003) for children to consider activities that benefited only themselves as 'responsibilities' (e.g., washing one's own clothes compared to washing clothes for the family).

Wordings used to describe responsibilities inferred subtle variations on their nature; conceptually similar items such as 'cleaning in the home' and 'sweeping' were combined into one item. In this case the two tasks were combined into one responsibility labelled 'clean home.' Data were only included if they were derived from the response of a child who was living with or providing assistance to an unwell person, or another individual describing first-hand accounts of child responsibility relating to parental illness. Responsibilities of other children, such as those in child- or youth-headed households where there were no adults (as opposed to having a co-resident adult too unwell to be considered head of household) were not added to this compilation.

Responsibility categories were created by grouping thematically similar tasks; labels were derived from Robson (2000), Robson et al. (2006), and Evans and Becker (2007, 2009). A summary of responsibilities is presented in *Table 2.5*, including sources in subscript.

Table 2.5
Children's Responsibilities by Category, Subcategory, and Type

Category	Subcategory	Activity
Personal care [3, 6, 7, 12, 23, 24, 25]	Medical care	-Accompany or take to hospital, clinic, or healer [1, 2, 11, 15, 20] -Buy or collect medications [2, 10, 11, 13, 20, 22] -Give medications [1, 2, 8, 11, 13, 15, 20, 21, 27] -Liaise between unwell person and healthcare workers [10, 13] -Prepare special foods [1, 2, 8, 13, 15] -Remind of appointments [15] -Remind to take medications [2, 14, 15, 21, 22]
	Intimate care	-Bathe unwell person [1, 2, 11, 13, 15, 16, 18, 20, 21, 26] -Brush unwell person's teeth [8] -Clean bodily fluids [1, 2, 15, 20] -Dress or change clothes [2, 8, 11, 13, 15, 27] -Emotional support [1, 5, 13, 20] -Feed/help to eat [1, 2, 8, 11, 13, 15, 16, 17, 18, 20, 26, 27] -Keep company [1, 8, 18,] -Lift unwell person or help to walk [1, 2, 8, 10, 11, 13, 15, 16, 27] -Massage unwell person [11, 20] -Shave unwell person [8] -Toilet unwell person [1, 2, 8, 10, 13, 15, 16, 18, 20]
Domestic responsibilities	Housework	-Clean home [1, 2, 8, 9, 10, 11, 13, 14, 15, 16, 17, 19, 20, 22, 25, 26] -Cook [1, 2, 9, 10, 11, 13, 14, 15, 16, 17, 18, 19, 20, 22, 25, 26, 27] -Cut or collect firewood [11, 13, 17, 19, 20, 22, 26] -Fetch water [1, 2, 11, 13, 15, 17, 19, 20, 22] -Forage [19, 20] -Grocery shopping [1, 2, 8, 9, 10, 15, 16, 20, 22] -Heat water/make tea or coffee [1, 2, 8, 13, 14, 15, 22] -Laundry [1, 2, 11, 13, 14, 15, 16, 17, 19, 20, 21, 22, 25, 27] -Make fire or light stove [2] -Manage finances [10, 16] -Tend crops, garden, or livestock [1, 2, 8, 13, 15, 17, 19, 20, 22, 26] -Wash dishes [8, 11, 15, 16, 20, 22]
	Childcare [2, 6, 8, 13, 14, 23, 24]	-Bathe children [15, 16, 20, 22] -Dress children [22] -Get children ready for school [22, 27] -Help with schoolwork [8, 22, 25] -Prepare children for school [15] -Supervise children [11, 15, 16, 22, 27] -Take children to school [11, 15]
	Income-generating activities [2, 10]	-Beg [15, 22] -Burn charcoal [20] -Casual farm work [3, 13, 15, 17, 19, 20, 22, 26] -Construction work [22] -Domestic work [13, 15, 19, 20, 22] -Errands for neighbours [13, 19, 22] -Factory work [13, 22] -Hairstyling [14] -Sell goods or work in shop [13, 15, 16, 17, 20, 22] -Sewing [20] -Transactional sex [5, 22]

Key: 1) Robson and Ansell (2000); 2) Robson (2000, 2004); 3) Steinberg et al. (2002); 4) Bray (2003); 5) Lindsey et al. (2003); 6) Akintola (2004); 7) Chimwaza and Watkins (2004); 8) Harris and Stuart (2006), Harris (2008); 9) Lamming (2006); 10) Martin (2006); 11) Robson et al. (2006); 12) Wood et al. (2006); 13) Abebe (2007); 14) Bray and Brandt (2007); 15) Evans and Becker (2007, 2009); 16) Moffett (2007); 17) Van Blerk and Ansell (2007); 18) Korevaar (2009); 19) Ruiz-Casares (2009); 20) Skovdal (2009a, 2009b), Skovdal and Ogutu (2009), Skovdal et al. (2009), Skovdal and Andreouli (2011); 21) Withell (2009); 22) Evans (2010a, 2010b); 23) Harms et al. (2010); 24) Kang'ethe (2010); 25) Mogotlane et al. (2010); 26) Skovdal (2010); 27) McArdle (2011)

Children's income-generating activities appeared to be within both formal and informal economies based on distinctions presented in Fields (2007) and

Hermann and Khan (2008) (cited in Basten, Loichinger, & Lutz, 2011). Formal sector employment tends to be capital intensive, technology-based, export driven, with modern services provided within formal industrial enterprises. Informal sector employment is often traditional, and if agricultural, subsistence; services are provided on an *ad hoc* basis, and are labour-intensive. Additionally, informal sector jobs provide poor job security, as they are non-contractual.

Responsibilities' prevalence

There is limited evidence on responsibility prevalence. Bray (2003) provides secondary analysis of Statistics South Africa's Time Use Survey (Budlender et al., 2001), which explores the prevalence of responsibilities undertaken by children in South Africa (n = ~5,000). Between 5-6% of boys and 10-22% of girls aged 10-17 engaged in 'general' caring. Domestic responsibilities including cooking and cleaning the home were much more common than caring (33-41% and 32-44% of boys, 65-80% and 55-65% of girls). The author notes that because such small numbers of the sample were engaging in specific care tasks that it was impractical to analyse each by type.

Time burden

Three studies quantified the time burden of children's responsibilities. In Bauman et al. (2006), time burden was assessed using mother's reports of their children's engagement in personal care items on the Parentification Scale (Mika et al., 1987). Personal care time burden fluctuated between their HIV/AIDS-ill mother's periods of relative of health (11.4 hours per week) and illness (14.4 hours per week). More than four-fifths of children (82%; n = 41) described themselves as having 'too much' responsibility (p. 63-64), as did nearly three-

quarters (72%; *n* = 36) of their mothers. However, there were several problems with the survey. First, only four items on the scale were used to assess children's time burden, all of which were intimate care responsibilities (feeding, mobility, bathing, dressing) and only three household responsibility items (making dinner for the family, cleaning up for family, and washing dishes for family). There were no responsibilities relating to the child's provision of medical care. While caring responsibilities were quantified in terms of hours per week, household chores were quantified on a three-point scale (never, rarely/sometimes, and often/sometimes). Second, the results were derived from mother's responses rather than the children's, likely distorting the true nature of children's responsibilities and their time commitment. Third, items in the Parentification Scale have not been adapted for sub-Saharan Africa (Moffett, 2007).

In secondary analysis of data from the Time Use Survey (Budlender et al., 2001), Bray (2003) found that among girls aged 15-17 years, responsibilities accounting for greatest time burdens included cooking/food preparation (100 minutes per day) and caring for children (96 minutes/day). Non-specified 'general caring' accounted for 96 minutes. Younger girls and boys spent less time engaged in each type of responsibility. Boys aged 15-17 spent more time farming (98 minutes) and tending animals (81 minutes) than girls (45 minutes farming and 15 minutes tending animals). These findings were similar to those reported in Evans (2010b). After analysing Time Use Survey data, Bray (2003) writes that,

> In summary, the available quantitative data suggest that much of the 'child labour' story in South Africa is about housework. What does not emerge from analyses of these data sets is who does what kind of domestic tasks, which groups of children spend significant time on these tasks, and what effects they have on children's lives in the short and long term. (p. 104)

Skovdal (2009b) found young carers spent around one-fifth of a normal 24-hour day providing care or attending to other responsibilities, though this varied substantially between weekdays (11%) and weekends (40%). The difference was attributed to schooling and studies, which put competing demands on children's time during the week. However, the results must be interpreted with caution as they were derived from a convenience rather than representative sample.

Other studies provide information regarding children's school attendance and performance, which for reasons discussed above was considered a useful proxy of time burden. In secondary analysis of data on reasons for poor school attendance from 270 Tanzanian children, Robson et al. (2006) found the most frequently cited reason for missing school was being needed at home to attend to domestic responsibilities, take care of farm animals, or work in the family shop, followed by caring for an unwell relative. One longitudinal survey in Tanzania that was not included in this review reported school attendance dropped 12-14 hours per week in the three to six months prior to parent's AIDS-related death, recovering in the following six months (Ainsworth, Beegle, & Koda, 2005). Unfortunately, this study did not investigate the relationship between parental illness and child responsibility, making the association tenuous. A few other studies presented qualitative evidence that children spend significant amounts of time on responsibilities due to parental illness. For instance, one 15-year-old girl from Kenya described her care burden by saying, 'You work throughout the day, no time for resting,' (Skovdal & Ogutu, 2009, p. 6), while in Lamming (2006), a girl who cared for her older, AIDS-ill brother reported being housebound due to her responsibilities.

Children reported they were unable to go to school or complete their homework, and were unable to socialise with friends due to their commitment to responsibilities (Barnard, 2002; Bauman et al., 2006; Evans, 2010b, 2010c; Evans & Becker, 2009; Harms et al., 2010; Lindsey et al., 2003; Martin, 2006; Robson, 2000; Ruiz-Casares, 2009; Skovdal, 2009a, 2009b, 2010; Skovdal et al., 2009; Thomas, 2006; Wood et al., 2006). In a few studies, children were reported to drop out of school to provide care and attend to responsibilities (Kang'ethe, 2010; Mogotlane et al., 2010), while others suggest children are less likely to attend school consistently and more likely to miss homework rather than drop out entirely (Bray, 2009; Robson et al., 2006). Orphaned children in Moffett (2007) said during their parents' illnesses they often had to miss school to provide care and attend to their requests, but following their parents' deaths they were able to attend school more regularly. In addition to Robson et al. (2006), a number of studies report that children miss school to attend to responsibilities other than caring, including childcare and domestic responsibilities (Evans, 2010c; Moffett, 2007; Ruiz-Casares, 2009; Skovdal, 2009a), highlighting a limitation in Bauman et al. (2006) which evaluated responsibility time burden using a limited set of caring responsibilities.

3.3.2 Parental illness and child responsibility

The onset of parental illness was cited as the beginning of children's involvement in nursing/personal care and increases in childcare responsibilities (Abebe & Skovdal, 2010; Evans, 2010c; Evans & Becker, 2009; Thomas, 2006). Skovdal (2009b) identifies four types of people children care for: ailing parents, ageing relatives, younger siblings, and abandoned community members. In Mogotlane

et al. (2010), NGO managers reported that children took over head-of-household duties mainly as a result of HIV/AIDS-illness and death, though other common causes included grandparents' aging and senility, and alcohol and drug abuse.

Evans and Becker (2007, 2009) suggest that children's responsibility time burden and intensity fluctuates with the swings in AIDS-ill parent's health, a notion supported by findings in Bauman et al. (2006), which found that children spent significantly more time providing care during their mother's periods of poorer health. However, no data were provided on time commitments for non-caring responsibilities. Without this information it is impossible to tell if the increased time burden of caring responsibilities is the addition of caring responsibilities to a child's total, or a general shift towards caring at the expense of domestic and other responsibilities.

Higher community HIV/AIDS-prevalence was associated with children's engagement in caring responsibilities (Bray, 2009). Abebe (2007) and Evans (2010c) both suggest an interruption in normal household dynamics as a result of higher prevalence and associated morbidity and mortality, resulting in many children living with and relying upon grandparents for care. This may lead to an interruption of the 'generational bargain' in which adults care for their children in addition to their parents (discussed in greater detail in the next section).

HIV/AIDS disclosure drew community support, but also stigma (Steinberg et al., 2002). Participants in Evans and Becker (2009) and Skovdal (2009b) describe extended family and community members refusing to help because of HIV/AIDS within the household; children reported being bullied and taunted during public, non-caring responsibilities like fetching water. Stigma was noted to result not

only from illness disclosure but also frequently from speculation, such as that following a hospital visit or a noticeable physical deterioration.

Children involved in medicine or treatment administration may find themselves with a complex and difficult task. Noted in the introduction, ART, which is essential to maintaining good health in HIV/AIDS-ill people, requires strict adherence (≥ 95%) to remain effective. Children were also noted to help their parents remember to take their ART at the appropriate time. In Evans and Becker (2009), children described having to provide a meal every three hours to help with their mothers' ART.

In Western contexts, research has found parental mental health disorders can result in children taking on responsibilities (Dearden & Becker, 2004; Schleicher, 2011). The numerous reports of children providing emotional care in the literature review (Abebe, 2007; Evans & Becker, 2007, 2009; Robson, 2000, 2004; Robson & Ansell, 2000) indicate a need based in parental mental health disorders. In a study of the impact of parental alcoholism on children in South Africa, Stevens (2010) notes the potential for role-reversal, or parentification, due to resulting incapacity. Unfortunately, this study did not present any data linking parental alcoholism and children's responsibilities aside from an anecdotal case from the author's experience as a counsellor.

3.3.3 Socio-demographic moderators

A number of articles argue that children are active social actors when taking on responsibility as they are responding to the need created by parental illness (Skovdal, 2009b; Skovdal & Ogutu, 2009; Skovdal et al., 2009). Qualitative evidence, on the other hand, suggests the decision to take on a larger share of re-

sponsibility, particularly the care of an unwell adult, is made collectively by adults members of the family or unilaterally by the head of household rather than the child him or herself, or that no other options exist and children's caring is dictated by necessity rather than preference (Martin, 2006; Robson, 2000, 2004; Robson et al., 2006; Van Blerk & Ansell, 2007). This section explores ten socio-demographic factors that existing research suggests moderates the relationship between parental illness and child responsibility.

Child gender

There was a general consensus between researchers that girls have greater responsibility workloads than boys, both in terms of time burden and the range of responsibilities. A UNICEF Project Officer in Robson (2000) described adult expectations of boys: 'people say, "at least you've got a girl," but don't expect anything from boys…expect them to be out the door,' (p. 66). Akintola (2006) and Robson (2004) provide examples of girls who provided care while male siblings played or attended school.

Bray (2003) challenges the assumption that boys do no work, noting that while they may not contribute to the same degree as girls, Time Use Survey data show boys still engage in personal care and domestic responsibilities. Skovdal (2009b) found little difference between boy and girl young carers in terms of time devoted to caring and responsibilities (20% versus 19% of the day), though the data were derived from a convenience rather than representative sample. Both articles acknowledge qualitative differences in the nature of boys' and girls' responsibilities. Bray (2003) points out that boys often engaged in tasks benefitting only themselves, like washing their own shirt, while girls washed clothes for the

entire family. Skovdal (2009a, 2009b) writes that while the strains of large-scale epidemic and poverty have created more fluidity with gender roles, and boys and girls are increasingly taking on opposite gender-specific responsibilities in times of need, specific tasks were still more common in one gender.

In cases where more help was required at home, families reported being more inclined to remove a girl from school than a boy, regardless of age (Abebe, 2007; Robson, 2000, 2004). Steinberg et al. (2002) found 10% of girls surveyed were out of school compared to 5% of boys. Interestingly, persons surveyed almost always knew the educational status of boys in the home, but one-quarter did not know the same about girls.

One consistent theme in the existing literature was a division of labour based on stereotypical gender roles. Typically, girls were responsible for personal care and domestic work, which they were taught from the age six or seven, while boys were responsible for earning money (Abebe, 2007; Abebe & Skovdal, 2010; Evans, 2010c; Evans & Becker, 2009; Kang'ethe, 2010; Ruiz-Casares, 2009). Even within agricultural tasks, girls attend to household gardens for sustenance, while boys care for livestock and work on farms with cash crops (Abebe, 2007; Robson & Ansell, 2000). A longitudinal survey of recently orphaned children in Tanzania found a relationship between household land plot size and children's school absence. While the effect was found among both boys and girls, boys' school attendance was most affected, which suggests girls may take on a greater share of subsistence agriculture and boys generally contribute in times of need (Ainsworth et al., 2005). Oftentimes, boys either left or were sent to find work outside the home (Abebe, 2007; Abebe & Skovdal, 2010; Evans & Becker, 2009;

Robson, 2000), which may explain why most of the studies focusing exclusively on young carers or children with ill parents often had more girl than boy participants. Nevertheless, girls reported earning money as well. Bray (2003) notes one of the ironies of African economies is that tasks such as domestic work, a stereotypically female activity, often offer greater and more consistent income opportunities outside the home compared to men's jobs like seasonal agricultural work. Additionally, there were reports of girls engaging in transactional sex, which their families apparently ignored due to their need of income (Evans, 2010c; Lindsey et al., 2003). Among South African children aged 15 to 17 years, Cluver, Orkin, Boyes, Gardner, and Meinck (2011) found 7.0% of girls and 3.9% of boys had engaged in transactional sex. Children's odds of engaging in transactional sex increased by five times with being AIDS-orphaned (OR 5.21; 95% CI: 1.50-18.11), by three times by having an AIDS-ill parent (OR 3.06; 95% CI: 1.34-7.00), and four times if both AIDS-orphaned and having an AIDS-ill parent (OR 4.30; 95% CI: 1.67-11.06).

Several articles identify a preference for gender-matching between child and adult care recipient. Where the child and care recipient were not gender-matched, the child would do most of the non-caring work and another gender-matched child or neighbour would provide intimate care (Evans & Becker, 2007, 2009; Robson, 2000; Robson & Ansell, 2000; Withell, 2009). Evans and Becker (2009) describe a boy who was subjected to ridicule for providing his mother with intimate care, suggesting social stigma for violating prescribed gender roles. Steinberg et al. (2002) found 72% of households to be female-headed, and 20% to be headed by women over 60, which may make girls much more likely to pro-

vide intimate care if a preference for gender-matching exists and/or remains in given communities. Still, the preference for gender-matching was subject to the availability of potential care providers, which several authors suggest is becoming increasingly limited as a result of increased burden and fewer available adults to provide care (Evans & Becker, 2007, 2009; Martin, 2006; Robson, 2000, 2004). Similarly, Skovdal (2009a, 2009b) notes that gender roles in rural Kenya have become more fluid as a result of the strains of disease and poverty. One adult participant noted how current demands and resource constraints challenge Luo community traditions, comparing a collectivist past to a more individualistic present.

Bauman et al. (2006) was the only study to evaluate the relationship between child gender and responsibility quantitatively, finding no link between the two. However, there were several problems with responsibility measurement, mentioned earlier and briefly described here. First, the results were derived from items on the Parentification Scale, which had not been adapted for sub-Saharan Africa. Second, only a small subset of the items was administered to participants in this study, and the rationale for item selection was not provided. Third and acknowledged by the authors, quantitative analysis was vulnerable to a Type II Error due to the relatively small sample size (n = 50).

Child age

Older children were identified as having greater amounts of responsibility. Robson (2000) posits that children between 15-17 years are likely to take on the most responsibility based on their inability to earn money in the formal sector, lower earning potential in the informal sector, and greater likelihood of having

completed compulsory education. Further, older children were viewed as having greater physical, emotional, and mental capacity (Skovdal, 2009b). Other articles place an emphasis on birth order, where the oldest child is viewed as the most capable and emotionally ready for greater responsibility (Evans & Becker, 2009). As such, the first-born takes on head-of-household responsibility in times of need, and if/when he or she leaves the next oldest becomes *de facto* head and responsible for childcare (Evans, 2010b, 2010c; Skovdal et al., 2009). Moffett (2007) and Ruiz-Casares (2009) report that in addition to taking on a larger share of household responsibilities in times of need, eldest children also allocated responsibilities among younger children in accordance with their ability. In AIDS-affected households, which were speculated to have greater caring and domestic needs, age was listed as an important factor in determining which child took on greater responsibility (Abebe & Skovdal, 2010). As noted in the above section on gender, Skovdal (2009a, 2009b) describes a cultural shift from gender specification of responsibilities towards competency based on age. 'If one is blessed with 4 [*sic*] children and the first three are boys and the last born is a girl and the parent is ill, it will be the boys that cook and not the younger girl,' (Skovdal, 2009b, p. 124).

Regardless, caring responsibilities were found to start relatively early. Evans and Becker (2009) report that children began caring for AIDS-ill parents at around 11-12, while Skovdal and Ogutu (2009) present the case of a boy in Kenya who began spoon feeding and washing his AIDS-ill father at age six. In Skovdal (2010), a female caregiver is quoted on the potential of a ten-year-old: 'That is pretty much a grown up. At that age she can do anything…wash dishes…fetch water, cook, mop the house and plaster it using cow dung. That's a woman,' (p.

98). Similar anecdotes appear in Robson (2000) and Bray (2009). Skovdal (2009b) writes of a general consensus among parents in a Kenyan sample that children below the age of five are not expected to contribute to the household. Upon reaching age five, they are socialised to become responsible adults.

Bauman et al. (2006) found no quantitative link between child age and amount of responsibility. However, there were limitations with this study discussed in the above section on child gender.

Parent type

Similar to the 'generational bargain,' a number of studies present evidence of reciprocal expectations of care between children and parents (Bray, 2009; Bray & Brandt, 2007; Evans & Becker, 2007, 2009; Skovdal, 2009b; Thomas, 2006). In Harris (2008), a boy was asked whether it was difficult to care for his father with a traumatic brain injury, to which he responded, 'No it wasn't that much difficult because I was taking him as my father. I wanted to do things for him as he did things for me.' There was also evidence that the disruption of the generational bargain due to the deaths of biological parents was common. Many children described having reciprocal care relationships with their elderly and frail grandparents (Abebe, 2007; Ruiz-Casares, 2009; Skovdal, 2009b; Skovdal & Ogutu, 2009). Bray (2009) identifies having elderly grandparents as a characteristic of children who provide care.

Martin (2006) suggests that in spite of reciprocity there is a clear divide between children and their parents; even when necessary, changes in the roles such as when a child has to care for his parent or earn money, cause major familial disruptions and stress between family members. In several Ugandan communities,

children caring for their parents were seen as violating cultural norms (Withell, 2009). Indeed, children's care roles may be a more uncommon feature of the 'generational bargain' when compared to other activities such as providing for material needs. For instance, Kenyan parents reported that while they expected their children to provide care and take over household responsibilities in times of need, they did not think that it was appropriate (Skovdal, 2009b). Programme staff in a South African NGO reported that when visited by a home community-based carer, children were sent away while elderly and adult household members were trained to care for the ill, even though 'It is the children who actually care for the sick when volunteers leave despite the fact they do not have any training,' (Akintola, 2004, p. 28).

Bray (2009) identifies child mobility as a predictor of greater responsibility. Evidence from other literature suggests possible explanations for this. First, children are occasionally sent to relatives' homes to provide care or help out in times of need, typically in the direction of rural and poor to urban and better off households (Robson, 2004; Robson & Ansell, 2000; Robson et al., 2006; Skovdal, 2009b; Van Blerk & Ansell, 2007). However, whereas exchange of non-orphaned children between related households appears to have been common in the past, due to constraints from high HIV/AIDS-prevalence this has given way to 'crisis fostering' of bereaved children (Oleke, Blystad, & Rekdal, 2005, p. 2635). Abebe and Skovdal (2010) report that foster parents sometimes view children as a source of labour in exchange for room and board and at the expense of education, which Van Blerk and Ansell (2007) describe as a 'cashing in' of the generational bargain (p. 874). Van Blerk and Ansell (2007) even suggest that the re-

source strain caused by introducing orphans into a household can require an immediate return on investment in the form of child labour for the household and its members to survive. Recent research indicates that foster carers in sub-Saharan Africa are generally more vulnerable than biological parents, being on average older, having poorer education, and caring for greater numbers of children with a higher dependency ratio (i.e., lower numbers of adults per children) (DeSilva et al., 2008; Monasch & Boerma, 2004). Taking in orphaned children presents challenges to household functioning as well; foster parents report the orphaned children they care for require more help for psychological and behavioural problems (K. Govender, Penning, George, & Quinlan, 2012). Foster parents of orphaned children exhibit poorer physical and mental health outcomes (K. Govender et al., 2012; Kuo & Operario, 2011; Kuo, Operario, & Cluver, 2012; Kuo, Reddy, Operario, Cluver, & Stein, 2013), lower levels of social support (Kuo, Fitzgerald, Operario, & Casale, 2012), and poorer economic outcomes (G. George, Govender, Bachoo, Penning, & Quinlan, 2013), which may be the result of their additional care burdens.

Some children reported a reluctance to live with foster parents out of fear of exploitation, or otherwise felt exploited for their labours in adopted homes (Abebe & Skovdal, 2010; Evans, 2010c; Harms et al., 2010; Korevaar, 2009; Moffett, 2007; Ruiz-Casares, 2009). Foster parents in Skovdal (2009b) report relying on adopted children in times of need to help feed their biological children. However, contrary to these reports, a longitudinal study in Parikh et al. (2007) found no difference in labour between cohabiting orphaned and non-orphaned children.

Children's educational attainment

With the 'generational bargain' it is implied that in return for care while young and dependent, children will care for their parents when they become old (Collard, 2001). Accordingly, it is suggested that children's education is seen as investment for both child and parent. A child in Van Blerk and Ansell (2007) was explicit about this, saying 'My step-father said I had to go to the field instead of to school but he was hurting himself by not allowing me to go to school as school was my future,' (p. 877).

As such, parents are generally reluctant to remove children from school to attend to household needs unless absolutely necessary (Steinberg et al., 2002). Qualitative evidence in Robson (2000, 2004) indicates that if children are to be taken from school in response to a household need, it is preferred that the child has reached some educational milestone such as the completion of primary education. Evans and Becker (2009) cite the overlap of operation hours in income-generating activities and schooling as another reason why children who are not in school are more likely to engage in responsibilities. However, much of the literature suggests that it is rarely a decision between children's educational attainment and contribution to the household; oftentimes children's school attendance and performance suffers, though they are rarely withdrawn from school to contribute to the household (Barnard, 2002; Bauman et al., 2006; Bray, 2009; Evans, 2010a; Evans & Becker, 2009; Skovdal et al., 2009; Thomas, 2006). In a secondary analysis of primary school attendance data from Tanzania (n = 270) Robson et al. (2006) found a small number of boys had left school to help at home or care for a ill person, though no girls had dropped out. Much more preva-

lent, particularly amongst girls, was poorer school attendance. On the other hand, a large proportion of girls (nearly one-quarter of those in single-parent households) had never attended school; the implication here is that girls who had never attended school had no educational opportunities to be sacrificed, and could take on large amounts of responsibility with little to no impact on future household wellbeing.

Adult presence

Several articles posit that children take on caring responsibilities because of a lack of alternatives, usually meaning no other adults are willing or able to provide care (Bray, 2003; Robson, 2000; Robson & Ansell, 2000; Skovdal, 2009a, 2009b; Wood et al., 2006). Bray (2009) identifies being from a single-parent household as a characteristic of children who provide care.

One of the reasons for the reluctance is that intimate contact between children and adults, particularly parents, relatives, or other guardians, is often considered highly inappropriate. Several caring children described being subject to taunts in their communities. One 17-year-old girl in Martin (2006) illustrated the conflict between her mother's need for care, lack of support, and her community's disapproval, saying, 'Some of my neighbours said I was not supposed to bathe my mother. But none of my mother's relatives came to help me and I didn't know what to do,' (p. 118).

As noted in the introduction, population data indicate that far fewer South African households are based around the nuclear family (56%) in comparison to the United Kingdom (86%) (Ziehl, 2005). Often, single household units include multiple generations plus the extended family (aunts, uncles, and cousins). Many

times these cousins are orphaned, particularly as a result of HIV/AIDS. In households with a dearth of adults, older children would have responsibility for their siblings or other co-resident children (Evans & Becker, 2009; Moffett, 2007; Steinberg et al., 2002). Children living with an adult reported fewer domestic responsibilities, particularly when there was a female adult between 18-25 (Bray, 2003).

Urban/rural location

Existing research suggests children in rural areas are likely to have more responsibility for a number of reasons. For one, homes in rural South Africa are often more difficult to clean, have no piped water or electricity, and are more reliant on subsistence agriculture than urban homes (Bray, 2003). In addition to rural location, children of rural origin were also reported to engage in more responsibilities, as they would be sent to an urban relative's home to help when someone was ill (Robson, 2004; Robson et al., 2006; Van Blerk & Ansell, 2007); high mobility was identified as a characteristic of children with greater responsibility (Bray, 2009).

In contrast, Evans and Becker (2009) suggest that compared to rural households, which often consist of the extended family, urban households tend toward a nuclear family makeup. The nuclear family unit reduces a household's connections the extended family, thereby limiting access to external sources of support. Accordingly, in times of need such as those resulting from illness, urban nuclear households must rely more on internal resources including the labour of children.

Poverty

For impoverished households, healthcare and transport are often unaffordable, causing household members to avoid treatment until they are severely ill (Evans & Becker, 2009; Harms et al., 2010). Qualitative evidence suggests that transport and treatment costs in sub-Saharan Africa are major obstacles to ART adherence, which is essential for maintaining good health in people ill with AIDS. As noted in the introduction, a survey of health care access in South Africa found that lower socio-economic status was the only significant predictor of barriers to health access when controlling for race, gender, age, and area type (Lalloo et al., 2004).

Among households affected by HIV/AIDS, illness can exacerbate already difficult financial situations. As HIV/AIDS mostly affects working and parenting age people, it is likely to decrease household income by incapacitating a working-age adult while increasing household expenditure in the form of medical care (Bachmann & Booysen, 2003; Steinberg et al., 2002). In a South African household survey, 46% of unwell people had been contributing to household income prior to illness; during illness, one-third of income was spent on healthcare (Steinberg et al., 2002).

In countries with school fees and expenses (e.g., uniforms), education may become unaffordable for children, thus providing them with more free time to contribute to their ill parents' caring needs and household survival (Abebe, 2007; Mogotlane et al., 2010; Withell, 2009). As noted earlier, children's responsibility time burden nearly quadrupled from around 11% on weekdays to 40% during weekends when school was no longer competing for children's time (Skovdal, 2009b). Additionally, children may have to contribute to lost income; half of

children with AIDS-ill parents in Barnard (2002) reported engaging in income-generating activities (cited in Bray, 2009). Skovdal (2009b) argues the pressing needs poverty presents result in households focusing on immediate returns in the form of income-generation or household maintenance rather than the long-term goals of children's education. Bray (2009) notes that more children provide care in areas with greater poverty and that where homes become increasingly impoverished, children take on more responsibilities. In the Survey of Activities of Young People, 15% of children indicated they engaged in income-generating activities to contribute to the household income (Bray, 2003).

Children in poorer homes may also end up with a greater share of household responsibilities. Parents in Evans and Becker (2009) indicated they would prefer to hire a domestic worker to help with household chores if they became unwell, though this option was generally cost-prohibitive. The same article reports that children engaged in income-generating activities during parental illness to help alleviate financial difficulties.

Healthcare access

Evans and Becker (2009) note that barriers to healthcare result in people delaying treatment until their health has seriously deteriorated. Reduced access to healthcare services, particularly ART, can result in greater household illness burden and thus more care provided by children (Bray, 2009). Eighty per cent of people in a survey of households in KwaZulu-Natal, South Africa, reported utilising local clinics, a higher utilisation rate than any other health care provider (Steinberg et al., 2002). Utilisation rates were highly influenced by travel time to the clinic; another survey in KwaZulu-Natal found that households within 30

minutes of travel time to a local clinic used them at a rate of ten times of those who had to travel between 90-120 minutes (adjusted OR = 10; 95% CI = 6.9-14.5) (Tanser, Bijsbertsen, & Herbst, 2006).

Home community-based care

Several articles point to home community-based carers as a means to reduce overall household illness burden, and as a result, the need for children to provide care or take on extra responsibility (Bray, 2009; Evans & Becker, 2009; Thomas, 2006). Home community-based carers primarily address the care needs of an unwell person, though they were noted to assist household members who provided care by giving them instructions and advice (Akintola, 2004). Carers also addressed household needs, providing material goods such as food and medicine, financial support, transport to hospital, counselling, and emotional support (Bray, 2009; Evans & Becker, 2009).

Several studies noted limitations to home community-based care. Akintola (2004) describes several challenges facing care organisations in South Africa. For one, though home community-based carers are intended to support family carers, household needs are often so great that the home community-based carer become the ill person's primary carer. In addition to caring for the ill, many home community-based carers also do household chores. Other home community-based carers reported such a large burden that they relied on community members for support.

Social support

Greater social support, as provided by friends, community members, relatives, NGOs, or faith groups, was identified as a protection against greater responsibili-

ties among children. Children with unwell parents felt their situation was improved with external support in the form of money for school fees, food, healthcare, medicine, advice, help with providing care, and other necessities (Bray, 2009; Evans, 2010b; Evans & Becker, 2009; McArdle, 2011; Moffett, 2007; Ruiz-Casares, 2009; Skovdal, 2009a, 2009b; Withell, 2009). According to Evans and Becker (2009), social support allows for the distribution of responsibilities across several people, such as other adults providing care and children serving children in assistance, migrant extended family members helping with household maintenance, and material support from friends, neighbours, and places of worship.

Social networks were also noted to present obstacles. First, extended family members were found to fight for control of land following adult illness or death (Abebe, 2007; Evans, 2010b, 2010c; Harms et al., 2010; Ruiz-Casares, 2009). Second, NGO support during parental illness or death sometimes resulted in jealousies and resentment from the community (Evans, 2010c). Third, potential social support networks became a source of stigma as parents' and children's real or suspected HIV/AIDS-illness were disclosed throughout the community (Harms et al., 2010; Moffett, 2007). Finally, qualitative evidence suggests that social support exists as an exchange network, requiring beneficiaries to contribute in some way to obtain the benefits (Bray, 2009; Skovdal, 2009a, 2009b; Thomas, 2006). Household illness can make contributions to the social support network very difficult, where long-term illnesses like HIV/AIDS and its associated burdens reduce families' interaction with the community, thus excluding them from the network and limiting potential benefits.

3.3.4 Differences between African and Western children's responsibilities

A small number of studies included data from children in both a Western country and sub-Saharan African, in which some substantial differences were noticed. Such comparisons are also useful as many measures of child responsibility resulting from parental illness were developed in Western contexts (Joseph et al., 2009; Mika et al., 1987; Sessions & Jurkovic, 1986).

Evans and Becker (2007, 2009) note that children in their Tanzanian cohort reported engaging in tasks not found among the English sample, including fetching water, tending livestock, and farming. Much of this is attributed to the generalised poverty and lack of development in Tanzania, which produced additional needs not found in the UK. Indoor plumbing, for instance, is ubiquitous in the UK but rare among traditional and informal homes that make up a large proportion of households in the subcontinent (Budlender et al., 2001). Second, subsistence agriculture is practically if not entirely non-existent in Western nations. Additionally, domestic responsibilities are noted to be more intensive and time consuming in sub-Saharan Africa (Evans & Becker, 2007, 2009; Robson & Ansell, 2000). Earlier in this review it was noted that poorer quality homes require more work and thus greater time commitments for maintenance (Bray, 2003; Budlender et al., 2001; Statistics South Africa, 2001b). In addition to increases in household work, quantitative evidence in Bauman et al. (2006) indicates children of AIDS-ill mothers in sub-Saharan Africa spent more time on the same types of caring activities than those in the United States.

Andreouli, Skovdal, and Campbell (2013) asked British young carers to respond to drawings that depicted the lives of young carers in Kenya and Zimbabwe to

identify ways in which their experiences differed. Most prominently, they noted greater poverty, more ill people, limited institutional support, and tasks that were more intensive, time consuming or unique to the sub-Saharan African setting, like walking miles to fetch water. Overall, while they felt the Kenyan and Zimbabwean young carers were harder working and more resilient, they felt it was worse to be a young carer in Africa, which the authors attribute to negative Western stereotypes about Africa. Interestingly, the British young carers compared their own experiences with community support unfavourably, noting greater isolation in the UK.

3.4 Research gaps

Given how little has been written about the relationship between parental illness and children's responsibilities in sub-Saharan Africa, there were several large gaps in the existing research. First, very few of the articles referenced in this review focused on parental illness and children's responsibilities. In a literature review of child carers in sub-Saharan Africa, Bray (2009) notes that because of the scattered nature of this data her review 'Draw[s] heavily on relevant studies of adult carers, of children who live with AIDS-ill parents and of the consequences of orphanhood owing to plausible (usually unidentified) inclusion of child carers in their samples,' (p. 18).

Second, in many of the studies reporting on the types of responsibilities children had, the data were presented in a piecemeal manner. Only a few articles (n = 6) included responsibility tables with categorisations (Abebe & Skovdal, 2010; Evans, 2010b; Evans & Becker, 2007, 2009; Robson, 2000; Robson et al., 2006), though in other articles much of the information was drawn from children's

quotes or other anecdotes. While there was overlap in the types of responsibilities described across studies, there were also a number of responsibilities that appeared in only one article.

Third and related to the above point was a lack of an adequate measure of children's responsibilities as they relate to parental illness, limiting the ability of research to evaluate their range and burden (Joseph et al., 2009). The South African Time Use Survey (Budlender et al., 2001), which uses a diary format to capture activities throughout the day, collects data in half-hour time slots, with each slot capable of accounting for three activities. The limit on the number of activities may serve as a barrier to capturing intricate yet low-time burden responsibilities such as giving or a reminding an ill person to take medicine. Indeed, the Time Use Survey, which uses items drawn from a United Nations expert panel (United Nations Secretariat Statistics Division, 1997) to avoid Western biases in existing classifications of activities, includes no medical care responsibilities. The frequency with which medical care responsibilities were identified in the literature review indicates that the Time Use Survey's items, which include several intimate care responsibilities, are too limited. Two existing measures of parentification, the Parentification Scale (Mika et al., 1987) and the Parentification Questionnaire (Sessions & Jurkovic, 1986) present a similar problem in that neither has been adapted for either the sub-Saharan or South African context (Anderson, 1999; Jurkovic, Morrell, & Thirkield, 1999; cited in Moffett, 2007). Other problems include both measures being retrospective, generally administered to formerly parentified children as adults rather than children during the time of interest, and while they include physically engaging responsibilities, the focus is on

the change in roles between children and parents (Boszormenyi-Nagy & Spark, 1973; in Earley & Cushway, 2002). While the former measure has been used in a study of children with AIDS-ill mothers in Zimbabwe (Bauman et al., 2006), many of its findings were inconsistent with qualitative evidence presented in this review. The Survey of the Activities of Young People (Statistics South Africa, 2001b) was designed to be administered to children within the South African context and includes income-generating activities from outside the formal sector such as begging that children are much more likely to be engaged in. However, there were two problems with the measure. First, each activity had a minimum time requirement, which as mentioned above may exclude highly demanding yet low-time burden responsibilities. Second, the measure does not include any caring responsibilities, a major component of the research in this thesis. Another measure, the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) (Joseph et al., 2009), which was specifically devoted to young carer responsibilities, was also not used for several reasons. First, it was published in 2009, following the initial literature review and exploratory study to generate items for a quantitative survey (described in the next chapter). Second, the tool was designed using data from young carers in the UK who, as discussed in the previous section, engage in a more limited range of responsibilities compared to those in sub-Saharan Africa. Third, the MACA-YC18 is a psychometric scale with its items selected via principal components analysis. The aim of this thesis was to identify rarely occurring but nevertheless important caring responsibilities, which may have been excluded due to their uncommon and/or infrequent nature. Thus, while each of the above measures serves a valuable purpose, they are inadequate to address research gaps identified in the literature review.

Fourth, only three studies present quantitative data; of these, only one (Bauman et al., 2006) presents data specifically collected to address this subject that was not derived from a secondary source. However, the data were reflective of a limited number of caring responsibilities derived from Western measures that had not been adapted to the context. Additionally, while the caring responsibilities were quantified in terms of hours per week, burden attributable to household chores was assessed via a three-point frequency scale, making it impossible to compare the relative burdens of caring and household responsibilities quantitatively. Further, no quantitative studies contextualised how parental illness affects children's responsibility by using comparison groups to establish what non-caring responsibilities and time burdens are considered 'normal' (Bray, 2009). Many qualitative studies suggest factors that may influence the relationship between parental illness and responsibility, though very little of this has been explored quantitatively. Only Bray (2003) presents data on responsibility prevalence, though these were derived from secondary analysis of Time Use Survey data, which do not focus on children's caring responsibilities.

Fifth, much of the existing research focuses on the impact of parental HIV/AIDS-illness, presenting few findings on other diseases or disabilities. As noted in the introduction, South Africa faces a quadruple disease burden, including non-HIV/AIDS communicable diseases, non-communicable diseases, and injuries in addition to HIV/AIDS (Bradshaw et al., 2003; Mayosi et al., 2009; Norman et al., 2007). The scale of the HIV/AIDS-epidemic has created a scenario in which people with all types of illnesses and disabilities have fewer options for care, and often have to rely on those within their own households.

Lastly, there is no longitudinal data exploring the relationship between parental illness and children's responsibilities. Longitudinal studies could compare children's responsibilities pre- and post-illness, and explore the effects of responsibilities to identify whether short-term positive effects such as increased competencies mask long-term negative outcomes (Bray & Brandt, 2007).

3.4.1 Studies' strengths and limitations

There were several limitations of the literature presented in this review. First, there were no studies using representative data that focused on the relationship between parental illness and child responsibility. The few studies that did use representative survey data were either not focused on this relationship (with this area being tangential to the findings) or had conducted secondary analysis of existing data on a related but different topic. Other studies recruited participants via convenience sampling methods like snowball sampling (Robson, 2000, 2004; Robson et al., 2006), community, healthcare, or social worker referrals (Lindsey et al., 2003; Skovdal, 2010; Skovdal & Ogutu, 2009; Skovdal et al., 2009), NGOs or schools (Bauman et al., 2006; Van Blerk & Ansell, 2007), or selection from an existing list such as the beneficiaries of a cash transfer programme (Skovdal, 2010) or a community-based organisation (Akintola, 2006).

Only one study quantitatively assessed the link between children's responsibilities, demographic factors, and maternal health (Bauman et al., 2006). While the study was able to produce significant findings such as the relationship between HIV/AIDS-ill mothers' relative health and children's amount of responsibility, the small, non-representative sample (n = 50) and use of an un-adapted Parentifica-

tion Scale may have prevented it from finding other significant results such as the impact of child gender and age.

There was a lack of studies incorporating theory to explain the relationship between parental illness and child responsibility. Only Evans and Becker (2007, 2009), Van Blerk and Ansell (2002), and Skovdal (2010) framed the relationship between parental illness and children's responsibilities within the context of a theory. Other studies like Evans and Becker (2007, 2009) and Skovdal and Andreouli (2011) incorporated theories such as resilience, though these tended to deal with children's outcomes.

Strengths of the reviewed literature include drawing attention to a phenomenon that is relatively well researched in developed nations though virtually ignored in sub-Saharan Africa (Becker, 2007). Utilisation of qualitative studies to identify and contextualise the issue were useful in presenting the relationship between parental illness and child labour. Additionally, three studies compared the phenomenon in developed and sub-Saharan African contexts (Andreouli et al., 2013; Bauman et al., 2006; Evans & Becker, 2007, 2009), highlighting differences between the settings.

4 Research questions

The following research questions were designed to address research gaps identified in the literature uncovered in this chapter. These questions guide the remainder of this study:

Nature of children's responsibilities

- What types of responsibilities do children in South Africa engage in?

Predictors of children caring for their parents

- Does parental illness predict children's engagement in intimate or medical care?
- What other factors predict children's engagement in intimate or medical care?

Predictors of children's responsibility workload

- Does parental illness predict greater responsibility workloads in children?
- What other factors predict greater responsibility workloads in children?

5 Hypothesised conceptual framework

A hypothesised conceptual framework of the relationship between parental illness and child responsibility and the impact of socio-demographic factors is described using an adaptation of the Ecological Systems Theory (Bronfenbrenner, 1979). The model was selected for its utility in evaluating an individual, in this case a child, within his or her environment. Variations of the model have previously been used to describe whether children take on caring responsibilities (Becker et al., 1998; Evans & Becker, 2007, 2009; Hill & Tisdall, 1997; Skovdal, 2009b). The hypothesised framework is presented in *Figure 2.2*.

The Ecological Systems Theory model divides the structure of the environment into five layers around the individual. The first of these is the microsystem, consisting of the individual. In this model, individuals are children and their demographic characteristics (age, gender, orphanhood, and completion of primary education), and parents and their health and demographics. The next layer, the

mesosystem, contains interactions between different individuals within the microsystem. The two factors within this system concern the nature of the relationship between child and parent: parent type (i.e., biological parent versus grandparent versus foster parent) and whether or not they are of the same gender.

The next layer, the exosystem, describes the larger social setting surrounding the child. Within this layer are household/community factors including adult presence, urban/rural location, poverty, access to healthcare, visits from home community-based carers, and social support. Factors within this layer are contextual rather than one in which children have a large role in shaping. As such, the exosystem layer typically does not include households, which are generally considered a component of the microsystems. However, the sub-Saharan African context may be different enough from the Western contexts where the model was developed to argue that children have a diminished active role compared to those in the United Kingdom or United States. As discussed earlier, households are typically non-nuclear in sub-Saharan Africa, especially in rural areas, including members from several generations and the extended family, or are polygamous. With greater numbers of co-residents, a child's active role may be reduced in favour of the head of household, who may make the majority of decisions for household members. While not denying a child's active role completely, evidence covered in this review implies that adults often assign children greater responsibility in response to household need, regardless of the child's own ideas or preferences (Robson, 2000).

The next layer, the macrosystem, concerns a child's cultural setting. As discussed in the introduction, research and government documents state that children are

often expected to take on substantial responsibility and to help out in the home when needed (Collard, 2001; DOH, 2001; Organization of African Unity, 1990; Robson, 2000; Skovdal, 2010; Van Blerk & Ansell, 2007). On the other hand, Robson (2004) and Skovdal (2009b) document conflicts between traditional and Western ideas (where childhood is viewed as a time for play and school, protected from work and labour) in Zimbabwe and Kenya, where child participants expressed both types of attitudes. Additionally, poverty is often placed at the macrosystem level. Whilst poverty would be a macrosystem-level factor in cross-national studies (e.g., responsibilities among children in South African and the United Kingdom), in this case it is evaluated as a comparative factor within the context. In other words, it is expected that socio-economic status differences within the population will have an impact on children's responsibilities, with the children in the poorest homes having a greater burden.

The chronosystem is the final layer of the model, consisting of changes to the child's environment over time. This may include personal changes to the child like becoming older or getting married, and the parent including becoming increasingly unwell, and external factors. Other temporal changes include HIV/AIDS and other illness prevalence and population age structure.

Factors within each layer interact with those in other layers to some extent. For instance, households with greater amounts of social support may be less affected by the limited options for care associated with poverty and greater travelling time to the local clinic, while the importance of gender-matching in child-administered intimate care may be reduced with lower adult presence.



Figure 2.2: **Hypothesised Conceptual Framework of Interaction Between Parental Illness, Socio-Demographic Factors, and Child Responsibility**

6 Chapter summary

The literature review identified a limited body of research exploring the relationship between parental illness and child responsibility. Many of the findings were drawn from studies focusing on adult carers and HIV/AIDS-affected children. Children reported caring for ill parents and grandparents while taking on additional chores (both in terms of range and time burden) to address household needs created through parental illness. The cumulative time burden of responsibilities has not been quantified, though proxies such as poor school attendance and performance indicate substantial demands.

Qualitative evidence indicates several factors increase the likelihood that children take on greater responsibility due to parental illness, including the child's being older and female, having completed primary school, reduced adult presence, living in a rural location, poverty, and obstacles to healthcare. Some factors were suggested to have complex interactions with child responsibility and parental illness, the most noticeable of which is the interaction between child and parent gender. Qualitative evidence indicates a number of factors protecting children from greater responsibility workloads, including being visited by a home community-based carer and greater social support.

There were several significant gaps in the literature, most notably a limited amount of quantitative data. Existing quantitative data were insufficient due to small sample sizes and convenience sampling methods, or reliance on data drawn from studies not focusing on the relationship between parental illness and child responsibility. Additionally, there were no adequate measures of child

responsibility that were either created for or adapted to the sub-Saharan African context that also included caring tasks.

The findings of the literature review were used to create research questions and a hypothesised conceptual framework that guide the remainder of this thesis.

Chapter 3: Exploratory study

The second phase of research comprising this thesis was the exploratory study, a qualitative, semi-structured survey that sought to obtain a wide range of responses from a large number of South Africa children for the development of a Child Responsibility Measure. *Section 1* describes the aims of the exploratory study and the research questions addressed. The methodology is presented in *Section 2*, covering study setting, sampling strategy, research ethics, questionnaire design, the research team, data collection, and analysis strategy. The findings are presented along with implications for the Child Responsibility Measure in *Section 3*. Strengths and limitations of the exploratory study are discussed in *Section 4* and *Section 5* summarises this chapter.

1 Exploratory study aims

The aim of the exploratory study was to generate items for a measure of children's responsibility that was specific to the South African context and included caring responsibilities. In the previous chapter, the lack of an appropriate measure meeting these criteria was identified as a major gap in the literature and an obstacle to quantitative analysis of the relationship between parental illness and child responsibility, the primary goal of this thesis. The resulting measure, the Child Responsibility Measure, was created using data from existing research on the relationship between parental illness and child responsibility and the findings of the exploratory study described in this chapter.

Very little data on the nature of children's responsibilities had been collected from samples in South Africa. While it can be argued that there is much similarity

in the nature of responsibilities among children across sub-Saharan Africa, an argument that was made in the literature review to justify the inclusion of studies from the entire subcontinent, South Africa differs enough in terms of income inequality and HIV/AIDS-prevalence to suggest potentially vast contextual differences. It was important to use a measure with a comprehensive range of children's responsibilities as research suggests that the labour burden children experience from parental illness is expressed in both the taking on of caring responsibilities and increases to their household chores and other domestic maintenance tasks.

The exploratory study addressed the following research question:

Nature of children's responsibilities

- What types of responsibilities do children in South Africa engage in?

2 Methodology

2.1 Study setting

The study was conducted in predominately isiXhosa-speaking black African urban and rural communities of the Western Cape province between September and December 2008. Study sites included the townships of Cape Town (Crossroads, Khayelitsha, Kuyasa, Nkanini, Gugulethu, Phillipi, Langa, and Nyanga) and townships outside other cities throughout the province: Beaufort West (Mandenkosi), Kraaifontein (Wallacedene), Oudtshoorn (Bongolethu), Paarl (Mbekweni), Stellenbosch (Khayamandi), Grabouw (Waterworks), and Worcester (Nuys). Using classifications in Statistics South Africa (2003), Cape Flats and

Wallacedene were classified as 'urban' and everything else as 'rural.' A map of the Western Cape is presented in *Figure 3.1*.



Figure 3.1: **Map of the Western Cape (Source: OpenStreetMap)**

2.2 Sampling strategy

Children aged 10-18 years were recruited via community- and school-based sampling methods in urban and rural areas of the Western Cape identified as highly deprived based in the Provincial Indices of Multiple Deprivation (Noble et al., 2006). In community-based sampling, interviewers approached households in designated areas and asked if there were children in the home who lived with an ill adult. School-based sampling consisted of approaching children in class-rooms with permission from school administrators. As with community-based sampling, children were asked if they were living with an ill adult. Those who

were eligible and said they would be interested in participating were given a consent form to be signed by themselves and a parent or related adult *in loco parentis*, which had to be completed by the time interviewers returned. Children not living with an ill person were excluded from this study for several reasons. Though the focus of this thesis is how responsibilities between children with healthy and ill parents differ, Robson (2000) argues that children with ill parents engage in the same types of responsibilities as those with healthy parents in addition to tasks resulting from familial illness, a notion supported by quantitative evidence from the UK (Warren, 2007). As such, interviewing children in healthy households would capture the 'normal' range of responsibilities, while interviewing children living with an ill parent or other adult would capture the 'normal' range plus any additional responsibilities relating to familial illness.

Recruitment focused on black African communities due to high HIV/AIDS prevalence and greater levels of deprivation. HIV/AIDS-prevalence is much higher in black African communities in the Western Cape (Shisana et al., 2005), even in places within relatively close proximity. For instance, while overall HIV-prevalence in the Western Cape is 14.9%, it is 12.9% in Mitchell's Plain, an Afrikaans-speaking, primarily coloured (mixed-race) township in the Cape Flats. In Khayelitsha, an isiXhosa-speaking, black African township 7.6 kilometres away but also in the Cape Flats, HIV-prevalence is 33.0% (Shaikh et al., 2006). Additionally, the focus on the most highly deprived areas tended to place the researchers in isiXhosa-speaking black African communities, which are typically more deprived than communities of other ethnic groups (Gradín, 2011).

2.3 Research ethics

Research with children is fraught with ethical issues beyond those normally associated with human subjects, most prominently those concerning competency of children to give informed consent and the potential of intended or unintended coercion (Morrow & Richards, 1996). This section primarily deals with the ethical concerns of the exploratory study. A more detailed discussion of research ethics with children as subjects is presented in *Chapter 4*, *Section 2*.

The children in the exploratory study were considered especially vulnerable for a number of reasons. First, many were living in a household that lacked full or adequate adult supervision due to illness. The author of this thesis, who also served as this study's project manager, observed several households in which a parent was bedridden due to illness. Second, many parents were HIV/AIDS-ill, raising concerns about stigma and community members associating the project, participants, and their families with AIDS. Similar to accounts in the literature review, children spoke of polarised reactions to disclosure among extended family and community members. While many children spoke of family, friends, and community members providing help, a substantial number described others' refusal to speak to household members or to provide any help with care or household chores following disclosure or suspicion of HIV/AIDS-illness. Third, the research dealt with sensitive subjects including parental illness and death and children's potentially embarrassing responsibilities. Robson (2001) describes the difficulty of conducting research on children with ill parents, many of whom had either just been parentally bereaved or were caring for a parent who was extremely ill and likely to die soon. Robson (2001) estimates that nearly half

of the nine interviews for the study reported in Robson (2000, 2004) and Robson et al. (2006) were stopped before completion because 'The young person was in tears and unwilling or unable to continue the conversation,' (p. 136). The last ethical consideration of working with vulnerable groups was the unbalanced dichotomy between adult interviewers working for a Western-backed research project and child research subjects in impoverished settings. However, the factors rendering such children vulnerable, including living with an ill parent and coming from an impoverished setting, were the same factors that made the research so important.

Interviewers acquired informed consent from both the child and a parent or related adult *in loco parentis*. Consent forms were provided in both English and isiXhosa, and interviewers read consent forms aloud with children unless requested otherwise. Each interviewer strived to ensure that children and their parents understood the nature, purpose, and potential value of the research, what participation would require of them, their right to refuse and withdraw at any time with no negative consequences, and the confidentiality of their responses. Consent forms included project manager (who is also the author of this thesis) and supervisor contact details in case the child or parent requested post-interview withdrawal or wanted to discuss any other issues; there were no instances of this. Interviewers were trained to respond to signs of distress in participants by pausing the interview to console the participant and asking the child if he or she would like to stop. The exploratory study consent form is presented in the appendix.

Hardcopy data were stored in a locked drawer in a locked office, first in Cape Town Child Welfare in the suburb of Athlone, then at the Department of Social Policy and Intervention at the University of Oxford. Softcopy data were stored on a password-protected computer. To ensure confidentiality of responses, children were referred to by their age and gender with no other identifying characteristics in both the findings section of this chapter and in all subsequent papers submitted for publication.

This study received ethical approvals from the Department of Social Policy Intervention (then known as the Department of Social Policy and Social Work) and the Inter-divisional Research Ethics Committees at the University of Oxford, and the Health Sciences Faculty Research Ethics Committee at the University of Cape Town. Ethics approval forms are presented in the appendix.

2.4 Questionnaire design

This section details the design of the exploratory study questionnaire, which aimed to elicit a wide and comprehensive range of children's responsibilities. An example of the girls' English language exploratory study questionnaire is presented in the appendix.

2.4.1 Building rapport

Building rapport with child participants, particularly when dealing with sensitive topics and/or shy respondents, can enhance the quality of data they provide. In a literature review of interviewers of child crime witnesses, Vallano and Compo (2011) found non-verbal (e.g., maintaining eye contact, smiling, open body position, and 'a warm and supportive voice intonation' [p. 2]) and verbal (e.g., using open-ended versus direct questioning) rapport building techniques increased

the accuracy of child reports. In addition to eliciting higher quality data, rapport building is as an ethical imperative. Furthermore, upsetting children during interviews could have resulted in obstacles to later recruitment, as many interviewed children were from the same community, neighbourhood, school, and even household. If the project acquired a reputation for distressing children, the research team would have likely faced higher rates of refusal within target communities. As such, it was important to make interviews as enjoyable as possible for participants.

Staff recruitment (described in *Section 2.5*) sought out interviewers with a high degree of empathy and training encouraged non-verbal and verbal rapport building techniques. The questionnaire was designed to generate rapport prior to the interview and to maintain it throughout. Steps for establishing and building rapport with child participants were guided by those in Noble-Carr (2007) and are described below:



Figure 3.2. **Participant self-portraits**

1) Beginning the interview with a task-based activity that established the interviewer's interest in the child, and learning about the child, his or her family and background. In this study, activities consisted of a cover-sheet where children drew a self-portrait (*Figure 3.2*), provided personal information, and drew their household, similar to the illustrated *About myself* sheet in Hill, Laybourn, and Borland (1996). Interest in the child and his/her life was further promoted with a *Milestones* section, in which children described all the major events in their lives, whether happy or sad.
2) Noble-Carr (2007) suggests interviewers share some of their own personal stories with participants. In this study each questionnaire contained a story of a young boy or girl with an unwell parent in lieu of interviewers sharing their own experiences.
3) Sensitive sections of the questionnaire like *Helping when someone is sick* and *Changes* (asking how the child's life had changed since the adult had become ill) followed rapport-building sessions. The above-mentioned *Milestones* section had the potential to be a sensitive, though it was entirely up to the children to disclose sensitive information.

2.4.2 Responsibilities

Children's responsibilities were primarily captured in two sections. The first section was entitled *Helping when someone is sick*, in which children described how they helped when someone in their home became ill. This section included some example responsibilities derived from the literature review, which were selected

based on prominence in existing research and their variation in range and included: cooking, shopping, waking up brothers/sisters in the morning, cleaning up around the house, washing clothes, feeding an adult, giving medication, and watching brothers/sisters. There was a concern that children would not have volunteered caring responsibilities without pre-selected examples, particularly if the child were shy or embarrassed. Rarely occurring but important responsibilities like bathing a parent or other tasks not uncovered in the literature review may not have been elicited without such prompts, resulting in an incomplete Child Responsibility Measure.

The second section devoted to capturing child responsibility was *My day*, adapted from the 'journal' questionnaire format used in Evans and Becker (2007, 2009); (adapted from Healthlink Worldwide, 2006). *My day* captures all activities from the time children woke up till they woke up the next morning. The format of this section is presented in *Table 3.1*.

Table 3.1
My Day Section of Exploratory Study Questionnaire

Time:	What I do	How long I do it	How I feel
(Example) 7am	I change my mother's sheets	Half an hour	I am proud that I am able to help my mom, but it makes me sad to see her so sick

2.4.3 Additional sections

Other sections in the questionnaire included *Changes*, in which children described the impact of familial illness on their own lives. Subheadings in this section focused on schooling, relationships, health, feelings, and an open section. In

Support, children were asked about how others helped them cope with parental illness. This section included subsections on emotional, medical, monetary and materials goods, and a space for open response. In the *Open page* children were asked about anything else they wanted to discuss about their parent's health or how it affected them. A *Confidential sickness report sheet* was used to collect information on parental illness. This section was used to pilot a verbal autopsy (Lopman et al., 2006) to identify HIV/AIDS-illness based on secondary child reports for use in the quantitative survey. The verbal autopsy is described in greater detail in *Chapter 4*, *Section 4.1*.

2.4.4 Pilot

Eleven children between 13-18 years from the Cape Flats townships were recruited to pilot the questionnaire over a weekend camping trip prior to the beginning of research. The group, referred to as the Teen Advisory Group or TAG Team, discussed attitudes toward illness in their communities and how they would best like to be interviewed.

The TAG Team suggested making the questionnaire more child-friendly and shorter overall as they experienced fatigue towards the end of interviews. Additionally, several children displayed signs of distress during discussions of familial illness, similar to that described in Robson (2001), serving as a reminder to project managers and interviewers of the sensitive nature of the interviews.

2.4.5 Translation

All questionnaire materials were translated into isiXhosa via a four-step process:

1) A native isiXhosa-speaker who was fluent in English translated information in the questionnaire, information sheet, and consent forms from English to isiXhosa.
2) Research team interviewers who were not involved in the original translation back-translated items from isiXhosa to English.
3) Back-translation was compared to the original English-language questionnaire to determine whether content and meaning had been preserved.
4) The project manager (the author of this dissertation) and the research team interviewers discussed inconsistencies between the original and back-translation. The goal of these discussions was to ensure the quality of the translation and that all research team members shared consistent understanding of the questionnaire's items. The final step repeated itself until the project manager and interviewers agreed on the meanings of items and the translated counterparts.

2.5 Research staff

Three isiXhosa-speaking interviewers were recruited to conduct interviews with participants. Each interviewer was selected for their prior performances with University of Oxford research projects with orphans and vulnerable children as research subjects (i.e., Cluver, Gardner, & Operario, 2007).

Interviewers received a week of extensive preparatory training where they practiced administering the questionnaire to each another. Additional training focused on ethical guidelines for obtaining informed and voluntary consent, maintaining participant confidentiality, and prompting for responses in an unbiased manner. The project manager, who is author of this thesis, supervised interviewers throughout fieldwork to monitor performance and address problems.

2.6 Data collection

Participants were given the option of being interviewed by research staff or completing the questionnaire on their own. Most children chose to be interviewed. Interviewers checked questionnaires returned by children who chose to complete it on their own to ensure every part had been filled in correctly, helping

the children if any sections were incomplete and to translate isiXhosa and Afrikaans responses into English. Interviewers handed completed questionnaires to the project manager for quality control, which consisted of checking for completeness of responses, consistency, and to ensure that instructions had been followed. Those not meeting the criteria were returned to interviewers to complete or correct with the interviewed children.

All interviews were conducted in a way that emphasised privacy. For participants recruited in the community, interviews were conducted in a separate room, a quiet corner of the home away from other people, or outside and out of earshot of anyone else. Similar to the experiences in Robson (2000), participants' parents occasionally insisted on being present throughout the interview. In such cases, research staff explained the need for privacy for children to respond openly and honestly. As many parents wanted to know what questions their children were being asked, they were offered a blank copy of the questionnaire to look through. Parents were allowed to sit with their children if they insisted on being with them during the interview. In schools, interviews were conducted in a quiet room provided by school administrators. If interviews were conducted simultaneously, care was taken to ensure children had adequate space to prevent others from overhearing.

2.7 Analysis strategy

The resulting data were thematically analysed to identify, code, and categorise children's responsibilities using the description of five elements of 'good code' described in Boyatzis (1998, pp. x-xi). The elements are presented below, along

with descriptions of how they were implemented for analysis of exploratory study data:

1) 'A label'

In the exploratory study labels included responsibility category (Personal care; Domestic responsibilities), subcategory (Intimate care, Medical care, Housework, Childcare, Income-generating activities), and each individual task. All category and subcategory labels were derived from the literature review, as were most individual responsibility types. New labels were created for responsibilities not previously identified in the review, which were designed to describe the task most accurately.

2) 'A definition of what each theme concerns (i.e., the characteristic or issue constituting the theme)'

Responsibilities were any task or activity performed *for the benefit of another person or group of people*. After individual responsibilities were coded, they were categorised as 'Personal care' (i.e., addressing the needs of the unwell person) or 'Domestic responsibility' (i.e., addressing the needs of the household), and placed within a subcategory based on the specific aspect of the need addressed. Responsibilities categorised as 'Personal care' were subcategorised as 'Intimate care' if assisting with a normal bodily need (e.g., toileting, bathing, feeding) or 'Medical care' if they addressed a medical need (e.g., administering medications/treatments, accompanying an ill person to a healthcare provider). Responsibilities categorised as 'Domestic responsibilities' were subcategorised as 'Housework' if they addressed basic domestic maintenance needs (e.g., cooking for the family, cleaning the home), 'Childcare' if they addressed care needs of

other healthy children in the home (e.g., bathing a child, walking a child to school/crèche), and 'Income-generating activities' if they addressed financial need (e.g., begging, domestic work, transactional sex).

3) 'A description of how to know when the theme occurs (i.e., how to "flag" the theme)'

Activities were coded as responsibilities when a participant explicitly stated that he or she performed a task for the benefit of another person. Most responsibility data were derived from the *Helping when someone is sick* and *My day* sections, though positive, relevant examples were found throughout the questionnaire. For instance, in the *Changes* section some children mentioned they had missed class because they had to accompany their parent to the clinic. Other responsibilities were identified in the *Support* and *Open page* sections, where children generally provided longer, open-ended qualitative responses.

4) 'A description of any qualifications or exclusions to identifying themes'

To be considered a responsibility, a task must have been performed for the benefit of another person or group of people. A task was not considered a responsibility if it was solely for self-benefit (i.e., there were no intended beneficiaries other than the child).

'Personal care' responsibilities had to benefit an ill person. Some 'Childcare' responsibilities like bathing and feeding were functionally similar to 'Intimate care' responsibilities, and were distinguished by the indication of any illness in the child. If he or she required care because of illness, the responsibility was considered 'Intimate care.' If there were no indications the child was unhealthy, the re-

sponsibility was categorised as 'Childcare.' The distinction is important due to the presence of illness in children, particularly HIV/AIDS and disability.

5) 'Examples, both positive and negative, to eliminate possible confusion when looking for themes'

The following are examples of a responsibility and a non-responsibility task: 'I cook dinner for the family,' and 'I make myself breakfast.' The former instance would be categorised as a 'responsibility' (subcategory 'Housework') because it is an undertaking that prepares food for the family. In the latter instance, the participant is the only beneficiary; therefore, this would not be categorised as a responsibility.

The following are examples of 'Intimate care' and 'Childcare' responsibilities: 'I feed my grandmother porridge.' 'I feed my little brother porridge.' The former instance is considered 'Intimate care' as incapacity in adults is considered illness or disability. The latter instance could be considered either 'Intimate care' or 'Childcare' depending on the health of the little brother. If the brother is identified as being ill or disabled, then the responsibility is considered 'Intimate care'; if he is not identified as being unwell the child is presumed to be healthy and the responsibility is considered 'Childcare.'

3 Findings

3.1 Participant characteristics

Participants included *n* = 349 children aged 10-18 who indicated they were living with an ill adult. Average age of participants was 13.4 years (SD = 2.30) at the time of interview. A majority of participants were female (60.7%; *n* = 212) and from an urban area (61.0%; *n* = 213). All children were living with at least one

unwell adult; one-quarter (24.4%; *n* = 85) were living with two or more ill people. Children identified *n* = 440 co-resident ill individuals, their relationship with whom is presented in *Figure 3.3*. Based on children's reports, the most common illnesses identified among unwell co-resident family members were HIV/AIDS (52.7%; *n* = 232), heart disease/high blood pressure (33.6%; *n* = 148), emotional problems (29.8%; *n* = 131), arthritis (27.0%: *n* = 119), diabetes (19.3%; *n* = 85), and disability (13.9%; *n* = 61). Other less frequent ailments included tuberculosis (4.3%; *n* = 19), alcohol/substance abuse (3.9%; *n* = 12), cancer (1.4%; *n* = 6), and epilepsy (0.9%; *n* = 4). In a small number of cases (2.3%; *n* = 10) the child considered a person to be unwell but could not identify a specific illness.

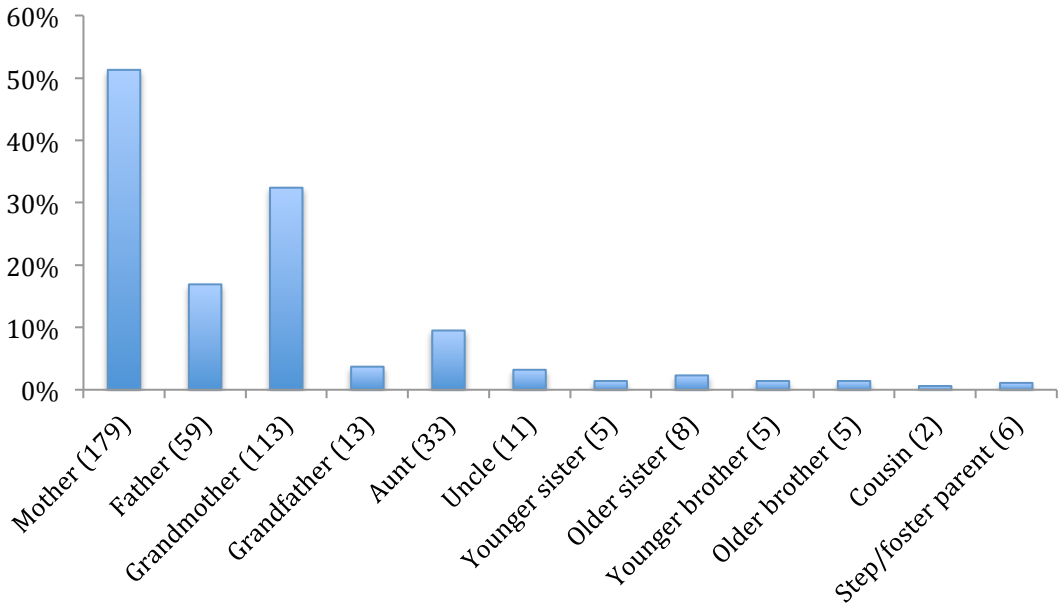


Figure 3.3. **Proportion of unwell people present in each child's household**

3.2 Nature of children's responsibilities

Children's responsibilities, which are presented by category and prevalence in *Table 3.2*, were similar to those described in the literature review. Around two-thirds of children were involved in personal care (64.5%; *n* = 225), and almost all

children reported engaging in some type of domestic responsibility (98.6%; *n* = 344).

Two-thirds of participants reported engaging in personal care responsibilities (64.5%; *n* = 225), and almost half engaged in intimate care (47.9%; *n* = 167). Surprisingly high numbers were engaged in helping their parent to eat (42.7%; *n* = 149), while few children were engaged in bathing (4.0%; *n* = 14), dressing (1.1%; *n* = 4), or cleaning up after someone had been ill (0.3%; *n* = 1). One-third of interviewed children (33.2%; *n* = 116) were giving an ill person medication, typically described as 'tablets.' One 16-year-old girl reported giving her grandmother injections, presumably insulin though not specified, to treat her diabetes. No child mentioned liaising between an ill adult and healthcare workers, preparing special foods or providing traditional medicines. While just over one in twenty of the children reported accompanying an ill person to the hospital (6.3%; *n* = 22), qualitative responses indicated this task tended to demand substantial time commitments. When asked what type of support she would like to receive, one 13-year-old girl who reported spending up to nine hours waiting with her AIDS-ill mother at the clinic told interviewers, 'I wish I could have someone to look after her whenever she goes [to the clinic].' Such long wait times are not that far outside the range normally experienced in sub-Saharan Africa, which have been noted to average between four to six hours (Hardon et al., 2007).

Over a quarter of children were caring for other children in the home (28.1%; *n* = 98). The most frequently cited childcare activity was 'look after children' (including helping with homework and supervising) (20.9%; n = 73). One 18-year-old girl whose mother was AIDS-ill told interviewers, 'When my mom gets sick I

have to come home and look after the children while she is at the hospital.' When asked what type of support she would like to receive she responded that 'It would be nice to have someone who looks after us while my mother is in the hospital.' This response hints at the tension in children taking on surrogate parenting roles as she is both caring for her siblings while asking for someone else to care for them, herself included.

A small number of participants were engaged in income-generating activities (3.2%; *n* = 11). None of the described jobs appeared to be in the formal economy. The most common job description was vending items such as bins, chips, or sweets, while a few others worked in shops. During fieldwork, a few children were observed to be cleaning sheep heads ('smiley') and shins to sell to raise money for school fees. One brother and sister pair were observed selling alcohol from a backroom in their home while their parents were out. Though they were responsible for the sale of alcohol over long periods of time, they moved freely around the house when not dealing with customers. Another 18-year-old girl delivered medicines and treatments throughout the community, though it was unclear whether this was done in exchange for money.

Table 3.2
Participant Responsibilities by Category and Subcategory

Category (%; *n*)	Subcategory (%; *n*)	Responsibility (%; *n*)
Personal care (64.5%; *n* = 225)	Intimate care (47.9%; 167)	Bathe the unwell person (4.0%; *n* = 14) Care/watch/check/keep company with unwell person (13.5%; *n* = 47) Clean up vomit and diarrhoea (0.3%; *n* = 1) Dress/change clothes (1.1%; *n* = 4) Help to eat/feeding (42.7%; *n* = 149) Lift/move unwell person (2.9%; *n* = 10) Massage unwell person (2.8%; *n* = 10) Toilet (0.3%; *n* = 1) Wash feet (0.6%; *n* = 2)
	Medical care (37.2%; *n* = 130)	Accompany to hospital/clinic (6.3%; *n* = 22) Buy/collect medications (1.1%; *n* = 4) Give treatment/medication (33.2%; *n* = 116) Remind to take treatment/medication (2.6%; *n* = 9)
Domestic responsibilities (98.6%; *n* = 344)	Housework (98.3%; *n* = 343)	Clean house/yard (95.7%; *n* = 334) Clean/make others' beds (6.0%; *n* = 21) Cook (77.1%; *n* = 271) Fetch water (5.4%; *n* = 19) Garden/plough (0.3%; *n* = 1) Grocery shopping (67.0%; *n* = 234) Heat water (14.3%; *n* = 50) Laundry (83.7%; *n* = 292) Serve food (6.0%; *n* = 21) Take out rubbish (1.7%; *n* = 6) Translate, read, and write documents (0.3%; *n* = 1) Wake family (44.1%; *n* = 154) Wash dishes (39.3%; *n* = 137)
	Childcare (28.1%; *n* = 98)	Feed children (2.6%; *n* = 9) Look after children (20.9%; *n* = 73) Take children to school (4.3%; *n* = 15) Wash children (9.5%; *n* = 33)
	Income-generating activities (3.2%; *n* = 11)	Farm work (0.3%; *n* = 1) Sell produce/goods/work in a shop (2.9%; *n* = 10)
Total: 99.7% (*n* = 348) engaged in at least one type of responsibility		

3.3 Relationship between parental illness and responsibilities

Several children linked increases in their responsibilities directly to parental illness. A 14-year-old girl from an urban township described the impact of her grandmother's illness:

> Since my grandmother became sick I now have to take on more responsibilities, and I am always worried and sometimes lose my mind. If she's sick I'm not even going to play. I just want to stay at home and look after her. This really affects me and I'm not always happy about this.

Several children reiterated a point discussed in the literature review, that children provide care for parents only when necessary, and times of need are varied. In the *My day* section one 12-year-old girl said, 'If my mother can't eat by herself

I feed her.' The conditional nature of this statement indicates that need for the girl's mother to be fed fluctuated with her relative health. Another 16-year-old girl described how her level of responsibility was dependent on the availability of people willing and able to help, stating, 'If there is a shortage of people in my home, for example my mother is at work, I must help. Even if my mother is there I must help her if she is busy.'

Other children discussed the indirect link between parental illness and domestic responsibilities. In the previous section, an 18-year-old girl with an AIDS-ill mother spoke about her surrogate parenting for other children in the house. Here, she is quoted on the changes to her duties as a result of her mother's incapacitation from illness: 'Since my mom got sick I've had to take on more responsibilities and be a mother to my sisters and brothers.' She continued to describe how this responsibility affected her own life, saying, 'I have to do housework and homework for them and I don't get time for myself. I miss class sometimes. I don't get enough sleep at night because my younger brother cries at night.'

Another child, a 12-year-old boy, was economically supporting his AIDS-ill mother and family, having dropped out of school to sell chips and sweets. Far from feeling empowered by the work they were engaging in, several children described their increased responsibility in a negative light. One 18-year-old girl who left university to care for her AIDS-ill mother said of her responsibilities, 'It is not nice to live with someone who is sick, because you have to do everything. You can't do stuff you want to do.' Another girl, 16-years-old, discussing her experience living with her diabetes-ill aunt following her own mother's death from AIDS, said, 'I am forced to help. [My aunt] can do it sometimes but a lot of times

we work very hard even if it is not for her being sick.' This quote is underscored by research suggesting that foster parents take in orphaned children under the guise of acquiring immediate labour benefit from that child (Skovdal, 2010; Van Blerk & Ansell, 2007).

A few children exhibited attitudes echoing the 'generational bargain' (Collard, 2001). One 16-year-old girl, speaking of the expectations of her to care for her grandmother, who was suffering from arthritis and heart disease, said 'I'm supposed to help her because there is no one to help except me, because when my grandmother is sick it is compulsory to help her.' Another child, a 14-year-old boy, was explicit about the role of reciprocity, saying:

> To have a parent is not something to play about. It is something you must care for. A parent must be cared for by those they gave birth to. A parent also does not give birth just for the sake of it but for us to care for them when something happens to them.

For other children, the pressure was external. One 15-year-old boy said, 'I am afraid not to look after [my unwell grandparents] as if I don't take care of them,' suggesting that he would be viewed as lazy or unhelpful within his own community. Conversely, according to some children there was stigma attached to caring. One 14-year-old boy described why he didn't help his grandmother, who was unable to walk, speak, or feed herself: 'I don't come near her. I don't help her because only older people come to help her. It is not that I don't like to come but just that it is a big task for children.'

Some children were mostly unaffected by parental illness in terms of responsibility. One 11-year-old boy described how his household faced need, though allocation of responsibility had left him out: 'My sister is the one who works very hard

but also my mother is helping.' This quote echoes a point in the literature review that girls are given a greater proportion of the responsibility burden.

3.4 Implications for the Child Responsibility Measure

Many of the responsibilities identified in the exploratory study were similar to those listed in the literature review, though there were a few notable differences. For instance, very few children were engaged in agricultural work (n = 1 for sustenance garden/plough work, and n = 1 earning money from farm work) despite a number children being recruited from farming areas. This type of work had been mentioned in a number of literature review articles, suggesting a high degree of prevalence in other sub-Saharan African countries. The lack of farming responsibility or work may reflect of the relative wealth of the Western Cape province, a lack of need for subsistence agriculture, and the mechanised (and thus non-labour-intensive and/or requirement of skilled labour) nature of farming in the province. Other findings support this notion, such as the low proportion of children who were fetching water (5.4%; n = 19), and the complete absence of any children who were collecting firewood or making fires for warmth or cooking. Several homes were observed to use paraffin gas for heat, though no children reported involvement in its supplying or use. Responsibility differences between the literature review and this study should not be overanalysed, however, as no study in the literature review producing data on children's responsibilities nor the exploratory study derived results from representative samples. Regardless, these differences highlight the importance of contextually relevant measures, which is particularly important given the quantitative, cross-sectional

survey is conducted in a different South African province. As such, items in the tool were derived from both the literature review and the exploratory study.

4 Exploratory study strengths and limitations

The exploratory study's strengths include a large sample size and geographic distribution of participants within the Western Cape province. The large sample increased representation of groups (e.g., boys and girls, urban and rural) and subgroups (e.g., urban boys, rural girls) within the study. Given the evidence from the literature review concerning the demographic factors moderating the impact of familial illness, the wide range of participants increased the likelihood that a comprehensive range of responsibilities were captured in this study.

Despite the large sample size and wide geographic spread of the exploratory study, comparisons to responsibilities in the literature review highlight differences between the Western Cape and other parts of sub-Saharan Africa and suggest omissions in this study's findings. In particular, the lack of any responsibilities concerning firewood and limited number of children engaged in agricultural tasks suggest that the findings of the literature review must be relied on more heavily in creating the Child Responsibility Measure than anticipated, as the next phase of research is conducted in different South African province.

A second limitation was noted when comparing the responses of children from the same household where presumably objective data, like the number of people in the home and how many of them were ill, were sometimes inconsistent. Such findings raise concerns about the reliability of children's responses. To counter this, both children and parents were interviewed in the next research phase, the

quantitative, cross-sectional survey, which it is hoped produced more accurate socio-demographic and parental health data.

5 Chapter summary

The exploratory study was conducted in response to a gap identified in the literature review, which was the lack of a measure of children's responsibilities designed for or adapted to the South African context that also included caring tasks. The gap presented a substantial obstacle to the next research phase proposed in this thesis, a cross-sectional survey, which aimed to evaluate the impact of parental illness on children's responsibilities quantitatively.

A total of *n* = 349 children living with an ill parent were interviewed using a mix of open-ended questions and a daily activity journal. Children reported engaging in a similar range of responsibilities as those identified in the literature review, including intimate and medical care and a variety of domestic responsibilities. Qualitative responses linked specific responsibilities to parental illness while highlighting the expectations of children and their sometimes contradictory nature. Data from both the literature review and exploratory study were used to create the Child Responsibility Measure, which is presented in the next chapter.

Chapter 4: Cross-sectional survey research methods

The third research phase of this thesis consisted of a quantitative, cross-sectional survey designed to address the research questions concerning the interaction between parental illness, socio-demographic variables, and child responsibility. This chapter begins with a discussion of the aims of the cross-sectional survey in *Section 1*, and the specific ethical considerations of working with children in *Section 2*. *Section 3* describes the study setting and sampling strategy. Questionnaire design is detailed in *Section 4* and research staff in *Section 5*. The process of data collection, including quality control and data entry, is described in *Section 6*, and the data analysis strategy in *Section 7*. Research challenges and constraints are discussed in *Section 8* and the strengths and limitations of the survey in *Section 9*. A brief summary of this chapter is presented in *Section 10*.

1 Cross-sectional survey aims

The aim of the quantitative, cross-sectional survey was to collect and analyse quantitative data from representative samples concerning the relationship between parental illness and child responsibility, noted in the literature review to be a substantial gap of existing research. The following research questions guided the quantitative survey's methodology:

Predictors of children caring for their parents

- Does parental illness predict children's engagement in intimate or medical care?
- What other factors predict children's engagement in intimate or medical care?

Predictors of children's responsibility workload

- Does parental illness predict greater responsibility workloads in children?
- What other factors predict greater responsibility workloads in children?

2 Research ethics

According to the British Psychological Society (2010), the cross-sectional survey meets several criteria for research involving more than minimal risk. First, the participants, children and parents in impoverished settings often affected by serious illnesses including HIV/AIDS and its associated stigma, were an inherently vulnerable group. The risk was exacerbated by the researchers' positions of power, which were backed by two universities, one local and one from a developed nation, granting the project the perception of authority. Second, the research involved sensitive topics including HIV/AIDS and children providing intimate care to an adult, which had a strong possibility of inducing psychological distress among participants (Robson, 2001). Lastly, the research involved potential 'labelling,' particularly with screening questions to determine whether households were 'ill' or 'healthy' (see *Section 3* in this chapter). Though ill and healthy categorisations were confidential, the nature of screening questions led some community members erroneously to believe the project only interviewed at illness-affected households. Additionally, some community members believed that participants received some monetary or tangible benefit from

the researchers, fostering resentment and jealousies. Project managers implemented a corrective strategy whereby security escorts and community guides, who were responsible for introducing the project to community members, stressed that the study was interested in both ill and healthy participants, and that researchers provided no tangible benefit for participation other than a certificate.

Though these characteristics of the target population enhanced their risk as participants, it was also what made them a group of interest. The British Psychological Society (2010) argues that research with vulnerable groups is justified 'if the longer-term gains outweigh the short-term immediate risks to participants.' Such risk-benefit analysis 'should not only be confined to considering the interests of the primary participants, but also consider the interests of any other stakeholders,' (p. 13).

In response to the potential risk to participants, project managers took extra precautions when drafting ethical guidelines, which were guided by five principles in Human-Vogel (2007):

1) Voluntary participation
2) Informed consent
3) Safety in participation
4) Privacy
5) Trust

To meet these standards, children and parents were given information sheets in isiZulu and English regarding the nature of the research. Interviewers obtained written consent only after participating parents and children had read and displayed an understanding of their roles in the research, their right to refuse to

participate and withdraw at any time without consequence, and the confidentiality of their responses. No children were interviewed or asked for consent prior to acquiring parental permission.

Participant privacy during interviews was a priority. Children and parents were often interviewed outside their homes or in a separate room to ensure they could answer freely and not feel any distress at talking about sensitive topics in front of family members. In cases where the participant displayed signs of distress, the interview was halted and participants were given the opportunity to withdraw. Responses were not shared between children and parents.

Staff members were required to make referrals in cases where abuse was suspected or participants were believed to be in immediate danger. Referrals were also made where household members were not receiving grants for which they were eligible. In some cases this was due to fraud, where an adult who was ostensibly caring for a child was not present and did not use grant money to support the household, while in others the families had difficulty with the application process. For each referral, staff completed a referral report sheet which included as much detail about the reason for referral as possible and collected multiple sources of contact for the person being referred including name, date of birth, address, contact number, and school information. Referrals in the urban field site were submitted to a local child welfare organisation, while referrals in the rural site were submitted to research partner Tholulwazi Uzivikele, which had the resources and contacts to properly address each case. Permission was required for all referrals concerning adults. Referrals concerning children did not require permission because of the potential for an abusive party (e.g., a related

adult) to deny approval and other issues concerning the limited power and inherent vulnerability of children. In addition to referrals, all participating adults and children were provided with a certificate that contained contact numbers of relevant social services, HIV/AIDS and child abuse hotlines, and the University of KwaZulu-Natal Research Ethics Committee. Examples of a referral report sheet, referral, and certificate are presented in the appendix.

This study received ethics approvals from the Department of Social Policy and Intervention (then known as the Department of Social Policy and Social Work) and Inter-divisional Research Ethics Committees at the University of Oxford, the Humanities and Social Sciences Ethics Committee at University of KwaZulu-Natal, and the KwaZulu-Natal provincial Departments of Health and Education. Project research staff received extensive training on ethical procedures. Ethics approval forms are all presented in the appendix.

3 Study setting and sampling strategy

The survey was conducted in predominately isiZulu-speaking urban and rural municipalities of KwaZulu-Natal province of South Africa. The urban site, Lamontville, is a township of Durban in the eThekwini district. The rural site, Umhlabuyalingana, is located in the Umkhanyakude district in the northern tip of the province (*Figure 4.1*). Urban data collection took place between September 2009 and April 2010, with supplemental collection from November to December 2010. Rural data collection took place between May and October 2010.



Figure 4.1: **Map of KwaZulu-Natal Province with census districts (source: South Africa Yearbook 2011/2012, http://www.southafrica.info)**

The sampling strategy was designed to recruit representative samples of children between 10 to 17 years of age and their parents or guardians 18 years or older (collectively referred to as 'parents' for the purposes of this thesis). Study sites within KwaZulu-Natal were selected using a set of scientific and logistical criteria. Potential sites were limited to census districts within the province with ≥ 30% HIV prevalence among antenatal clinic attendees to limit research to areas highly affected by AIDS, though all eleven census districts within KZN exceed-

ed this cut-off. Among these, eThekwini (41.6% antenatal prevalence) and Umkhanyakude (39.3% antenatal prevalence) (DOH, 2008) were selected for their representivity of urban and rural sites based on distinctions in Statistics South Africa (2003).

Within each district, one municipality was selected for further stratification based on logistical criteria. The eThekwini district is composed entirely of the eThewkini Metropolitan Municipality and was by default selected for the urban site. Within Umkhanyakude, the Umhlabuyalingana Municipality was selected for logistical considerations including a project partnership with Tholulwazi Uzivikele (http://www.tuproject.org/), a local home community-based care NGO. Additionally this site was highly representative of a deep rural area, being several hours' drive from the closest urban centre (Empangeni, 255km away) and having low population density and limited service availability. Each site was stratified into operationally defined 'sub-districts,' which varied between the two field sites. For the purposes of site selection, sub-districts were classified as the smallest locally recognised or distinguishable geopolitical unit.

Using data available on the Statistics South Africa website (www.statssa.gov.za) eThekwini was divided into wards, which were limited to those with only urban households; those containing households classified as 'rural' or 'tribal' in Statistics South Africa (2003) were excluded. The exclusion was based on higher levels of deprivation associated with rural areas. Using Provincial Indices of Multiple Deprivation ranking data from Noble et al. (2006) and eThekwini ward homestead categorisations from Statistics South Africa, a correlation analysis was run to find if wards containing 'rural' or 'tribal' households were more de-

prived, which was the case (r = .358, p = 0.01). Inclusion of wards with rural and/or tribal homesteads would likely have skewed results due to crossover bias and urban/rural comparisons would have been less valid. The exclusion of such wards reduced the eligible number from 100 to 75.

Ward 74, comprising half the township of Lamontville, was randomly selected from among the top quintile (20%) of deprived wards based on scoring in the Provincial Indices of Multiple Deprivation (Noble et al., 2006) and local knowledge regarding community safety. In Ward 74, sub-districts for stratification were Enumerator Areas (EAs), or workload-defined boundaries for census enumerators. For project staff, boundaries were identified using aerial photography. EAs were randomised for temporal order of approach, with each EA being exhausted before beginning work in the next. Responses from Ward 74 were later supplemented with data from Ward 75, adjacent to Ward 74 and also mostly within the township of Lamontville and of a similar socio-demographics. Indeed, ward boundaries within Lamontville appeared arbitrary aside from the apparently strong political influence of ward councillors (described in *Section 3.1* of this chapter).

Project managers initially attempted to replicate the same stratification strategy in the rural site, though it became apparent that this was not feasible. For one, though wards and Enumerator Areas exist in the rural site, they are much larger due to lower population density and much harder to identify and distinguish from one another due to homogeneity of terrain and a lack of landmarks. Instead, households were stratified based on a locally recognised geopolitical boundary, the isigodi or tribal area. Randomising all isigodis was impractical in the Umhla-

buyalingana Municipality as some sites were physically unsuitable for coverage due to poor roads, dense vegetation that limited visibility, and in some areas difficulty in securing political and community buy-in (described in *Section 3.1* of this chapter). Instead, local knowledge of each of these factors was used to determine the temporal order of selected sub-districts in the rural site based on accessibility, visibility, and socioeconomic variability between isigodis.

Households within designated sub-districts were screened for eligibility using the flowchart in *Figure 4.2*; the full sampling sheet that was used in the field, which includes the eligibility-screening flowchart, is presented in the appendix. The eligibility-screening flowchart was designed to produce eligible child/parent pairs and categorise them as either 'ill' or 'healthy,' while ostensibly excluding 'healthy' child/parent pairs in households with another 'ill' adult to avoid cross-over bias. While the eligibility-screening flowchart was successful in producing eligible child/parent pairs (see *Sections 2* and *2.3* of the next chapter), it became apparent during fieldwork that the flowchart produced inaccurate illness categorisations. Interviewers reported that some respondents initially denied but later admitted to having an illness, explaining they harboured a mistrust of researchers prior to interview. Later, analysis found a high degree of inconsistency between screening and questionnaire data regarding the health of the parent. The outcome was unsurprising given the stigma surrounding HIV/AIDS in South African communities and misconceptions that the research was only interested in and provided benefits to people who were ill.

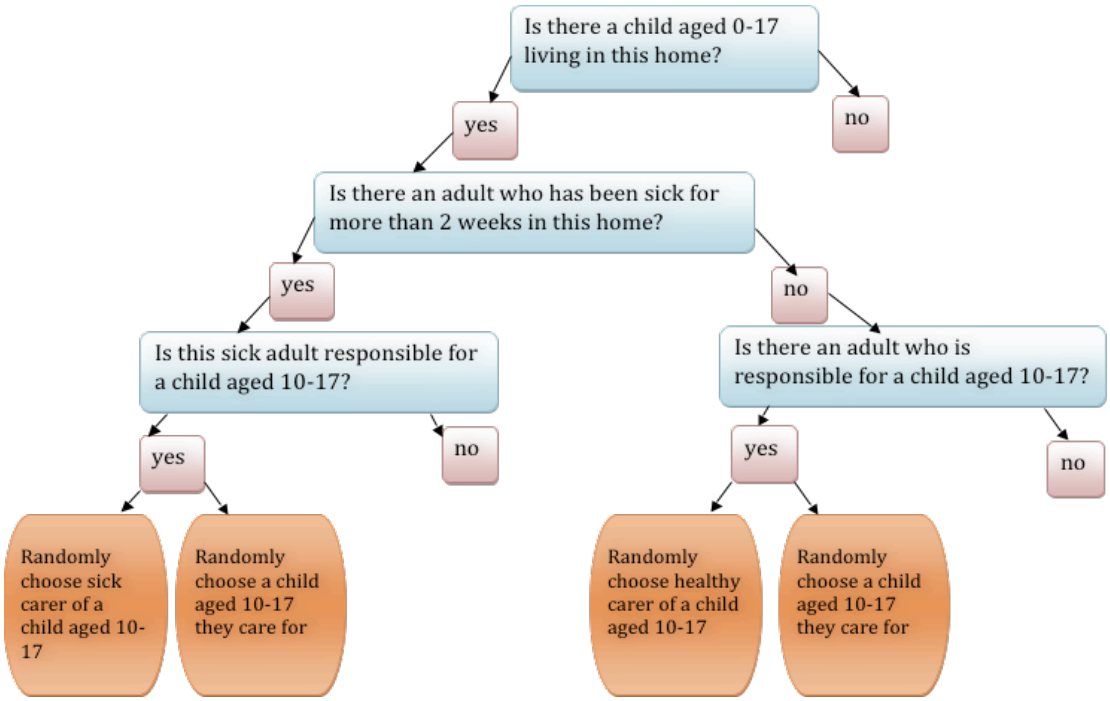


Figure 4.2: **Eligibility screening flowchart**

3.1 Community and political buy-in

Political buy-in for the urban site consisted of receiving the permission of the Ward councillor, Ms Octavia Mthembu, the eThekwini Chief Whip Ms Fawzia Peer, and the Municipality Speaker Councillor, Mr James Nxumalo. Security escorts (described in *Section 5.1* of this chapter) conducted the bulk of urban community buy-in, first by distributing flyers in each Enumerator Area prior to field team visits, then through their accompaniment of the team during fieldwork. Flyers contained a description of the project in isiZulu, plus the names and phone numbers of project managers and field coordinators who were isiZulu-speakers. Per the advice of Councillor Mthembu, the project did not hold a meeting to introduce the project to the community as had been done with one of the primary investigator's study in neighbouring Umlazi (Kuo, 2010).

The political buy-in process was more complicated in the rural site. Though there were Ward Councillors, they did not appear to hold as much power or in-

fluence. Research partner Tholulwazi Uzivikele advised the project to secure permission to conduct research from the tribal authority, which appeared to be the true source of political power in the rural site. Tholulwazi Uzivikele provided the bulk of initial buy-in, presenting at a tribal authority meeting on the proposed research project. The tribal authority meeting is headed by the regional nkosi, or king, who holds authority over all local tribal leaders, known as induna, who in turn oversee each isigodi. All present gave their consent for the study to be conducted within the area. The next step involved sending letters to every induna to inform them of the possibility of research being conducted in their isigodi. Research team members telephonically contacted indunas to request permission to conduct research in their isigodis on specific dates. All induna requested a project member, usually a field coordinator who was fluent in English and isiZulu, to speak at an upcoming community meeting and answer any questions community members had. On occasion, the induna requested the presence of the entire field team. Most of the community buy-in took place during community meetings within the designated isigodi, though community guides also distributed informational flyers in the days prior to interviewers' assessment of eligibility.

3.2 Power calculation

Power calculations estimate a minimum number of participants required to reject a null hypothesis (H_0) correctly. Quantitative studies with too few participants lack adequate power and are unable to find statistically significant differences between a null and experimental hypothesis (H_1). Studies with adequate sample sizes are less likely to fail to reject a H_0 correctly, known as a Type II Er-

ror. This study required a minimum of *n* = 216 child/parent pairs to avoid a Type II Error. The process by which this number was calculated is described in this section.

The main comparison in this study was the difference in responsibility time burdens between children with ill and healthy parents. The null and experimental hypotheses are summarised below:

- H_0: Parental illness has no impact on the amount of time children spend on their responsibilities.
- H_1: Children with ill parents spend significantly more time on their responsibilities than children with healthy parents.

To date no study in sub-Saharan Africa has made comparisons in this regard (see *Chapter 2*); fortunately, a separate study administered the exploratory study questionnaire to children with healthy parents (*n* = 275) (Cluver, Operario, Lane, & Kganakga, 2012). Data were collected from children in the Cape Flats region of Cape Town, where most of the data in the exploratory study had been collected. Responsibility time burden sums were derived from each group's responses to the *My day* section of the exploratory study questionnaire (see *Chapter 3*, *Section 2.4.2*). Children with ill parents reported a mean of 143.36 (SD = 143.37) minutes per day on responsibilities. Children with healthy parents reported a mean of 91.29 minutes per day on responsibilities (SD = 85.08).

The resulting averages and standard deviations were analysed using the G*Power 3 statistical analysis programme (Faul, Erdfelder, Lang, & Buchner, 2007) to calculate the minimum sample size necessary for multiple regression analysis. Additional figures were required to calculate the minimum sample size, including α (.01), β (.99), effect size (*r* = .22), and number of predictors (14). α

and β were set conservatively to account for a large number of regression analyses that were to be conducted. Effect size was calculated using the means and standard deviations of each group's responsibility time burdens and an effect size calculator on the website http://www.uccs.edu/~faculty/lbecker/. The number of predictors was calculated by adding the number of potentially moderating socio-demographic factors identified in the literature review (10) plus the number of parental illness indicators (four; general health and functioning, HIV/AIDS-illness, other chronic illness, and mental health). Parental illness indicators are described in greater detail in the next section.

4 Cross-sectional survey design

Research materials consisted of a child and a parent questionnaire, both of which are presented in the appendix. Questionnaires used in this study were designed to capture data for multiple analyses beyond the scope of this thesis, though this section describes only those relevant to its research questions.

4.1 Parental illness

The parent questionnaire contained several measures of physical and mental health. The 12-Item Short Form Health Survey (Ware, Kosinski, & Keller, 1996) was used to assess parent general health and functioning. The 12-item measure is a shortened version of the longer 36-item Short Form Health Survey, which had previously been validated in South African populations (Kuo, 2010; Ncama et al., 2008), and exhibits a high degree reliability on the Physical and Mental Component Scores (α = 0.83 and α = 0.95), which were highly correlated to scores on the 36-item measure (r = 0.951 and r = 0.969) (Ware et al., 1996). Given the equal utility of either measure, the shorter version of the Short Form

Health Survey was preferred due to the large amount of material in the parent questionnaire and the possibility of respondent fatigue

Parental HIV/AIDS-illness was assessed via a verbal autopsy described in Lopman et al. (2006), which had been developed in Zimbabwe to identify AIDS-related death in communities with greater than 20% HIV-prevalence. The verbal autopsy exhibited a sensitivity of 83% and specificity of 75% in identifying AIDS-related death. To meet the specific needs of the quantitative survey described in this chapter, implementation and analysis of the verbal autopsy was adapted in consultation with the authors. Additionally, the purpose of the verbal autopsy in this thesis was to identify HIV/AIDS-illness rather than HIV/AIDS-related death. Parents were categorised based on the number of symptoms reported; three or more symptoms were categorised as 'HIV/AIDS-ill' and no symptoms as 'non-HIV/AIDS-ill.' Parents reporting one or two symptoms were assessed via discriminatory factor analysis, which exhibited 87% accuracy in identifying HIV/AIDS-illness. Other indicators of HIV/AIDS-illness included a CD4 count of ≤ 200 cells/mm^3, child or parental reports that the parent was taking ART, and explicit disclosure. Use of the verbal autopsy had two major advantages over relying on participants voluntarily disclosing their status. First, it allowed for identification of HIV/AIDS-illness without stigmatising participants. Second, some patients would have been unaware of their HIV-status and would thus have been unable to disclose it. Parents were also asked about additional illnesses, which included tuberculosis, cancer, diabetes, epilepsy, asthma, hypertension, arthritis, and any other type of disability. These illnesses were derived from the Health

Systems Trust Annual Review (DOH & Medical Research Council, 2007) and the Demographic and Health Survey (Ijumba & Padarath, 2006).

Mental health was assessed using standardised measures of anxiety and depression. Parental anxiety was assessed using the Beck Anxiety Inventory (Beck, Epstein, Brown, & Steer, 1988), a 21-item scale that exhibits high degree of reliability (α = 0.94) (Fydrich, Dowdall, & Chambless, 1992) that has been used in South African populations (A. L. Pillay, 2001; A. L. Pillay, Edwards, Sargent, & Dhlomo, 2001; A. L. Pillay & Sargent, 1999; A. L. Pillay & Schoubben Hesk, 2001; Steele, 2003). The Center for Epidemiological Studies Depression Scale (Radloff, 1977) was used to determine parental depression. The 20-item scale has been assessed for cultural validity in South African populations (Smit, Van den Berg, Bekker, Seedat, & Stein, 2006) where it exhibits a high degree of reliability (α = 0.88-0.91) (Hamad, Fernald, Karlan, & Zinman, 2008; Stetz & Brown, 2004).

4.2 Socio-demographic variables

Child and parent age, gender, gender-matching, and level of education were assessed using demographic questions from the South African Census (Statistics South Africa, 2001a). Child/parent relationships were divided into three categories: biological, grandparent, and foster. Categorisations were based on qualitative evidence in the literature review suggesting that grandparents often require care due to age and frailty while foster parents sometimes agree to adopt a child in direct exchange for their labours. It was suspected that differences in parenting relationships would manifest as differences in parenting quality. In preliminary analyses, the parent types were compared on parenting quality using chil-

dren's responses to the Alabama Parenting Questionnaire (Elgar, Waschbusch, Dadds, & Sigvaldason, 2007).

The ratio of adults to children was used to determine adult presence. The adult:child ratio was used rather than the dependency ratio, which includes adults ≥ 65 years as dependents. In this study, though adults ≥ 65 years were assumed to require care on a not infrequent basis, they were considered to be active participants in childcare and household maintenance due to health and demographic circumstances limiting the number of able-bodied, younger adults. Child/parent pairs were categorised as urban or rural based on the site in which they had been recruited. Poverty was assessed using three measures. The first consisted of two items from South African Food Consumption Survey (Labradios, 2000). The second consisted of the top eight socially perceived necessities for children from the Indicators of Poverty and Social Exclusion (Wright, 2008), each item having been endorsed by over 80% of respondents in the nationally representative South African Social Attitudes Survey (U. Pillay, Roberts, & Rule, 2006). Both of these measures were administered to children. The third measure was the Economic Asset Index (Filmer & Pritchett, 1998, 2001), which has been adapted to the South African context with factor and principal component analysis of Demographic and Health Survey data on ownership and access (Booysen, 2001; cited in Kuo, 2010). Social support was assessed using parent responses to the Medical Outcomes Study (MOS) Social Support Survey (Sherbourne & Stewart, 1991), which had been used in South Africa prior to this study (Brandt, 2007; cited in Breuer, Myer, Struthers, & Joska, 2011; Swartz et al., 2005). Access to healthcare was measured by children's estimates of travel time to their local

clinic, a known indicator of healthcare utilisation in KwaZulu-Natal province (Tanser et al., 2006). Both children and parents were asked whether a home community-based carer had visited their household in the previous month; houses were categorised as 'visited' if either child or parent answered yes to this question.

4.3 Outcomes – The Child Responsibility Measure

All outcomes in the quantitative survey were assessed with a tool created using data from the literature review and the exploratory study. This measure, a 23-item survey called the Child Responsibility Measure (*Table 4.1*), captured information on whether a child engaged in a specific responsibility, how many times in the previous week he or she had engaged in it, and how long it took each day. Similar responsibilities were collapsed into one item, such as 'collect firewood/make fires.' The various income-generating activities were summarised in one variable that included a qualitative section where children could indicate the exact nature of their work: 'doing jobs for money (what kind…?).' This reduced the number of items in the measure, which can sometimes be too long for child participants (Joseph et al., 2009) while allowing for a broad range of responses.

Additionally, farm work, whether subsistence or commercial, was included despite being very uncommon in the exploratory study. It was suspected that farm work was anomalously rare in the Western Cape province compared to the rest of sub-Saharan Africa given the numerous mentions in literature review articles, and was suspected to be more common in KwaZulu-Natal.

Regrettably, the variable 'feed/help an adult to eat' was unintentionally excluded from the Child Responsibility Measure, an error only discovered well after all da-

ta had been collected and analysed (December 2012). 'Feed/help an adult to eat' was one of the most frequently identified intimate care responsibilities in the literature review (*Chapter 2*, *Section 3.3.1*, *Table 2.5*), and the most prevalent in the exploratory study (*Chapter 3*, *Section 3.2*, *Table 3.2*). Its unfortunate exclusion from the measure was not for any scientific or logistical reason; it was an oversight of its creator, the author of this thesis, who recommends that any future use of this measure include the 'feed/help an adult to eat' variable.

Table 4.1
Child Responsibility Measure

Responsibility	How many days in the week?	How long does this take you?
1) Wash other people's clothes		
2) Clean your home, yard, or other parts of the house		
3) Work in food garden or tend animals		
4) Fetch water		
5) Collect firewood/make fires		
6) Do the grocery shopping		
7) Cook for other people		
8) Wash the dishes		
9) Do jobs for money (what kind?.....)		
10) Walk your siblings/other children to school/crèche		
11) Wash your siblings/other children		
12) Feed your siblings/other children		
13) Collect medicine from the clinic for a sick person		
14) Remind a sick person to take their medicine		
15) Give a sick person their medicine/treatment (what kind?.....)		
16) Take a sick person to the clinic		
17) Help a sick person to get dressed		
18) Massage a sick person/rub body		
19) Stay with sick person		
20) Wash or bathe a sick person (feet, face, or other parts)		
21) Help a sick person get around the house		
22) Help a sick person to use the toilet		
23) Clean up after person has been sick (vomit, diarrhoea or other bodily fluids)		

4.4 Translation

Similar to the translation strategy that was used in the exploratory study, all questionnaire materials were translated into isiZulu via a four-step process reiterated here:

1) A native isiZulu-speaker who was fluent in English translated information in the questionnaires, information sheet, and consent forms from English to isiZulu.
2) Research staff interviewers who were not involved in the original translation back-translated items from isiZulu to English.
3) Back-translation was compared to the original English-language questionnaire to determine whether content and meaning had been preserved.
4) The project managers, one of whom is the author of this thesis, research team interviewers, and field coordinators discussed inconsistencies between the original and back-translation. The goal of these discussions was to ensure the quality of the translation and all research team members shared a consistent understanding of the meanings of the questionnaires' items. The final step repeated itself until project managers, interviewers, and field coordinators agreed on the meanings of items and the translated counterparts.

5 Research staff

Two project managers, one of whom is the author of this thesis, supervised research staff in the two field sites and the Durban office. This section describes the project's research staff.

5.1 Field staff

Field staff consisted of field coordinators (2), interviewers (15), security escorts (4; urban site only), and community guides (5; rural site only). Field coordinators identified designated sub-districts, supervised interviewers in the field, and assessed hardcopy questionnaires for quality. Interviewers were responsible for approaching designated homes, assessing for eligibility, and conducting interviews, in addition to responding to ethical issues in the field, including reporting suspected cases of abuse to field coordinators and project managers. Interviewers were required to be fluent in both isiZulu and English.

Urban field staff applicants were recruited through the University of KwaZulu-Natal and shortlisted based on the strength of their CVs for an in-office interview.

Successful applicants were selected based on responses during in-office interviews and previous work with University of Oxford projects (Kuo, 2010).

In the urban site, field coordinators and interviewers were trained in an office in the Health, Economics, and HIV/AIDS Research Division of the University of KwaZulu-Natal. Training focused on introducing the project, determining eligibility, administering the questionnaire, and ethical considerations including obtaining informed and voluntary consent and managing referrals. All field team members were provided with a *Fieldwork Pack* for reference, which is included in the appendix along with an example of the training schedule.

Training in the rural site was conducted in a building of research partner Tholulwazi Uzivikele, who also recruited applicants. The training process was similar to that in the urban site with some variations. Given the lack of exposure to research in the rural site, applicants were initially screened based on their CV for literacy and English language skills rather than research experience (of which there was none), from which a group of 30 trainees were selected. Based on the recommendations of research partner Tholulwazi Uzivikele, all 30 shortlisted applicants were given training in the same categories described above and then observed practicing the questionnaire with each other. Applicants were then assessed on retention of knowledge, ability, and personality. All potential interviewers who attended the training received a certificate, an example of which is presented in the appendix. Ten applicants were then selected for more intensive training to become interviewers (one left after completing her training to take a job at a newly opened KFC). In addition to staff recruited in the rural site, six in-

terviewers and one field coordinator relocated to Umhlabuyalingana to continue working with the project and assisted with the practice portions of training.



Image 3.1: **Interviewer Siyabonga Msomi, wearing a project shirt and identification badge, administers a *Teen Talk* questionnaire to a young girl in the urban research field site (Lamontville)**

Security escorts and community guides served similar functions to one another, though there were fundamental differences in their roles based on the requirements of each field site. In the urban area, high levels of violent crime created safety concerns for all staff in the field. The presence of security escorts deterred crime by projecting community legitimacy on the project and implying consequences for anyone causing problems for team members. In the rural site, community guides also provided community legitimacy, where community members often distrusted the motives of field staff, and led field staff through the difficult

and vast terrain, where it was easy to become disoriented and lost. Both of these concerns are discussed in more detail in *Section 8* of this chapter. Security escorts were referred to the project through the Ward Councillors of Wards 74 and 75. Community guides were former home community-based carers selected from among interviewer applicants who had received training but did not meet the specific criteria.

5.2 Data team

The data team consisted of four data enterers and one data manager who were based in an office at the Health, Economics, and HIV/AIDS Research Division of the University of KwaZulu-Natal in Durban. The primary role of the data team was to convert hardcopy data into an electronic SPSS database, but included other responsibilities such as telephonically confirming or supplementing incomplete information from questionnaires with interviewed participants. Telephonic confirmation and supplementation were only done when the required information was not considered sensitive. The data manager was responsible for merging databases into a main file, quality controlling data entries, and ensuring the secure storage of hardcopy data. Data team members were recruited through the University of KwaZulu-Natal. Applicant CVs were shortlisted for interviews based on previous experience working with databases. During interviews, applicants were asked to transfer hardcopy data to an electronic database and compare another entry with hardcopy data to detect and correct any errors. Data team members were trained on inputting and merging data with the assistance of an expert in statistical analyses from the University of KwaZulu-Natal.

In the rural site, a supplemental team of four office workers assisted with the quality control process, described in the next section. Office staff members were also responsible for inventorying questionnaire materials and creating interview packs for field staff. Office staff members were recruited from among the trained applicants who had not been selected as interviewers in the rural site.

6 Data collection

Children and parents completed self-report questionnaires with the assistance of interviewers; participants were given the option to complete questionnaires on their own. Given low participant literacy rates, particularly in the rural field site, interviewers often read the entire questionnaire to participants. Interviews were conducted mostly in isiZulu, with qualitative responses recorded in English based on interviewer translations.

6.1 Quality control and data management

All completed questionnaires were quality controlled at three levels. At the first level, interviewers checked completed questionnaires before leaving participants' homes to address any readily apparent errors in addition to a final check of all completed questionnaires at the end of each workday. Questionnaire pairs without identified errors were submitted to field coordinators. At first, field coordinators evaluated every questionnaire for quality, transitioning to spot-checking a portion of questionnaires as quality and output increased.

The second level of quality control differed slightly between the urban and rural sites. In the urban site project managers checked all submitted questionnaires; in the rural site, office staff checked all submitted questionnaires and project man-

agers only a fraction. Every questionnaire was assessed by two members of the office staff; if either identified an error in the questionnaire it was returned to the interviewer for correction. In these cases, the interviewer was responsible for returning to the interviewed participant for clarification, correction, and completion, and resubmitting the questionnaire. Questionnaires that passed this stage of quality control were sent to the Durban office for data entry.

The third level of quality control occurred during data entry. This was often the most thorough level of quality control, as successful entry into the database required close attention to the questionnaire. Data enterers could return questionnaires to the field for correction, but as discussed in *Section 5.*2 of this chapter, more often they telephonically contacted participants to address errors.

6.2 Data entry and storage

Enterers captured hardcopy data from submitted paper questionnaires into the database on a new, blank SPSS database each day. At the end of each day, the data manager merged the separate databases into two databases for child and parent responses. Once data had been entered, questionnaires were kept in a locked storage room with a rigid protocol and documentation process for access. At the end of data entry, the data manager merged child and parent databases into one comprehensive database. All data entry took place between October 2009 and December 2010.

7 Analysis

Quantitative survey data were analysed in SPSS versions 18-20 in four steps: cleaning, descriptives, bivariate associations, and multiple regressions. All four steps were performed using syntax. This section describes each step in kind.

7.1 Data cleaning

Cleaning of survey data, which was conducted in consultation with an expert in statistical analysis from the University of KwaZulu-Natal, consisted of creating new variables reflecting the scores on standardised measures and correcting outliers, errors, and missing values that would skew the results of analysis. Scores from standardised measures were achieved either through recommended scoring techniques, as with the 12-Item Short Form Health Survey, or based on interpretations from previous research. Each scoring rationale and technique is described alongside the descriptive statistics of each measure in the next chapter. Every change was made using syntax, or barring that, a note in the syntax file, to preserve the integrity of the database, leaving an electronic record of any changes.

Typographical and input errors were corrected if the intended entry was apparent (e.g., invalid entry of '11' where valid entries are between 1-4, recoded to '1' in syntax). Missing values in categorical or continuous data fields were corrected with two types of mean imputation, guided by Schlomer, Bauman, and Card (2010). Sample mean imputation, which involved replacing missing values with the entire sample's mean response, was used with 'stand alone' data (i.e., data that were not part of a larger measure). An example of this type question would be the number of asthma attacks a person had in the previous month; if the respondent indicated the presence of asthma but the entry for number of attacks was missing, the missing value would be recoded to the mean number of attacks reported by every other participant who indicated having asthma. The second was entry mean imputation, which used the participant's mean score on a scale to replace missing values, provided the scale contained at least 50% valid en-

tries. Though the methods used to replace missing values in data cleaning can result in biased variance and co-variance estimates (Carter, 2006; Schlomer et al., 2010) the risk was minimised by the low proportion of missing values (< 1%).

7.2 Descriptive statistics

Categorical predictor variables including parent type are described using frequencies and *n*, and continuous predictor variables with means and standard deviations. Standardised measures are presented with α-coefficients to assess the internal reliability of scales, using the following indicators described in D. George and Mallery (2003): '_ > .9 – Excellent, _ > .8 – Good, _ > .7 – Acceptable, _ > .6 – Questionable, _ > .5 – Poor, _ < .5 – Unacceptable,' (p. 231). All continuous predictor variables were assessed for skewness and Kurtosis (peakedness).

Data on skewness and Kurtosis were presented only for abnormally distributed continuous predictor variables. Acceptable ranges are +/- 1.90 for skewness and +/- 3 for Kurtosis. Those falling outside the acceptable range for either skewness (positive only) or Kurtosis were transformed using either a logarithmic or square root transformation; negatively skewed variables were reversed before transformation. All transformations required values above 0; sufficient values were added to continuous variables that ranged at or below zero before transformation. For example, if 0 were the lowest value +1 was added to all values within the variable; if -6 were the lowest value +7 was added to all values within the variable and so on. In other cases, the variables were dichotomised if there was a good theoretical rationale or existing research guiding such binary categorisation. Descriptive statistics are presented in *Chapter 5*, *Sections 2* and *3*.

7.3 Bivariate associations

Bivariate analyses were conducted to determine what predictor variables would be included in multiple regression models in conjunction with evidence from the literature review and theoretical considerations. Predictors were parental illness and socio-demographic variables, and outcomes were child responsibility variables. Additional bivariate analyses were conducted to reduce the risk of multicollinearity in regression analyses where there were multiple indicators of the same factor (e.g., poverty) or if there were theoretical reasons to assume a relationship between the factors (e.g., poverty and living in a rural area). Multicollinearity and its associated problems are discussed in the next section.

Group differences (two groups) were assessed with a *t*-test for continuous outcomes or Pearson's Chi-square for dichotomous variables. Continuous predictors with either continuous or dichotomous outcomes were analysed using a Pearson's *r*. ANOVAs were used to determine differences where there were three or more comparison. Though generally used for continuous variables, Lunney (1970) considers ANOVA to appropriate for dichotomous outcomes provided there are at least 20 degrees of freedom if the smallest response category is at least .2, or at least 40 degrees of freedom if the smallest category response is below .2. Though there were a large number of bivariate analyses, cut-off for significance was set at $p \leq .05$ as the associations were primarily used to determine inclusion in multiple regression analyses rather than to draw conclusions regarding the relationship between parental illness, socio-demographic variables, and child responsibilities. However, some of the findings in bivariate association analyses are used to contextualise the findings of regression analyses. Results of bivariate analyses are presented in *Chapter 5*, *Section 4*.

7.4 Multiple regression analyses

Multiple regression analyses were conducted to answer the following research questions:

Predictors of children caring for their parents

- Does parental illness predict children's engagement in intimate or medical care?
- What other factors predict children's engagement in intimate or medical care?

Predictors of children's responsibility workload

- Does parental illness predict greater responsibility workloads in children?
- What other factors predict greater responsibility workloads in children?

There were two stages of multiple regression analysis: preliminary examination of individual parental illnesses and stepwise regression analyses. Preliminary regression analyses were conducted to determine the predictive nature of four types of parental illness separately (poor physical health, HIV/AIDS, chronic illness, and depression or anxiety) on child responsibility outcomes to avoid multicollinearity, or when two predictor variables have a high degree of interdependence or strong linear relationship. As the predictor variables within a regression model control for one another, multicollinearity presents a problem 'both to the proper specification and the effective estimate of the type of structural relationship commonly sought through the use of regression techniques,' (Farrar & Glauber, 1967, p. 93). In other words, including two closely associated variables in a regression model reduces the ability of the analysis to identify what would otherwise be significant associations.

The second stage of multiple regression analyses consisted of stepwise regressions that included all relevant parental illness indicators and socio-demographic factors. Socio-demographic variables were grouped together based on the hypothesised socio-economic model (*Figure 4.3*). For each child responsibility outcome, predictor variable groups were introduced in successive models with forward-entry blocks. As the research questions pertained to impact of parental illness on child responsibility and the moderating impact of socio-demographic variables, each regression model included at least one parental illness variable, which was always in the first block. This also allowed for assessment of the moderating impact of socio-demographic variables with the introduction of each successive block. Subsequent blocks were parent type, followed by household/community factors, and child demographics.

Linear regressions were used to assess predictor variables impact on children's total responsibility time, a continuous outcome variable. Logistic regressions were used with dichotomous child responsibility outcomes (engagement in intimate care, medical care, childcare, and income-generating activities) and reported as odds ratios (OR) with confidence intervals. Given the large number of regression analyses conducted in this thesis, significance is assessed at a conservative $p \leq .01$ with 99% confidence intervals (CI) given for odds ratios. Predictor variables for total responsibility time, a continuous variable, were reported as standardised coefficients to allow for the comparison of the relative strengths of different predictors (i.e., between dichotomous and continuous predictors).

Logistic regressions were used for dichotomous outcomes because the resulting coefficients from linear regressions, while showing direction and relative magni-

tude of an effect, are not interpretable for several reasons. First, dichotomous dependent variables have minimum and maximum values of 0 and 1. Predicted values in a linear regression extend in either direction indefinitely, and unless the slope of the line is 0, it will produce values that are both less than 0 and greater than 1. Such values provide limited insight into the probability of an outcome. Second, linear regressions rely on assumptions of normality and homoscedasticity, or equal statistical variance from the regression line, of data; given only two possible values, dichotomous data can be neither. While violation of the former assumption is not so problematic with large sample sizes, in the latter it results in greatly overestimated standard errors of a model, rendering significance tests invalid (Pampel, 2000).

Odds ratios are used instead of risk ratios to express the impact of predictor variables upon dichotomous outcomes as they are considered the best estimate of relative risk in logistic regressions (Deeks, 1998). Unlike risk ratios, odds ratios can be used to express the regression coefficient in multiple regression analysis of dichotomous outcomes (Altman & Deeks, 1998; Bland & Altman, 2000; Glas, Lijmer, Prins, Bonsel, & Bossuyt, 2003). However, odds ratios must be interpreted with caution; whereas risk ratios are more intuitive (e.g., a relative risk of 2 indicates that the presence of a predictor increases the risk of an outcome occurring by a factor of 2), odds ratios greatly exaggerate risk in either direction, particularly if instances of the outcome are relatively common in the sample (> 10%) (Altman & Deeks, 1998; Deeks, 1998; Sedgwick & Marston, 2011; Zhang & Yu, 1998). Additionally, there is some debate around whether the appropriate expression of the magnitude of significant effects is ‘odds’ or ‘likelihood’

(Barendregt, 2010; Sedgwick & Marston, 2010, 2011). In this thesis, magnitude of significant effects in logistic regressions is described in terms of 'odds' to avoid conflating odds ratios and relative risk and thus overstating observed effects.

Predictor variables were selected for bivariate associations with individual outcomes and the theoretical associations outlined in the literature review (*Chapter 2*). Parent type, a categorical variable with three possible values, was separated into three dummy variables: biological parent, grandparent, and foster parent. Biological parent served as the constant in regressions.



Figure 4.3: **Hypothesised Conceptual Framework of Interaction Between Parental Illness, Socio-Demographic Factors, and Child Responsibility**

8 Research challenges and constraints

Challenges in the urban area consisted primarily of threats of violent crime and inclement weather in the form of extreme rain and heat. Project managers, in consultation with local police, the Ward Councillor, and staff members familiar with the dangers of fieldwork in townships, devised strategies to minimise the risk of crime. Discussions resulted in the conclusion that community acceptance was most crucial to security in the field. Prior to launch two security escorts whom the Ward Councillor referred to the project were hired to accompany field staff between households. Other measures adopted to ensure security included: female staff always traveling in pairs or with a male staff member or security escort; never displaying highly desirable objects like jewellery, money, or mobile phones; making sure a field coordinator, project manager, or security escort knew staff whereabouts at all times; and parking vehicles at the home of someone known to a security escort.



Image 4.2: **Security Escort Nana Tau in an informal settlement of the urban field site (Lamontville)**

Extreme weather cost the study valuable fieldwork time; almost no fieldwork was conducted in November 2009 due to heavy rains. Durban's hilly terrain and lack of shade made extreme heat, often exceeding 40˚C, a challenge to interviewers and field coordinators, who walked from household to household. Project managers provided coolers and water bottles to help field staff cope with the heat. Regardless, fieldwork on extremely hot days was often shortened.

In addition to security and weather issues in the urban site, there were challenges with regards to the rapidly changing geography of Lamontville, where entire Enumerator Areas had been demolished and rebuilt within the span of fieldwork. Though some government-issued homes had been built before urban fieldwork finished, these homes were not approached for interviews as this would have

negated randomisation and introduced bias (e.g., interviewing families with newly received homes).

The rural field site presented different challenges, many of which are detailed in a published account of this portion of data collection (Casale, Lane, Sello, Kuo, & Cluver, 2013). Unlike the urban site, crime was not a major issue in Umhlabuyalingana, though there were still implicit threats of violence to the field team. Local staff and research partner Tholulwazi Uzivikele informed project managers that no research had been ever conducted in the area. As a result, community members were unfamiliar with the purposes of research, often confusing it for either a government programmes to provide immediate assistance and money or a plot against the community. Accusations against the project's intentions included Satanism, stealing children to sell to China, or tricking community members into signing away their property (in the consent forms). In several cases, God was invoked to scare away field team members, and in one frightening instance, an interviewer and field coordinator were compelled to pray to prove they were not Satanists while a man stood by with a panga knife, or machete, to supervise. He later told the interviewer that if either she or the field coordinator were male, he would have attacked them. The accusations also led to the less dangerous but more frequent problem of refusal. To counteract this problem, research materials were altered to highlight the project's working relationship with Tholulwazi Uzivikele, which was respected throughout the community. Further, community guides, who also had worked in many of the communities as home community-based carers for Tholulwazi Uzivikele, were given more training to introduce the project prior to the arrival of interviewers, and began dis-

tributing isiZulu-language flyers that had been designed to address community members' concerns and included the phone number of an isiZulu-speaking staff member.

Also unlike the urban site, there were substantial political and geographic obstacles to fieldwork. As noted in *Section 3.1* of this chapter, political buy-in was a multi-stage process, where one delay could deny the project access to a designated site. On several occasions, community members refused to cooperate because their induna or chief had either not yet given permission or news of the permission had not adequately communicated to the community. In two other cases, indunas were unreachable due to poor cell phone reception, while another conducted his oversight of the community from a distance, living in the closest urban centre of Empangeni; the latter was prevented from holding a meeting to inform the community that he had granted the project permission. In one case, a succession crisis had resulted in uncertainty over who was the true induna and factionalism among the various candidates' supporters. Approval from one candidate would have put the team at odds with supporters of the other candidate. The isigodi in question was avoided to prevent conflicts between the project and community members.

As noted in *Section 3* of this chapter, Enumerator Areas were impractical to use as sub-districts, or the unit of stratification, in the rural site due to out-dated aerial maps and few landmarks to identify and distinguish between specific sites, problems also noted in Budlender et al. (2001) and Mathee et al. (2010). While sub-districts in the urban site were entirely geospatial, those in the rural site

were geo-cultural, more often defined by tribal identity than physical boundaries. Project staff relied on local knowledge for isigodi boundaries.

Another major problem of the rural site's geography was the lack of visibility due to high-growing vegetation, noted in another study that collected data in rural KwaZulu-Natal (Steinberg et al., 2002). During rural fieldwork rollout, the field team frequently became lost in unfamiliar locations. As a result of these factors, sites were later selected based on accessibility and visibility, though project managers, working with local partners, used local knowledge and maps to target areas of varying socio-economic and geographic range.



Image 4.3: **Interviewer Xolani Zungu scales a tree to see over vegetation to locate households in the rural field site (Umhlabuyalingana)**

9 Methodological strengths and limitations

The major limitation of the quantitative survey was the variation in stratification and allocation between the urban and rural sites. Attempts were made to increase the representivity of the rural sample and mimic the positive aspects of

randomisation through socioeconomic and geographic variation of isigodis, though it is possible that some unknown difference between the sites biased the samples. Another limitation was the use of self-report surveys, which for a variety of reasons including stigma, lack of knowledge, or self-reflection bias, may not accurately capture the health, responsibility, and demographic aspects of participants' lives. However, these were the only methods for which the study could have collected relevant data within the setting.

The study also had substantial strengths, including the large sample size (n = 4,952 participants, n = 2,476 pairs), use of standardised measures that are valid and reliable in the South African context, and collection of data in two diverse settings. To the author's knowledge, this is the largest study exploring the relationship between parental illness and child responsibility, the only site quantitatively comparing differences in responsibilities between children affected and unaffected by parental illness, and the largest paired child/parent study conducted in sub-Saharan Africa. As such, data from the survey are an important contribution to knowledge on this topic in the subcontinent generally and South Africa specifically.

10 Chapter Summary

This chapter presents the methodology of a cross-sectional quantitative survey used to collect data from a large and representative sample of children and parents in an urban and rural setting of KwaZulu-Natal province. Included in this chapter was a description of ethical issues inherent in working with vulnerable

populations, questionnaire design, data collection, analysis strategy, and the challenges faced in the field.

Results of the survey are presented in the next two chapters, starting with descriptive results and bivariate associations in *Chapter 5* and multiple regression analyses in *Chapter 6.*

Chapter 5: Descriptives and bivariate associations

This chapter provides descriptive statistics of predictor and outcome variables and the results of bivariate analyses. Bivariate analyses examined the relationship between predictor and outcome variables in addition to associations between related predictor variables. The chapter begins with a description of the aims in *Section 1*. Descriptive statistics of participant demographics are presented in *Section 2*, standardised predictors including children's responsibilities in *Section 3*, and bivariate associations in *Section 4*. The chapter is summarised in *Section 5*.

1 Chapter aims

The aim of this chapter is to present descriptive statistics on participants' socio-demographic and health variables and bivariate associations between predictor and outcome variables. Bivariate analyses served two purposes. The first purpose was to identify statistically relevant variables for inclusion in multiple regression analyses presented in the next chapter. The second was to contextualise the results of regression analyses. While regression analyses can identify the drivers of an outcome, bivariate association analysis can identify overarching demographic characteristics that entail greater responsibilities in children. For instance, where bivariate analyses may find that significantly greater numbers of children from the rural site engaged in intimate care, regression analyses may find that when controlling for the myriad socio-demographic factors location is no longer significant, and that the driver is distance from local clinic. Both factors

would be important for interventions seeking to reduce children's involvement in intimate care, but while regression analyses may identify the driving factor (i.e., distance from the clinic), bivariate associations can identify specific groups who are most at risk, which in this case would be children from a rural site.

2 Participant demographics

In total, *n* = 4,952 participants (2,476 pairs) were included for analysis in the quantitative study. Seven interviewed pairs were removed prior to analysis due to ineligibility or ethical considerations. These factors included five incomplete child interviews, one pair where the interviewed 'parent' was a paid domestic worker, and one pair where the child interviewed was 18 at the time of recruitment. Of the five incomplete questionnaires, two were stopped because the child refused to continue, another two where the child stopped for an unspecified reason, and one where the child interview was not conducted.

Nearly all participants were black African (99.9%; *n* = 2,473); the remainder were ethnically coloured/mixed race (0.1%; *n* = 3). A vast majority spoke isiZulu at home (95.9%; *n* = 2,374). Other languages included isiXhosa (2.6%; *n* = 64), Xitsonga (0.6%; *n* = 16), Sesotho (0.5%; *n* = 12), Siswati (0.1%; *n* = 3), English (0.1%; *n* = 3), Sishangani (0.1%; *n* = 3) and Sepedi (< 0.1%; *n* = 1).

2.1 Parents

At the time of recruitment, parents' mean age was 44.23 years old (SD = 13.87) with a range of 18 (*n* = 9) to 92 (*n* = 1) years old. The vast majority of interviewed parents were female (88.7%; *n* = 2,197).

2.2 Children

All children were between the ages of 10 and 17 at the time of recruitment as per eligibility requirements with a mean age of 13.57 years (SD = 2.23). The children were nearly evenly divided by gender, with just over half girls (53.9%; *n* = 1,334).

Children were dichotomised between those aged 10-14 and 15-17 based on suggestions in existing literature about 15-17 being the 'prime age for caring' (Robson, 2000, p. 66) and previous analyses of child labour using this dichotomisation (Bray, 2003; Budlender et al., 2001; Rama & Richter, 2007). The majority of children were in the 10-14 age bracket (62.5%; *n* = 1,548).

Nearly one-third of children were orphaned (32.0%; *n* = 793). Sixty-six (2.7%) had lost both parents. The majority of children who had lost only one parent (*n* = 727) had lost their father (59.7%; *n* = 434).

2.2.1 Education

Children's mean grade (including the last year of education for those not attending school) was seventh grade (6.87; SD = 2.43). Among children in this sample, nearly fifteen per cent had completed ninth grade (14.9%; *n* = 370). Nearly all children in the sample were attending school (97.8%; *n* = 2,420). Sixteen of the 55 children who were not attending school (29.1%) had completed primary education; six (10.9%) had completed twelfth grade. Nine children (16.4% of those not attending) had never attended school.

Children 16 years and older were dichotomised based on whether they had completed primary school. Of the *n* = 614 children 16 years or older, 51% (*n* =

313) had completed primary school education. While families are hesitant to remove children from school to take on responsibilities, Robson (2000, 2004) suggests children who have completed primary school are more likely to sacrifice schooling for responsibility than those who have yet to reach this milestone. The rationale is that the educational milestone indicates a level of attainment, giving the child better future prospects and securing the parent's own future. Given a normal educational trajectory (i.e., starting school at the appropriate age and progressing year-by-year) children are expected to finish primary school by the time they are 16 years of age (see *Chapter 2*, *Section 3.3.3* for a more detailed discussion).

2.3 Parent type

Biological mothers and fathers accounted for the majority of participant parents, comprising 63.8% (*n* = 1,574) of all parents. The majority of biological parents were mothers, making up 91.6% of biological parents and 58.2% of all parents (*n* = 1,441). Grandparents accounted for 19.5% (*n* = 485) of the sample, the vast majority of whom were grandmothers (96.5%; *n* = 468). Nineteen parents (0.9%) were classified as 'other,' and included cousins (*n* = 8), neighbours or family friends (*n* = 6), in-laws (*n* = 4), and social worker/care worker (*n* = 1). Parent types are summarised in *Figure 5.1*.

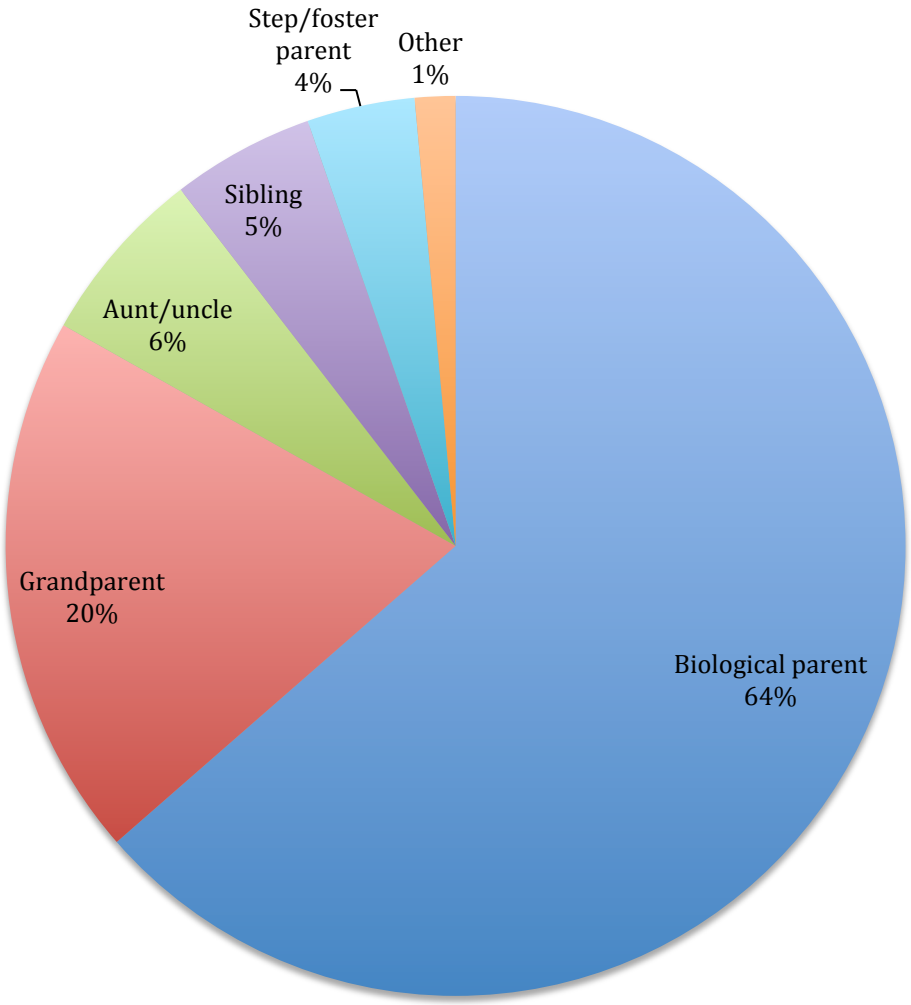


Figure 5.1: **Parent types**

Children were asked whom they identified as their primary caregiver. In 92.1% (*n* = 2,279) of the pairs, the child-identified primary caregiver was the same as interviewed parent. Of the 7.9% (*n* = 189) pairs where the child-identified primary caregiver was not interviewed, 44.4% (*n* = 84) of the interviewed guardians were grandmothers, 20.6% (*n* = 39) biological mothers, 19.0% (*n* = 36) biological fathers, 11.1% (*n* = 21) sisters, 4.2% (*n* = 8) brothers, and 0.5% (*n* = 1) uncles.

For the purposes of analyses, parent types were placed into three categories and transformed into dummy variables: biological parents, grandparents, and all others or foster parents. Parental categorisations were based on existing evidence covered in the literature review. First, children being cared for by grandparents can indicate a disruption of the 'generational bargain' according to Van Blerk and Ansell (2007), resulting in children, rather than their adult parents, providing care for elderly grandparents. Second, qualitative evidence suggests that foster carers (i.e., non-biological parents or grandparents) sometimes exploit fostered children for their labours, expecting them to contribute to household maintenance to a greater degree than non-fostered children (Abebe & Skovdal, 2010; Evans, 2010c; Harms et al., 2010; Korevaar, 2009; Ruiz-Casares, 2009; Skovdal, 2009b; Van Blerk & Ansell, 2007). This is described in greater detail in *Chapter 2*, *Section 3.3.3*.

For comparison, the Alabama Parenting Questionnaire (APQ) (Frick, 1991) a standardised measure of parenting style was included in the child questionnaire. The APQ was analysed using ANOVA and *t*-tests to assess underlying differences between the three parental categorisations. The APQ measures three factors: positive parenting, inconsistent discipline, and poor supervision. Higher scores denote better parenting. Analysis only included pairs where children had identified the interviewed parent as their primary caregiver.

ANOVA analysis showed significant differences between the different parental types ($F[2, 2{,}276] = 4.07$; $p = .017$). Underlined scores denote significantly greater values (see *Table 5.1*).

Table 5.1
Mean APQ Scores by Parent Type for Children Who Identified Interviewed Adult as Primary Caregiver (ANOVA)

	Parent type (SD)			Overall
	Biological parent (*n* = 1,496)	**Grandparent (*n* = 434)**	**Foster parent (*n* = 349)**	
APQ score	35.06 (4.66)	34.62 (4.83)	34.33 (4.99)	34.86 (4.75)**

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Mean differences were compared in three separate *t*-tests to determine the direction of the effect. Only scores between biological parents and foster parents, with biological parents scoring 'better,' were significantly different (t[1,843] = 3.42; $p < .001$). Results are presented in *Table 5.2*.

Table 5.2
Mean APQ Scores by Parent Type for Children Who Identified Interviewed Adult as Primary Caregiver (t-test)

	Parent type (SD)		Mean difference
	Biological parent (*n* = 1,496)	**Grandparent (*n* = 434)**	
APQ score	35.06 (4.65)	34.62 (4.83)	.44

	Biological parent (*n* = 1,496)	**Foster parent (*n* = 349)**	
APQ score	35.06 (4.66)	34.33 (4.99)	.73**

	Grandparent (*n* = 434)	**Foster parent (*n* = 349)**	
APQ score	34.62 (4.83)	34.33 (4.99)	.29

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Given theoretical considerations surrounding the different parent types (e.g., severing of the 'generational bargain' with children being cared for by grandparents and evidence that foster carers exploit children for their labours), all three variables were included in further analyses. In regressions, the variables were analysed as 'dummy variables' with biological parent as the constant.

2.3.1 Child/parent gender-matching

More than half the pairs in the sample were gender-matched (55.0%; *n* = 1,362). Of those pairs, 88.8% (*n* =1,209) were female pairs and the remaining 11.2% (*n* = 153) male.

2.4 Household characteristics

2.4.1 Urban/rural location

Participants were nearly evenly divided between those recruited from the urban (48.3%; *n* = 1,197) and rural sites (51.7%; *n* = 1,297).

2.4.2 Adult presence

Mean household size was six members (SD = 2.68), the same as that found in a household survey of KwaZulu-Natal province demographics (Provide Project, 2009). Household size ranged from two (*n* = 95) to 40 members (*n* = 1). The household size of 40 was an outlier; the next largest household size was 21 (*n* = 1). The mean number of adults per household was 2.95 (SD = 1.27), with a range of one (*n* = 433) to 13 (*n* = 1). Mean number of children was 3.04 (SD = 1.75) with a range of 1 (*n* = 440) to 28 (*n* = 1).

The number of adults was divided by the number of children within each household to provide an indicator of adult presence. Number of adults, children, or total people in a household is not useful in assessing adult presence; rather, these absolute numbers are likely indicative of poverty or rural location; polygamous households, rare in urban areas but common in rural areas, were often spread across multiple homes in the rural field site. Higher adult:child ratios were taken to indicate greater adult presence. The mean ratio per household was 1.27 adults to children (SD = 1.01). The ratio statistic was both skewed (skewness = 2.13)

and peaked (Kurtosis = 6.82). A square root transformation reduced both to within acceptable ranges (skewness = 1.01; Kurtosis = 1.15). Adjusted adult:child ratio was used as an indicator of adult presence in bivariate associations presented in *Section 4* of this chapter.

2.4.3 Access to healthcare services

Children reported a mean travel time of 29.42 minutes (SD = 25.52) to their local clinic. Based on clinic utilisation data from KwaZulu-Natal (Tanser et al., 2006), travel times were dichotomised at two cut-offs: > 30 minutes and > 50 minutes. Households were evenly divided at the > 30 minute cut-off, with 47.9% (*n* = 1,186) requiring more than half an hour to travel time to get to their local clinic. Fourteen-point-six per cent (*n* = 362) of households required more than 50 minutes of travel time to the local clinic. The two dichotomisations were compared on bivariate associations to evaluate which had greater association with outcome variables (*Section 4.3.3*).

2.4.4 Home community-based carer presence

Home community-based carers had visited 12.0% (298) of households at least once in the previous month, according to the combined reports of children and parents. Between children and parents, there was little agreement on whether the household had been visited by a home community-based carer; positive responses overlapped in only 21.1% (*n* = 63) of cases. In most cases of disagreement, the carer had identified the presence of a home community-based carer but the child had not (75.3%; n = 177).

3 Standardised predictor and outcome variables

3.1 Parental illness

3.1.1 General health and functioning

Mean scores on the 12-Item Short Form Health Survey (SF-12) were calculated using recommended scoring techniques; designated items were reversed, weighted, and transformed to a 0-100 scale where higher scores denote better health. Parents' mean SF-12 score was 68.22 (SD = 19.33). Internal reliability of the SF-12 was 'good' (α = .86).

The two primary subscales, the Physical and Mental Component Summaries, were both dichotomised at the lowest quintile of scores to use as a predictor variable in bivariate association analyses. For the Physical Component Summary with a mean of 70.95 (SD = 24.50) this was a score of 47. For the Mental Component Summary with a mean of 65.96 (SD = 18.36), this was 50.

3.1.2 Chronic illnesses

The most prevalent illness among the parental cohort was tuberculosis (*n* = 808; 32.6%), followed by arthritis (*n* = 733; 29.6%), hypertension/high blood pressure (*n* = 701; 28.3%), and HIV/AIDS (*n* = 679; 27.4%). One hundred and seventy-four parents (7.0%) described themselves as having some type of disability. Listed disabilities included hearing impairments, work/crime injuries, strokes, and being wheelchair bound. Disability descriptions were provided as qualitative responses, making it difficult to separate the various ailments into discrete categories. Half the parent sample had at least one illness (*n* = 1,203; 48.6%), and almost one-third reported two or more (*n* = 730; 29.5%). Parental illness prevalence is presented in *Figure 5.2*.

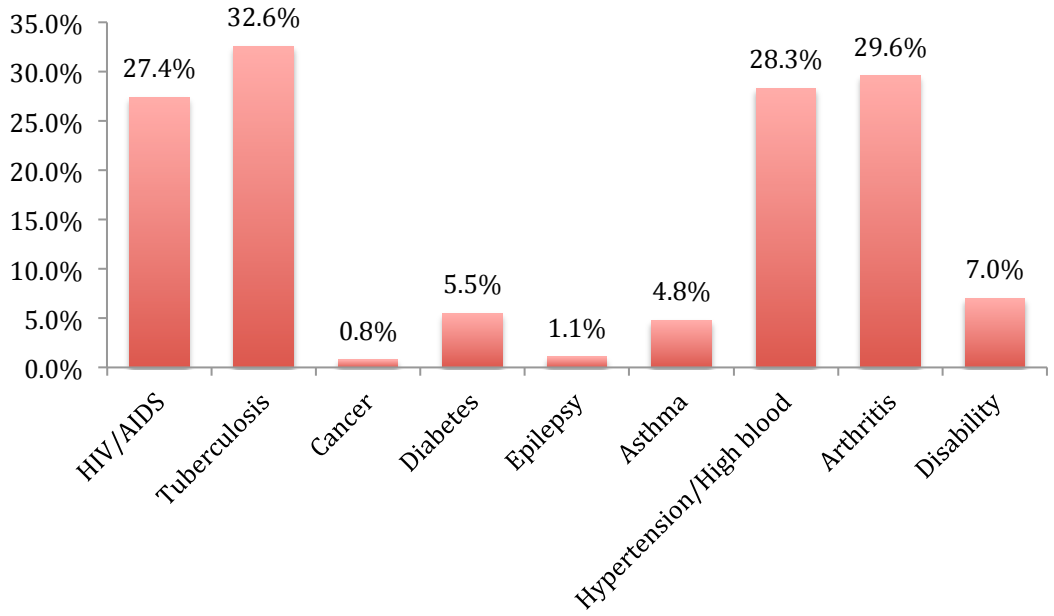


Figure 5.2. **Prevalence of chronic illnesses among parental cohort**

3.1.3 Mental health

Parental mental health was assessed using three tools. The first of these is the Mental Component Summary of the SF-12, on which participants were dichotomised at the low quintile (see *Section 3.1.1* of this chapter for more detail). Internal reliability of this measure was 'acceptable' (α = .72).

The two remaining scales were standardised measures of specific mental health disorders: the Beck Anxiety Scale and the Center for Epidemiologic Studies Depression Scale. Mean parental anxiety score was 12.07 (SD = 12.83 range: 0-63). Internal reliability of this scale was 'excellent' (α = .95). Scores were comparable to those reported among a sample of isiXhosa-speaking South African students (M = 14.94; SD = 11.56; α = .92) (Steele, 2003). Fifteen per cent (*n* = 376; 15.2%) of parents met or exceeded scores for 'severe' anxiety, at which point they were dichotomised.

Mean parental depression score was 13.54 (SD = 12.32, range: 0 to 60). Internal reliability in this scale was 'excellent' (α = .95). When analysed as a categorical variable 35.7% (*n* = 883) of the sample met or exceeded the cut-off for clinically significant depression (≥ 16, Radloff, 1977). Depression scores were similar to that of another study of parents in KwaZulu-Natal province (12.53; SD = 9.75; 30.33% meeting or exceeding cut-off) (Kuo, 2010).

3.2 Socio-economic factors

3.2.1 Poverty

Household poverty was measured via three consumption surveys: the Economic Asset Index, the Indicators of Poverty and Social Exclusion, and the South African Food Consumption Survey.

Parents' mean score on the Economic Asset Index was .10 (SD = 1.91; range = -8.88 to 23.00), similar to scores in similar South African populations reported in Kuo (2010) (.05; SD = .67; range = -4.42 to 1.11) and Booysen (2001) (-.06; SD = 1.07; range = -12.17 to 2.32). The greater range of responses was likely due to inclusion of both urban and rural samples (Booysen, Van der Berg, Burger, von Maltitz, & Du Rand, 2008). However, this index was highly skewed (3.52) and peaked (45.37). As the purpose of the measure was to identify the effects of poverty, participants were divided into quintile categories as recommended (Booysen, 2001) and dichotomised at the lowest scoring quintile (-1.26), which is used in further analyses.

Indicators of Poverty and Social Exclusion, a scale administered to children, had a mean score of 6.52 (SD = 2.12; range = 0-8), indicating children's families were

able to afford nearly seven out of the eight items on the survey. This measure had 'good' internal reliability (α = .84).

Children's mean score on the Food Consumption Survey was .64 (range: 0-14). The scale's two items asked first how many days in the previous week the child did not have enough food to eat, and second how many days in the previous week the child had gone to bed without food. Participant responses were highly skewed (3.33) and peaked (12.09), which along with the low mean indicated that hunger was an uncommon occurrence among participants in this study. The first item of the Food Consumption Survey was used to categorise children based on whether the child was experiencing hunger, which has been identified as an indicator of poverty in South Africa (May, 1998; referenced in Woolard, 2002). Though in resource-deprived settings there are demographic differences in intra-household food allocation, potentially making child hunger an inconsistent indicator of poverty, it is unclear which (i.e., age and gender) are favoured; a literature review of intra-household food distribution in low- to middle-income countries found that research variously indicates younger and older children and women as 'favoured,' with no trends in preference in any specific region (Berti, 2012). The second Food Consumption Survey variable was excluded as it may indicate a type of punishment rather than an inadequate amount of food rather than resource constraints. Fourteen per cent (*n* = 346) of children reported not having enough to eat at least one day in the previous week.

3.2.2 Social support

Scores on the Medical Outcomes Social Support Survey were adjusted to fit a 0-100 scale. Parents' mean score was 65.15 (SD = 32.01). Scale reliability was 'ex-

cellent' (α = .99). Scores were similar to a study of 149 adults receiving antiretroviral medication in KwaZulu-Natal (64.4; SD = 14.7; α = .64) (Ncama et al., 2008). For further analyses, social support scores were dichotomised at ≥ 70, the score at which social support is considered 'adequate and available' (Kornblith et al., 2001, p. 447). Half the child sample reported scores ≥ 70 (51.7%; *n* = 1,281).

3.3 Children's responsibilities

This section covers children's responses to the Child Responsibility Measure, which recorded the prevalence of children's engagement in and time spent on each category, subcategory, and type of responsibility. Mean times were derived only from children who indicated engaging in the specific responsibility.

3.3.1 Prevalence

Nearly every child had engaged in some type of responsibility in the previous week (98.2%; *n* = 2,432) and one-fifth (19.5%; *n* = 482) of children were providing care. The most common types of medical care tasks were reminding an ill person to take their medicine (11.0%; *n* = 272) and giving the ill person medicine (10.2%; *n* = 253). Children who were administering medicine or treatment were asked to give qualitative answers describing what was being administered. Among those mentioned were tuberculosis medication (*n* = 13), ART (*n* = 10), diabetes medication (*n* = 3), asthma medication (*n* = 3), traditional medicine (*n* = 3), epilepsy medication (*n* = 1), medication to help with throat cancer treatment (*n* = 1), and mental health disorder medication (*n* = 1). The remainder were tablets for flu, pain, or were not otherwise specified. A number of children indicated they did not know what the medication was for (*n* = 16). One child refused to tell interviewers the type of medicine she was providing.

One in ten children (9.8%; *n* = 243) reported providing intimate care for an unwell person. The most prevalent intimate care task was massaging or rubbing the body of the ill person (4.9%, *n* = 121), followed by staying with/looking after the ill person (4.6%; *n* = 113). Less than three per cent of participants indicated they engaged in the remaining intimate care responsibilities.

Nearly all children engaged in some type of domestic responsibility (98.2%; *n* = 2,431), and nearly the same number engaged in a type of housework (97.8%; *n* = 2,232). The most common responsibility was washing dishes (85.9%; *n* = 2,127), followed by cleaning the home and yard (82.0%; *n* = 2,030).

One-quarter (26.6%; *n* = 659) of children were providing care for other children within their home. The most prevalent responsibility within the childcare subcategory was feeding other children (20.0%; *n* = 496).

One in twenty children (5.2%; *n* = 128) engaged in income-generating activities. Rather than being provided with a list of different types of income-generating activities, children were asked to give qualitative responses to describe how they earned money. The reason for this was the wide-range of income-generating responsibilities that emerged in the exploratory study (see *Chapter 3*, *Section 3.3.1*, and *Chapter 4*, *Section 4.3*). Several responsibilities were the same as those categorised as housework, such as collecting firewood (*n* = 8), fetching water (*n* = 6), working in a garden (*n* = 6), herding cattle (*n* = 3), cleaning yards (*n* = 2) and washing laundry (*n* = 1). Income-generating activities differed from housework in that the child was being paid for their services. Some income-generating activities appeared to be part of the formal sector such as product promotions (*n* = 2), working at the local grocery story (*n* = 1), and modelling (*n* = 1). Other jobs were

indicative of the informal economy, including selling goods from a tuck shop (*n* = 9), taxi conductor (*n* = 3), and catching fish (*n* = 1). The remaining income-generating activities were not clearly part of either the formal or informal economy, such as hairstyling (*n* = 9), cutting trees (*n* = 3), cutting grass (*n* = 2), auto mechanics/car repair (*n* = 2), building chicken coops (*n* = 1), working at a car wash (*n* = 1), and roofing (*n* = 1).

3.3.2 Time burden

Children spent on average ten hours per week engaging in their responsibilities (9 hours, 56 minutes per week; SD = 11h52m). Among children engaging in personal care responsibilities, mean time spent on those responsibilities was nearly three and a half hours per week (3h23m; SD = 11h54m). Intimate care (excluding 'stay with a sick person') accounted for nearly two hours (2h00m; SD = 4h07m), and medical care accounted for just over an hour per week (1h05m; SD = 0h45m).

Staying with an ill person required the most amount of time of any intimate care responsibility at seven hours per week (7h26m; SD = 13h01m). The time burden of this task was four times greater than helping an ill person get around the house (1h48m; SD = 2h51m), the next most time-intensive responsibility. In further analyses (bivariate associations and regressions), staying with an ill person is not included as an instance of intimate care. Therefore, if staying with an ill person is the only intimate care responsibility a child engages in, he or she is not categorised as engaging in intimate care. This is because other intimate care responsibilities involve physical touching and might be bound by cultural stand-

ards of what is acceptable between children and adults, particularly if they are of opposite sexes.

Medical care tasks with the highest time burden were taking an ill person to the clinic, which on average required an hour per week of the child's time (1h04m; SD = 1h38m), followed by collecting medicine from the clinic at three-quarters of an hour (0h49m; SD = 1h13m). These responsibilities were unique among medical care tasks in that they contained a transport component yet lacked an administrative role (i.e., the child had no direct involvement in treatment). The two remaining tasks, reminding an ill person to take their medicine (0h34m; SD = 1h23m), and giving an ill person their medicine (0h33m; SD = 1h06m), were both involved in medical treatment administration. Additionally, both were performed at greater frequency and less time per instance than transport-related medical care tasks (*Table 5.3*).

Table 5.3:
Mean Frequency and Time Spent on Medical Care Responsibilities, Grouped by Nature of Task (Treatment Administration Versus Clinic-Based Responsibility)

		Mean frequency, days per week (SD)	Mean time per day of responsibility (SD)	Mean week time per day of responsibility (SD)
Treatment administration	Remind sick person to take medicine	3.50d (2.31)	9.65m (16.51)	34.06m (83.41)
	Give sick person medicine	3.55d (2.24)	9.28m (16.69)	32.82m (66.32)
Clinic-based responsibility	Collect medicine from the clinic	1.76d (1.56)	26.84m (28.65)	48.79m (72.81)
	Take sick person to the clinic	1.55d (1.17)	42.83m (60.51)	63.66m (98.42)

Children spent a mean of nearly nine hours per week on domestic responsibilities (8h46m; SD = 10h36m); housework accounted for the vast majority of time spent on responsibilities, with nearly seven hours per week (6h55m; SD =

9h20m). The most time consuming domestic responsibility was cooking for other people (3h10m; SD = 4h22m).

Childcare responsibilities accounted for a mean of just over two hours of responsibility per week (2h28m; SD = 2h49m). The most time-demanding responsibility within the subcategory was walking other children to school/crèche (1h33m; SD = 0h12m). Income-generating activities on average required nearly six hours (5h58m; SD = 11h33m).

Children's responsibility prevalence and time burden are summarised in *Table 5.4*.

Table 5.4
Prevalence and Time Burden of Responsibilities in the Previous Week Among Participant Children

Responsibility	% engaging (*n*)	Mean responsibility time (minutes)(SD)
Total	98.2% (2,432)	556.25 (714.02)
Personal care	19.5% (482)	202.81 (524.31)
Intimate care*	8.2% (203)	120.45 (247.32)
Clean up after person has been sick	0.7% (18)	76.28 (147.59)
Help sick person get around the house	1.6% (39)	108.31 (170.65)
Help sick person get dressed	2.9% (73)	100.15 (22.05)
Help sick person to use the toilet	0.9% (23)	83.41 (88.11)
Massage sick person/rub body	4.9% (121)	55.02 (127.32)
Stay with sick person*	4.6% (113)	426.26 (780.99)
Wash or bathe sick person	1.2% (29)	102.34 (263.27)
Medical care	15.6% (385)	65.29 (44.61)
Collect medicine from the clinic	3.5% (86)	48.79 (72.81)
Give sick person their medicine	10.2% (253)	32.82 (66.32)
Remind sick person to take their medicine	11.0% (272)	34.06 (83.41)
Take sick person to the clinic	2.1% (53)	63.66 (98.42)
Domestic responsibilities	98.2% (2,431)	526.34 (635.57)
Housework	97.8% (2,232)	474.95 (560.41)
Clean your home, yard, etc.	82.0% (2,030)	118.45 (199.84)
Collect firewood/make fires	35.0% (867)	113.12 (157.50)
Cook for other people	49.3% (1,220)	190.44 (262.11)
Do grocery shopping	17.1% (424)	101.69 (146.39)
Fetch water	45.6% (1,129)	119.03 (186.16)
Wash dishes	85.9% (2,127)	104.81 (139.93)
Wash other people's clothes	42.1% (1,042)	87.54 (116.80)
Work in food garden or tend animals	31.9% (789)	110.71 (182.18)
Childcare	26.6% (659)	127.99 (168.69)
Feed other children	20.0% (496)	63.87 (93.44)
Walk other children to school/crèche	8.5% (211)	93.10 (11.52)
Wash other children	17.7% (438)	75.56 (112.59)
Income-generating activities	5.2% (128)	357.81 (692.82)

Note: *** 'Stay with sick person' not included as 'intimate care' responsibility in analyses due to the lack of contact between sick person and child**

The *n* = 2,476 children's sample engaged in a sum of 22,954 hours of responsibility in the week prior to interview. The vast majority of this time was dedicated to domestic responsibilities (92.9%; *n* = 21,325).

4 Bivariate associations

This section reports on correlations, *t*-tests, ANOVAs, and chi-squares among and between predictor variables and selected outcome measures. Where there were significant differences, larger scores are underlined to clarify directionality. *P*-

values of all predictor-outcome associations are presented in *Table 2.25* at the end of this chapter.

Selected outcome measures included engagement in intimate, medical, and childcare, income-generating activities, and total responsibility time. Personal care was not included in this or further analyses, as it was a summary of engagement in either intimate or medical care responsibilities. While domestic and housework responsibility time burdens were included in the sums of 'total responsibility time,' engagement in either was not included as outcome variables for a number of reasons. First, nearly all children engaged in domestic (98.2%) or housework responsibilities (97.8%) (see *Table 5.4*); differences on engagement in these activities would have been irrelevant. Second, differences in engagement in domestic and household responsibilities were not a focus of this thesis; evidence presented in the literature review and the exploratory study suggest that most children engage in these responsibilities regardless of parental illness. Robson (2000) and Bray (2003) argue the impact of parental illness on children's responsibilities is in the time burden and intensity. While engagement in either activity is not used as an outcome in and of itself, time devoted to each activity within this category and subcategory of child responsibility is a vital component of the outcome variable 'total responsibility time.'

Bivariate associations between predictor variables were only run if they fell within the same factor (e.g., three measures of mental health) or there were evidence or theoretical reasons for doing so (e.g., evidence of strong association between rural location and poverty).

The purpose of bivariate associations was twofold. First, bivariate associations were run prior to regression analyses to identify socio-demographic factors that were more strongly associated with children's responsibilities. Second, where there were several measures of the same factor (e.g., three measures of parental mental health), bivariate associations identified which was most closely associated with outcomes and thus used as a predictor. Additionally, bivariate associations between predictors were conducted to identify potential sources of multicollinearity in regression analyses.

4.1 Child demographics

4.1.1 Child age

Being an older child was significantly associated with engagement in medical care ($x^2[1] = 14.04$; $p < .001$), childcare ($x^2[1] = 4.67$; $p = .031$), income generating responsibilities ($x^2[1] = 23.81$; $p < .001$), and greater total responsibility time ($t[1{,}651.05] = -6.79$; $p < .001$) (*Table 5.5*).

Table 5.5
Bivariate Associations, Child Age and Responsibility Outcomes

Responsibility outcome	10-14 years (*n* = 1,548)	15-17 years (*n* = 928)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	7.6% (118)	9.2% (85)	1.6%
Medical care	13.4% (208)	19.1% (177)	5.7%***
Childcare	25.1% (389)	29.1% (270)	4.0%*
Income-generating activities	3.5% (54)	8.0% (74)	4.5%***
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	477.59 (647.24)	687.47 (796.56)	209.88***

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

4.1.2 Child gender

Being a female child was significantly associated with engagement in intimate care ($x^2[1] = 9.19$; $p = .002$) and childcare ($x^2[1] = 71.89$; $p < .001$), and ap-

proached significance with medical care ($x^2[1] = 3.82$; $p = .051$). Girls reported spending nearly five more hours per week on responsibilities than boys ($t[2,293.25 = -10.94$; $p < .001$). Significantly more boys than girls engaged in income-generating activities ($x^2[1] = 10.70$; $p = .001$) (*Table 5.6*).

Table 5.6
Bivariate Associations, Child Gender and Responsibility Outcomes

Responsibility outcome	Boys (*n* = 1,142)	Girls (*n* = 1,334)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	6.4% (73)	9.7% (130)	3.3%**
Medical care	14.0% (160)	16.9% (225)	2.9%
Childcare	18.5% (211)	33.6% (448)	15.1%***
Income-generating activities	6.7% (77)	3.8% (51)	2.9%***
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	395.96 (522.04)	693.77 (819.99)	297.81***

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

4.1.3 Orphanhood

Having lost one or more parent was positively associated with children's engagement in medical care ($x^2[1] = 7.28$; $p = .007$), income-generating activities ($x^2[1] = 4.58$; $p = .032$), and greater total responsibility time burden ($t[1,245.72 = -10.94$; $p = .043$), while being non-orphaned was positively associated with childcare ($x^2[1] = 4.62$; $p = .032$) (*Table 5.7*).

Table 5.7
Bivariate Associations, Orphanhood and Responsibility Outcomes

Responsibility outcome	Orphaned (*n* = 793)	Non-orphaned (*n* = 1,683)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	8.8% (70)	7.9% (133)	0.9%
Medical care	18.4% (146)	14.2% (239)	4.2%**
Childcare	23.8% (189)	27.9% (470)	4.1%*
Income-generating activities	6.6% (52)	4.5% (76)	2.1%*
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	602.80 (841.32)	534.32 (644.51)	68.48*

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Several impacts of being orphaned could influence these associations, including surviving/adoptive parents suffering from poorer health due to transmissibility of an illness such as HIV/AIDS, stress, financial shock of a parental death, or lost educational opportunities. For these reasons orphaned and non-orphaned children were compared on theoretically related predictor outcomes (*Table 5.8*).

Being orphaned was negatively associated with completion of compulsory education by at 16 ($x^2[1] = 4.19$; $p = .041$) and positively associated with having either a grandparent ($x^2[1] = 39.17$; $p < .001$) or foster parent ($x^2[1] = 125.78$; $p < .001$) as primary carer, and parental HIV/AIDS-illness ($x^2[1] = 9.66$; $p = .002$), anxiety ($x^2[1] = 8.70$; $p = .003$), and depression ($x^2[1] = 5.98$; $p = .014$). Orphaned children were significantly poorer as indicated by significant differences compared to non-orphaned children on the Indicators of Poverty and Social Exclusion ($t[1,446] = 3.16$; $p = .002$), the Economic Asset index ($x^2[1] = 6.94$; $p = .008$) and greater prevalence of hunger ($x^2[1] = 4.61$; $p = .032$). Given the strong association with outcomes, orphanhood is used in regression analyses, though associated predictor variables are controlled for.

Table 5.8
Bivariate Associations, Orphanhood and Potentially Related Predictor Variables

Predictor variables	Orphaned (*n* = 793)	Non-orphaned (*n* = 1,683)	Mean difference
Dichotomous predictors: % (*n*)			
Completion of compulsory education	46.1% (119)	54.5% (194)	8.4%*
Grandparent caregiver	26.9% (213)	16.2% (272)	10.7%***
Foster parent	29.1% (231)	11.1% (186)	18.0%***
Parental HIV/AIDS-illness	31.4% (249)	25.5% (430)	5.9%**
Parental anxiety	18.3% (145)	13.7% (231)	4.6%**
Parental depression	39.1% (310)	34.0% (573)	5.1%*
Economic Asset Index (poverty)	23.1% (183)	18.5% (312)	4.6%**
Hunger (poverty)	16.2% (128)	13.0% (218)	3.2%*
Continuous predictors: mean (standard deviation)			
SF-12 (general health)	66.59 (19.92)	68.99 (19.00)	2.40**
Poverty & Social Exclusion (poverty)	6.32 (2.24)	6.62 (2.06)	.30**
Adult:Child ratio	1.05 (.41)	1.06 (.39)	.01
Social support	65.08 (31.18)	65.18 (32.41)	.10

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

4.1.4 Level of education

Children who had not completed compulsory education by age 16 engaged in significantly more childcare ($x^2[1] = 1.33$; $p = .002$). No other association was significant (*Table 5.9*). Further chi-square analyses found that among children aged 16-17 years, girls (54.7%; $n = 192$) were more likely to have completed compulsory education than boys (46.0%; $n = 121$) ($x^2[1] = 4.55$; $p = .033$).

Table 5.9
Bivariate Associations, Completion of Compulsory Education and Responsibility Outcomes

Responsibility outcome	Completed compulsory education (*n* = 313)	Not completed compulsory education (*n* = 301)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	9.3% (29)	12.0% (36)	2.7%
Medical care	18.5% (58)	23.9% (72)	5.4%
Childcare	22.7% (71)	33.9% (102)	11.2%**
Income-generating activities	7.3% (23)	9.7% (30)	2.4%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	715.40 (833.19)	719.26 (866.60)	3.86

Note: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$

4.2 Parent type

ANOVAs found significant differences between the three parent groups on children's engagement in intimate ($x^2[1] = 15.99$; $p < .001$), medical ($x^2[1] = 17.28$; $p < .001$), and childcare ($x^2[1] = 13.43$; $p = .001$) (*Table 5.10*).

Table 5.10
Bivariate Associations, Parent Type and Responsibility Outcomes (ANOVA)

Responsibility outcome	Biological parents (*n* = 1,574)	Grandparents (*n* = 485)	Foster parent (*n* = 417)	Sample mean
Dichotomous responsibility outcomes: % (*n*)				
Intimate care	7.8% (123)	12.2% (59)	5.0% (21)	8.2%***
Medical care	15.0% (236)	21.0% (102)	11.3% (47)	15.6%***
Childcare	29.0% (457)	21.4% (104)	23.5% (98)	26.6%***
Income-generating activities	9.1% (83)	5.6% (27)	4.3% (18)	5.2%
Continuous responsibility outcomes: (standard deviation)				
Total responsibility time (min)	555.05 (662.15)	562.10 (809.20)	555.35 (783.75)	556.25 (714.02)

Note: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$

Further analyses were conducted with *t*-tests exploring individual associations between two parent type categories. Children with grandparents as caregivers engaged in significantly more intimate care than those with biological parents or foster parents. Children being cared for by biological parents engaged in significantly more childcare than both those cared for by grandparents and foster par-

ents; additionally, their higher prevalence of engagement in intimate and medical care than those with foster parents approached significance (p = .051 and p = .053) (*Table 5.11*).

Table 5.11
Bivariate Associations, Parent Type and Responsibility Outcomes (t-test)

Responsibility outcome	Parent type (SD)		Mean difference
	Biological parent (n = 1,496)	**Grandparent (n = 434)**	
Dichotomous responsibility outcomes: % (n)			
Intimate care	7.8% (123)	12.2% (59)	4.4%**
Medical care	15.0% (236)	21.0% (102)	6.0%**
Childcare	29.0% (457)	21.4% (104)	7.6%***
	Biological parent (n = 1,496)	**Foster parent (n = 349)**	
Dichotomous responsibility outcomes: % (n)			
Intimate care	7.8% (123)	5.0% (21)	2.8%
Medical care	15.0% (236)	11.3% (47)	3.7%
Childcare	29.0% (457)	23.5% (98)	5.5%*
	Grandparent (n = 434)	**Foster parent (n = 349)**	
Dichotomous responsibility outcomes: % (n)			
Intimate care	12.2% (59)	5.0% (21)	7.2%***
Medical care	21.0% (102)	11.3% (47)	9.7%***
Childcare	21.4% (104)	23.5% (98)	2.1%

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Contrary to hypotheses suggesting that foster parents take in orphaned children in exchange for contributions to household maintenance (see *Chapter 1*, *Section 3.1* and *Chapter 2*, *Section 3.3.3*), children with foster parents did not engage in significantly more income-generating activities or have significantly greater responsibility time burdens. Nevertheless, this relationship is further assessed in regression analyses.

4.2.1 Child/parent gender-matching

Gender-matching was significantly associated with children's engagement in intimate care ($x^2[1] = 8.96$; $p = .003$) and childcare ($x^2[1] = 47.62$; $p < .001$). Children in gender-matched pairs had nearly fours more hours of responsibility than non-matched children ($t[2459.61] = -8.08$; $p < .001$) (*Table 5.12*).

Given that 88.8% of gender-matched pairs were female/female and girls were found to have greater responsibility (*Section 4.1.2* of this chapter), there is a strong possibility that these associations are tied to child gender; indeed, the associations listed here are similar to those found in that section on child gender. For instance, being in non-gender-matched pairs, which primarily consisted of boys with female carers, approached significance in terms of greater engagement in income-generating activities ($p = .058$); in bivariate analysis of child gender, boys were found to engage in income-generating activities in significantly greater proportions.

The effect of gender-matching is further assessed in multiple regression analyses, in which child gender is controlled for.

Table 5.12
Bivariate Associations, Child/Parent Gender-Matching and Responsibility Outcomes

Responsibility outcome	Gender-matched (*n* = 1,362)	Non-matched (*n* = 1,113)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	9.7% (132)	6.4% (71)	3.3%**
Medical care	16.6% (226)	14.3% (159)	2.3%
Childcare	32.2% (438)	19.8% (221)	12.4%***
Income-generating activities	4.4% (60)	6.1% (68)	1.7%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	657.21 (784.42)	433.20 (594.73)	224.01***

Note: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$

4.3 Household characteristics

4.3.1 Urban/rural location

Children from the urban site engaged in significantly more intimate ($x^2[1] = 14.37$; $p < .001$) and medical care ($x^2[1] = 10.27$; $p = .001$) than those from the rural site. More rural children engaged in childcare ($x^2[1] = 149.99$; $p < .001$) and had greater total responsibility time ($t[2473] = -9.48$; $p < .001$) (*Table 5.13*).

Table 5.13
Bivariate Associations, Urban/Rural Location and Responsibility Outcomes

Responsibility outcome	Urban (*n* = 1,197)	Rural (*n* = 1,279)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	10.4% (124)	6.2% (79)	4.2%***
Medical care	18.0% (215)	13.3% (170)	4.7%***
Childcare	15.4% (184)	37.1% (475)	21.7%**
Income-generating activities	4.5% (54)	5.8% (74)	1.3%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	418.16 (654.23)	685.81 (743.12)	267.65***

Note: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$

There were several significant differences between pairs from urban and rural sites on other socio-demographic variables. Parents from the urban site scored better on the Short Form Health Survey ($t[2,471] = 2.27$; $p = .023$), and had lower

rates of HIV/AIDS-illness ($x^2[1] = 293.06$; $p < .001$), anxiety ($x^2[1] = 9.00$; $p = .003$), and depression ($x^2[1] = 66.16$; $p < .001$). Urban households were less likely to be impoverished as indicated by scores on the Economic Asset Index ($x^2[1] = 343.45$; $p < .001$), Indicators of Poverty and Social Exclusion ($t[2,367.31] = 17.81$; $p < .001$), and child hunger ($x^2[1] = 55.97$; $p < .001$). Urban households also reported higher adult:child ratios ($t[2,328.23] = 15.26$; $p < .001$). Although previous research has found more people in rural households on average (Steinberg et al., 2002), these data suggest there are fewer adults per child in rural households. Children in rural households reported longer travel times to the local clinic (> 30 minutes: $x^2[1] = 172.95$; $p < .001$; > 50 minutes: $x^2[1] = 243.19$; $p < .001$). Parents in urban households were more likely to report having adequate and available social support ($x^2[1] = 15.37$; $p < .001$), contrary to a suggestion in Evans and Becker (2009) that nuclear households in urban areas would reduce connections to extended family, and as a result, have lower social support. However, the social support scale did not account for the source of social support; it is possible that urban households receive less social support from extended families, yet much more from their communities. Rural households were significantly more likely to have been visited by a home community-based carer in the previous month ($t[1,732.83] = -14.33$; $p < .001$), which was unsurprising given the presence of home community-based care organisation and rural research partner Tholulwazi Uzivikele (*Table 5.14*).

Table 5.14
Bivariate Associations, Urban/Rural Location and Potentially Related Predictor Variables

Responsibility outcome	Urban (*n* = 1,197)	Rural (*n* = 1,279)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Parental HIV/AIDS-illness	18.8% (225)	35.5% (454)	16.7%***
Parental anxiety	12.9% (155)	17.3% (221)	4.4%**
Parental depression	27.6% (330)	43.2% (553)	15.6%***
Economic Asset Index (dichotomised)	4.6% (55)	34.4% (440)	29.8%***
Hunger (poverty)	8.7% (104)	18.9% (242)	10.2%***
Adequate social support	52.1% (668)	47.9% (613)	4.2%***
Travel time to local clinic (> 30 min)	34.3% (410)	60.7% (776)	26.4%***
Travel time to local clinic (> 50 min)	3.2% (38)	25.3% (324)	22.1%***
Home community-based carer presence	2.9% (35)	20.6% (263)	17.7%***
Continuous responsibility outcomes: mean (standard deviation)			
SF-12 (general health)	69.14 (19.49)	67.37 (19.16)	1.77*
Adult:Child ratio	1.17 (.41)	.94 (.34)	.23***
Indicators of Poverty and Social Exclusion	7.25 (1.70)	5.83 (2.25)	1.42***

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Despite the strong relationships with other predictor variables, urban/rural location was still used as a predictor variable in regression analyses due to its strong association with responsibilities and importance as a contextual factor of children's responsibilities.

4.3.2 Adult presence

Children in households with lower ratios of adults to children engaged in significantly more childcare (r = -.229; p < .001), and had greater total responsibility time burdens (r = -.088; p < .001). Interestingly, higher household adult:child ratios were significantly correlated with children's engagement in intimate care (r = .054; p = .007) (*Table 5.15*).

Table 5.15
Bivariate Association, Adult:Child Ratio and Responsibility Outcomes

	Intimate care	Medical care	Childcare	Income-generating activities	Total responsibility time
Adult:Child ratio	.054**	.022	-.229***	-.013	-.088***

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

4.3.3 Access to healthcare services

Dichotomisation of travel time to a local clinic with a higher cut-off (> 50 minutes) was associated with more responsibility outcomes than the dichotomisation with a lower cut-off (> 30 minutes). The higher cut-off dichotomisation was significantly associated with children's engagement in childcare ($x^2[1] = 23.48$; $p < .001$), and income-generating activities ($x^2[1] = 4.53$; $p = .033$), and greater total responsibility time ($t[436.90] = -8.26$; $p < .001$). Interestingly, significantly fewer children who were further from a clinic at the > 50 minute cut-off engaged in medical care ($x^2[1] = 6.54$; $p = .011$). From these results, which are summarised in *Table 5.16*, it appeared that the higher cut-off travel time variable was a better indicator of reduced healthcare access, and as such was used in regression analyses.

Table 5.16
Bivariate Associations, Travel Time to Local Clinic and Responsibility Outcomes

Responsibility outcome	> 30 minutes travel time (*n* = 1,186)	≤ 30 minutes travel time (*n* = 1,290)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	7.8% (93)	8.5% (110)	0.7%
Medical care	15.4% (183)	15.7% (202)	0.3%
Childcare	28.8% (342)	24.6% (317)	4.2%**
Income-generating activities	5.8% (69)	4.6% (59)	1.2%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	664.52 (807.41)	456.71 (599.07)	207.81***

	> 50 minutes travel time (*n* = 362)	≤ 50 minutes travel time (*n* = 2,114)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	6.6% (24)	8.5% (179)	1.9%
Medical care	11.0% (40)	16.3% (345)	5.3%*
Childcare	37.0% (134)	24.8% (525)	12.2%***
Income-generating activities	7.5% (27)	4.8% (101)	2.7%*
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	894.22 (868.61)	498.38 (667.34)	395.84***

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

4.3.4 Home community-based carer

Children from households that had been visited at least once by a home community-based carer in the previous month engaged in more medical care ($x^2[1] = 10.12$; $p = .001$), childcare ($x^2[1] = 24.87$; $p < .001$), and income-generating activities ($x^2[1] = 14.38$; $p < .001$), and had greater total responsibility time ($t[343.10] = -4.92$; $p < .001$) (*Table 5.17*).

Table 5.17
Home-Based Carer Presence and Responsibility Outcomes

Responsibility outcome	Carer present (*n* = 298)	Carer not present (*n* = 2,178)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	10.4% (31)	7.9% (172)	2.5%
Medical care	21.8% (65)	14.7% (320)	7.1%***
Childcare	38.6% (115)	25.0% (544)	13.6%***
Income-generating activities	9.7% (29)	4.5% (99)	5.2%***
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	793.62 (912.26)	524.01 (676.30)	269.61***

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

The association between being visited by a home community-based carers and greater responsibility in children was expected given that only homes with the most unwell members and in the greatest need would be eligible for such services. Indeed, parents in households visited by a carer exhibited poorer health (t[2,471] = 5.64; $p < .001$), more HIV/AIDS-illness (x^2[1] = 43.38; $p < .001$), and clinically significant anxiety (x^2[1] = 21.89; $p < .001$) and depression (x^2[1] = 33.26; $p < .001$), in addition to those households being poorer based on parental Economic Asset Index scores (x^2[1] = 16.65; $p < .001$), children's Indicators of Poverty and Social Exclusion scores (t[2,474] = 2.94; $p = .003$), and hunger (x^2[1] = 25.81; $p < .001$). Additionally, more of the homes visited by a carer were further from the local clinic in terms of travel time (x^2[1] = 11.54; $p = .001$) (*Table 5.18*).

Table 5.18
Home Community-Based Carer Presence and Predictor Variables

Responsibility outcome	Carer present (*n* = 298)	Carer not present (*n* = 2,178)	Mean difference
Dichotomous responsibility outcomes (per cent engaging, *n*)			
Poor parental health and functioning	27.2% (81)	17.6% (384)	9.6%***
Parental HIV/AIDS-illness	36.6% (109)	26.2% (570)	10.4%***
Parental chronic illness (non-HIV/AIDS)	33.9% (101)	35.5% (773)	1.6%
Parental anxiety	24.2% (72)	14.0% (304)	10.2%***
Parental depression	50.7% (151)	33.6% (732)	17.1%***
Economic Asset Index	28.9% (86)	18.8% (409)	10.1%***
Hunger (poverty)	23.6% (70)	12.7% (276)	10.9%***
Time to clinic (> 50 min)	21.1% (63)	13.7% (299)	7.4%***
Continuous responsibility outcomes: mean (standard deviation)			
Adult:Child ratio	1.14 (.88)	1.28 (1.03)	.14*
Indicators of Poverty and Social Exclusion	6.18 (2.12)	6.57 (2.12)	.39**

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Home community-based carer presence was used in regression analyses, which controls for parental illness, to determine whether being visited by a carer was a significantly protective factor against children's engagement in caring tasks and responsibility workload.

4.4 Standardised predictor and outcome variables

4.4.1 Parental illness

Physical health and chronic illness

All parental chronic illnesses were associated with children's engagement in medical care. Parental HIV/AIDS, tuberculosis (TB), and diabetes were each significantly associated with three outcomes (intimate, medical, and childcare). No type of parental illness was significantly associated with children's engagement in income-generating activities. An additional variable was created to analyse the impact of non-HIV/AIDS chronic illnesses, which dichotomised only those par-

ents not identified as HIV/AIDS-ill. Nearly half of non-HIV/AIDS-ill parents (48.6%; *n* = 874) had at least one non-HIV/AIDS chronic illness. Parental non-HIV/AIDS chronic illness was significantly associated with children's engagement in intimate care ($x^2[1] = 53.36$; $p < .001$) and medical care ($x^2[1] = 100.13$; $p < .001$). Interestingly, childcare was *more* prevalent among children whose parents did not have a chronic illness ($x^2[1] = 5.94$; $p = .015$). This finding could be the result of the large number of bivariate analyses conducted in this chapter without using a correspondingly conservative *p*-value or Bonferroni correction. Bivariate analyses of associations between parental illness types and children's responsibilities are summarised in *Table 5.20*.

Table 5.20
Bivariate Associations, Parental Chronic Illness and Responsibility Outcomes

Responsibility outcome	Poor health and functioning (*n* = 465)	Better health and functioning (*n* = 2,011)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	17.8% (83)	6.0% (120)	11.8%***
Medical care	33.8% (157)	11.3% (228)	22.5%***
Childcare	29.7% (138)	25.9% (521)	3.8%
Income-generating activities	7.5% (35)	4.6% (93)	2.9%*
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	675.11 (862.93)	528.77 (672.19)	146.34***

	HIV/AIDS (*n* = 679)	Non-HIV/AIDS (*n* = 1,797)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	12.2% (83)	6.7% (120)	5.5%***
Medical care	24.9% (169)	12.0% (216)	12.9%***
Childcare	34.5% (234)	23.7% (425)	10.8%***
Income-generating activities	5.6% (38)	5.0% (90)	0.6%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	640.21 (764.74)	540.10 (731.97)	100.11**

	Tuberculosis (*n* = 416)	Non-TB (*n* = 2,060)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	11.1% (46)	7.6% (157)	3.5%*
Medical care	25.0% (104)	13.6% (281)	11.4%***
Childcare	32.5% (135)	25.4% (254)	7.1%**
Income-generating activities	6.5% (27)	4.9% (101)	1.6%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	642.91 (831.89)	538.75 (686.67)	104.16*

	Cancer (*n* = 20)	Non-cancer (*n* = 2,456)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	25.0% (5)	8.1% (198)	16.9%**
Medical care	40.0% (8)	15.4% (377)	14.6%**
Childcare	45.0% (9)	26.5% (650)	18.5%
Income-generating activities	5.0% (1)	5.2% (127)	0.2%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	716.70 (959.18)	554.94 (711.85)	161.76

	Diabetes (*n* = 136)	Non-Diabetes (*n* = 2,340)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	19.9% (27)	7.5% (176)	12.4%***
Medical care	31.6% (43)	14.6% (342)	17.0%***
Childcare	21.3% (29)	26.9% (630)	5.6%
Income-generating activities	3.8% (5)	5.3% (123)	1.5%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	585.68 (833.42)	554.54 (706.63)	31.14

	Epilepsy (*n* = 27)	Non-epilepsy (*n* = 2,448)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	18.5% (5)	8.1% (198)	10.4%*
Medical care	33.3% (9)	15.4% (376)	17.9%**
Childcare	22.2% (6)	26.7% (653)	4.5%
Income-generating activities	7.4% (2)	5.1% (126)	2.3%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	320.71 (454.44)	558.85 (715.98)	238.14

	Asthma (*n* = 120)	Non-asthma (*n* = 2,356)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	13.3% (16)	7.9% (187)	5.4%*
Medical care	28.3% (34)	14.9% (351)	13.4%***
Childcare	26.3% (25)	26.9% (634)	0.6%
Income-generating activities	7.1% (8)	5.1% (120)	2.0%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	496.53 (549.05)	559.29 (721.43)	62.77

	Hypertension (*n* = 700)	Non-hypertension (*n* = 1,776)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	13.0% (91)	6.3% (112)	6.7%***
Medical care	26.3% (184)	11.3% (201)	15.0%***
Childcare	26.7% (187)	26.6% (472)	0.1%
Income-generating activities	6.3% (44)	4.7% (84)	1.6%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	581.59 (738.79)	546.27 (703.98)	35.32

	Arthritis (*n* = 733)	Non-arthritis (*n* = 1,743)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	13.1% (96)	6.1% (107)	7.0%***
Medical care	25.0% (183)	11.6% (202)	13.4%***
Childcare	25.5% (187)	27.1% (472)	1.6%
Income-generating activities	5.0% (37)	5.2% (91)	0.2%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	548.74 (806.19)	559.41 (671.71)	10.67

	Disability (*n* = 174)	Non-disability (*n* = 1,602)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	12.1% (21)	7.9% (182)	4.2%
Medical care	24.7% (43)	14.9% (342)	9.8%***
Childcare	24.7% (43)	26.8% (616)	2.1%
Income-generating activities	5.2% (9)	5.2% (119)	0.0%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	706.08 (1,042.39)	544.93 (681.80)	161.15*

	Chronic illness (non-HIV/AIDS) (*n* = 874)	Non-chronic illness (*n* = 1,602)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	11.1% (97)	6.6% (106)	4.5%***
Medical care	19.9% (174)	13.2% (211)	6.7%***
Childcare	23.7% (207)	28.2% (452)	4.5%*
Income-generating activities	5.4% (47)	5.1% (81)	0.3%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	552.82 (656.47)	562.55 (809.31)	9.73

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

To evaluate the validity of illnesses accounted for in the survey, parents indicating an illness were compared on general health and functioning (SF-12) scores to those who did not. Every type of parental chronic illness was significantly associated with poorer general health and functioning as measured by the SF-12 (*Figure 5.3*).

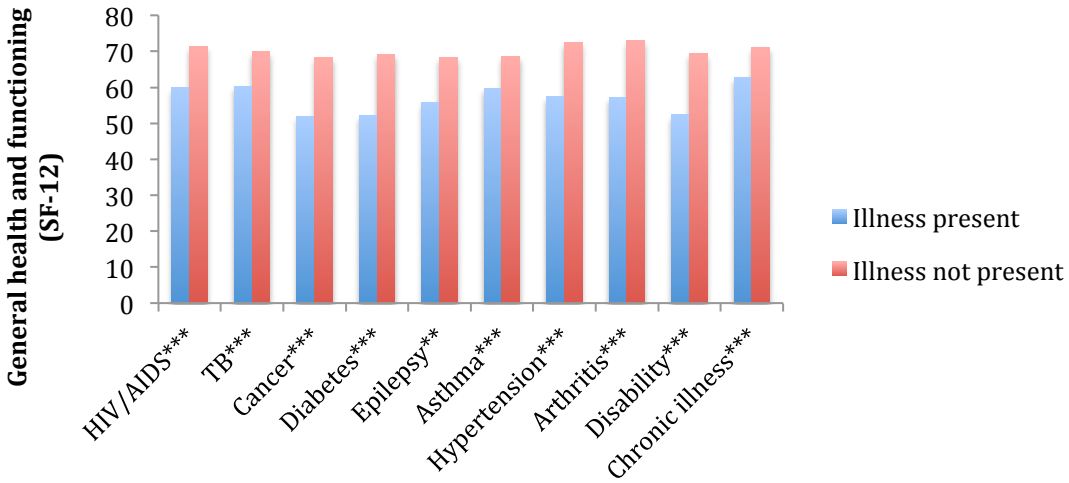


Figure 5.3: **Bivariate associations, parental chronic illness and general health (SF-12)**
***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Several chronic illnesses were significantly associated with greater age: diabetes (t[2,471] = 18.66; $p < .001$), asthma (t[2,471] = 5.01; $p < .001$), hypertension (t[1,179.23] = -19.93; $p < .001$), disability (t[2,471] = 11.52; $p < .001$), and combined non-HIV/AIDS chronic illness (t[1,552.44] = -19.55; $p < .001$); parental HIV/AIDS-illness was significantly associated with being younger (t[2,470] = 13.62; $p < .001$) (*Figure 5.4*).

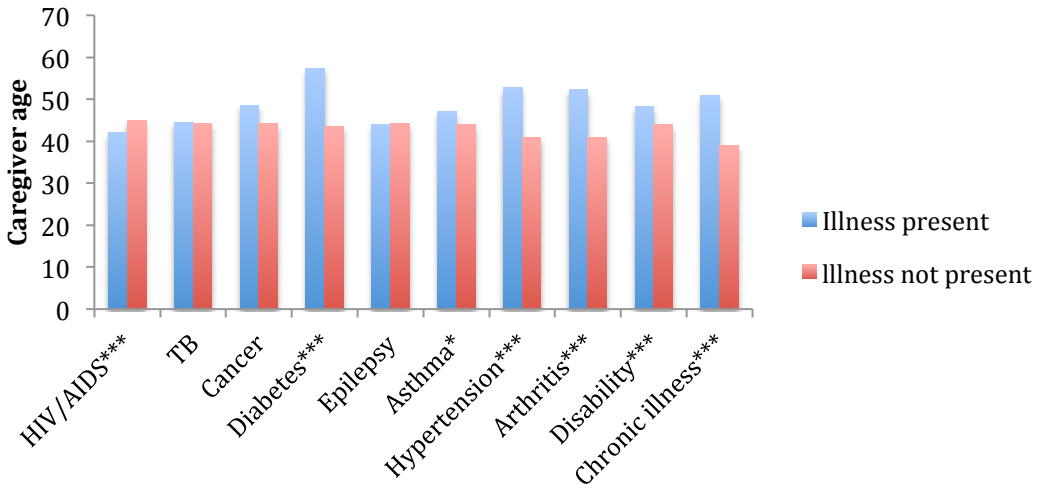


Figure 5.4. **Bivariate associations, parental chronic illness and age**
Note: $*p \leq .05$, $**p \leq .01$, $***p \leq .001$

Two parental chronic illness variables were selected for use in regression analyses: HIV/AIDS-illness and non-HIV/AIDS chronic illness. Parental HIV/AIDS-illness was selected for several reasons. First, it was associated with more child responsibility outcomes than any other chronic illness variable other than tuberculosis. While parental tuberculosis was significantly associated with the same outcomes, it was also significantly associated with HIV/AIDS-illness ($x^2[1] = 260.35$; $p < .001$); indeed, tuberculosis infection is much more likely among HIV/AIDS-ill individuals due to the suppression of the immune system (Lawn, Bekker, Middelkoop, Myer, & Wood, 2006) and may merely indicate people whose HIV/AIDS-illness had a greater impact on their ability to resist other infections. As such, the associations between parental TB illness and children's responsibilities are likely to have been due to compromised immune systems among HIV/AIDS-ill participants. Second, parental HIV/AIDS-illness was significantly associated with being younger. Illness in younger parents may have different affects on household needs compared to illness in older parents. For instance, a younger parent is more likely to be earning money and an illness in that

person can result in a lost income. Third, specifics of the illness's course and treatment may affect children's responsibility outcomes differently. HIV/AIDS-treatments in the form of ART require strict adherence to a complex regimen to maintain effectiveness, which entail greater involvement in administration and reminding for a child with a HIV/AIDS-ill parent than one with a hypertension-unwell parent. Additionally, HIV/AIDS-ill individuals cycle through periods of relatively good and poor health. While a child may be providing medical care in the form of treatment administration consistently, periods of need for intimate care may be more sporadic than for parents with other illnesses. Lastly, HIV/AIDS-stigma may limit household members' access to healthcare or reduce social support from the community and extended family.

Non-HIV/AIDS chronic illness was selected for use in regression analyses to capture the effect of illnesses other than HIV/AIDS on children's responsibilities. The variable was included in regression analyses due to its strong association with both children's intimate and medical care responsibilities, and because it included illnesses affecting a small number of parents such as cancer (n = 20) and epilepsy (n = 27). Additionally, the unexpected association between parental chronic illness and lower prevalence of children's engagement in childcare prompts further investigation.

Mental health

Parent's scores on the Becker Anxiety Inventory and Center for Epidemiologic Studies Depression Scale were dichotomised at standardised cut-off points (BAI ≥ 26; CES-D ≥ 16), and on the Mental Component Score of the SF-12 at the poorest scoring quintile. Of the three mental health measures, only depression was

associated with all responsibility outcomes. A combined variable indicating whether parents had either type of mental health problem (37.9%; *n* = 938) was also significantly associated with all outcome measures (*Table 5.21*).

The combined parental anxiety/depression variable was selected for use in regression analyses as the only parental mental health indicator because it accounts for both types of parental mental health disorders without risking multicollinearity, a realistic concern given the strong association between the two parental mental health disorders ($x^2[1] = 477.45$; $p < .001$).

Table 5.21
Bivariate Associations, Anxiety, Depression, and Combined and Responsibility Outcomes

Responsibility outcome	Mental Component Summary, lowest quintile (*n* = 562)	Mental Component Summary, remainder (*n* = 1,914)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	14.9% (84)	6.2% (119)	8.7%***
Medical care	28.1% (158)	11.9% (227)	16.2%***
Childcare	29.7% (167)	25.7% (492)	4.0%
Income-generating activities	6.6% (37)	4.8% (91)	1.8%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	629.56 (825.34)	534.73 (676.60)	94.83*

	Anxiety (*n* = 376)	Non-anxiety (*n* = 2,100)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	14.4% (54)	7.1% (149)	7.3%***
Medical care	23.9% (90)	14.0% (295)	9.9%***
Childcare	25.5% (96)	26.8% (563)	1.3%
Income-generating activities	8.0% (30)	4.7% (98)	3.3%**
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	604.80 (740.11)	547.56 (709.08)	57.24

	Depression (*n* = 883)	Non-depression (*n* = 1,593)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	11.6% (102)	6.3% (101)	5.3%***
Medical care	22.1% (195)	11.9% (190)	10.2%***
Childcare	30.7% (271)	24.4% (388)	6.3%***
Income-generating activities	6.9% (61)	4.2% (67)	2.7%**
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	625.14 (782.00)	518.07 (670.60)	107.07***

	Combined (*n* = 938)	Neither anxiety nor depression (*n* = 1,538)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	11.4% (107)	6.2% (96)	5.2%***
Medical care	21.9% (205)	11.7% (180)	10.2%***
Childcare	30.5% (286)	24.3% (373)	6.2%***
Income-generating activities	7.0% (66)	4.0% (62)	3.0%***
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	632.32 (788.90)	509.86 (660.19)	122.46***

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

4.4.2 Socio-economic factors

Poverty

Of the three measures of household poverty (Economic Asset Index, Indicators of Poverty and Social Exclusion, and 'hunger'), 'hunger' was significantly associated with the most child responsibility outcomes including engagement in intimate ($x^2[1] = 8.28$; $p = .004$), medical ($x^2[1] = 23.29$; $p < .001$), and childcare ($x^2[1] = 13.36$; $p < .001$), and greater total responsibility time ($t[395.28] = -5.4$; $p < .001$). Being in the poorest quintile of the Economic Asset Index was associated with children's greater engagement in childcare ($x^2[1] = 39.47$; $p < .001$) and greater total responsibility time ($t[635.15] = -4.89$; $p < .001$). On the Indicators of Poverty and Social Exclusion, where lower scores denote greater poverty, poorer

children were more likely to engage in childcare (r = -.078; p < .001), income-generating activities (r = -.047; p = .020), and have greater total responsibility time (r = -.125; p < .001). Interestingly, this was the only poverty measure to be significantly associated with children's engagement in income-generating activities (*Tables 5.22* and *5.23*).

Child hunger was selected for use as an indicator of poverty in regression analyses for two reasons. First, hunger was significantly associated with a greater number of children's responsibility outcomes than either of the other poverty measures. Second, the presence of hunger may identify extremes of poverty (where a child does not have enough to eat) amidst generalised poverty (where it is rare for a household to have a refrigerator or car). Both the Economic Asset Index and the Indicators of Poverty and Exclusion focused primarily on material assets, and were highly influenced by location as indicated by in *Section 4.3.1* and *Table 5.14* of this chapter. Child hunger was also significantly associated with urban/rural location, but as noted above, it is likely a better indicator of extreme poverty, which would be expected to be more common in resource-poor rural communities. However, the myopic focus of this indicator (child hunger as assessed by one variable) holds implications that are elucidated in the discussion.

Table 5.22
Bivariate Associations, Socio-Economic Status and Responsibility Outcomes

	Intimate care	Medical care	Childcare	Income-generating activities	Total responsibility time
Indicators of Poverty and Social Exclusion	-.028	-.007	-.078***	-.047*	-.125***

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Table 5.23
Bivariate Associations, Poverty, Hunger, and Responsibility Outcomes

Responsibility outcome	Economic Asset Index, poorest quintile (*n* = 495)	Economic Asset Index, top 80% (*n* = 1981)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	7.9% (39)	8.3% (164)	0.4%
Medical care	13.1% (65)	16.2% (320)	3.1%
Childcare	37.8% (187)	23.8% (472)	14.0%***
Income-generating activities	5.9% (29)	5.0% (99)	0.9%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	695.86 (890.53)	521.37 (658.28)	174.49***

	Not enough food at least once a week (*n* = 346)	Enough food all week (*n* = 2,129)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	12.1% (42)	7.6% (161)	4.5%**
Medical care	24.3% (84)	14.1% (301)	10.2%***
Childcare	34.7% (120)	25.3% (539)	9.4%***
Income-generating activities	7.2% (25)	4.8% (103)	2.4%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	811.05 (985.46)	515.00 (650.54)	296.05***

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Social support

Inadequate social support as indicated by scores < 70 on the Medical Outcomes Social Support Survey were significantly associated with children's greater engagement in intimate ($x^2[1] = 8.62$; $p = .003$), medical ($x^2[1] = 9.10$; $p = .003$), and childcare ($x^2[1] = 11.92$; $p = .001$) (*Table 5.24*).

Table 5.24
Bivariate Associations, Social Support and Responsibility Outcomes

Responsibility outcome	Adequate social support (*n* = 1,281)	Inadequate social support (*n* = 1,195)	Mean difference
Dichotomous responsibility outcomes: % (*n*)			
Intimate care	6.6% (85)	9.9% (118)	3.3%**
Medical care	13.4% (172)	17.8% (213)	4.4%**
Childcare	23.7% (303)	29.8% (356)	6.1%***
Income-generating activities	5.0% (64)	5.4% (64)	0.4%
Continuous responsibility outcomes: mean (standard deviation)			
Total responsibility time (min)	572.67 (663.66)	538.65 (757.88)	34.02

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

5 Chapter summary

Responsibilities were nearly ubiquitous among children in the sample. Almost every child was engaged in some type of domestic responsibility and around one-fifth was providing care to an unwell person. On average, children engaged in ten hours of responsibilities per week.

Several factors were associated with children having greater total responsibility time, providing care for an unwell person, and caring for other children in the home. These included:

- Being an older or female child
- Child and parental gender-matching
- Greater distance to a local clinic
- Being visited by an home community-based carer
- Poor parental physical health, HIV/AIDS-illness, chronic illness, and mental health disorders
- Poverty
- Lack of social support

Some associations were counter-intuitive such as being from an urban area's association with less time spent on responsibilities but a greater engagement in providing care despite better overall parental health and lower illness preva-

lence. Regression analyses, covered in the next chapter, were necessary to explore this and other relationships and to identify drivers of child responsibility. Predictor-outcome associations are summarised in *Table 5.25*.

Several predictor factors including poverty/socio-economic status and parental physical and mental health were assessed with multiple measures. To avoid multicollinearity in regression analysis, only one variable per factor was used in the models. For each outcome, variables were selected using the strength and number of associations with child responsibility outcomes found in this chapter and the theoretical considerations and suggestions of existing research presented in the literature review (*Chapter 2*). Hypothesised moderating socio-demographic factors are presented along with their indicative measures in *Table 5.26*. Selected measures are indicated with '*'.

Table 5.25
Summary, Significance of Predictor and Outcome Associations

	Intimate care	Medical care	Childcare	Income-generating activities	Total responsibility time
Parental illness indicator					
Poor physical health	< .001***	< .001***	.097	.011*	.001***
HIV/AIDS	< .001***	< .001***	< .001***	.555	.007**
Tuberculosis	.020*	< .001***	.003**	.182	.017*
Cancer	.006**	.002**	.062	.973	.313
Diabetes	< .001***	< .001***	.151	.419	.670
Epilepsy	.049*	.010**	.603	.597	.085
Asthma	.036*	< .001***	.142	.448	.348
Hypertension	< .001***	< .001***	.944	.115	.268
Arthritis	< .001***	< .001***	.420	.859	.734
Disability	.054	.001***	.556	.999	.046*
Combined chronic illness (non-HIV/AIDS)	< .001***	< .001***	.015*	.730	.746
Poor mental health (MCS from SF-12)	< .001***	< .001***	.059	.085	.013*
Anxiety (BAI)	< .001***	< .001***	.606	.008**	.165
Depression (CES-D)	< .001***	< .001***	.001***	.004**	.001***
Combined, depression and anxiety	< .001***	< .001***	.001***	.001***	< .001***
Household/community factors					
Adult:Child ratio (transformed)	.007**	.269	< .001***	.511	< .001***
Urban/rural location	< .001***	.001***	< .001***	.152	< .001***
Poverty (hunger)	.004**	< .001***	< .001***	.063	< .001***
Economic Asset Index (dichotomised)	.772	.097	< .001***	.624	< .001***
Indicators of Poverty and Social Exclusion	.161	.726	< .001***	.020*	< .001***
Adequate social support (MOS)	.003**	.003**	.001***	.686	.234
Time to clinic (> 30 min)	.534	.875	.017*	.162	< .001***
Time to clinic (> 50 min)	.239	.011*	< .001***	.033*	< .001***
Home community-based carer presence	.139	.001***	< .001***	< .001***	< .001***

	Intimate care	Medical care	Childcare	Income-generating activities	Total responsibility time
Parent type					
Parent type (biological parent, grandparent, foster)	< .001***	< .001***	.001***	.667	.982
Biological parent vs. grandparent	.003**	.002**	.001***	-	-
Biological parent vs. foster	.051	.053	.025*	-	-
Grandparent vs. foster	< .001***	< .001***	.046*	-	-
Child/parent gender-matching	.003**	.113	< .001***	.058	< .001***
Child factors					
Age	.177	< .001***	.031*	< .001***	< .001***
Gender	.002**	.051	< .001***	.001***	< .001***
Orphanhood	.434	.007**	.032*	.032*	.043*
Completion of compulsory education	.278	.102	.002**	.248	.955

***Note*: *$p \leq .05$, **$p \leq .01$, ***$p \leq .001$**

Table 5.26
Factors and Selected Measures

Factor		Measures
Child factors	Child age	Child age (dichotomised, 10-14 and 15-17)*
	Child gender	Child gender*
	Orphanhood	Whether a child has lost either his mother or father*
	Level of education	Completion of compulsory education*
Parental factors	General health and physical illness	General health and functioning (SF-12)
		Lowest quintile of Physical Component Scores (SF-12)*
		HIV/AIDS-illness*
		Tuberculosis illness
		Cancer
		Diabetes
		Epilepsy
		Asthma
		Hypertension
		Disability
		Combined chronic illness (non-HIV/AIDS)*
	Parental mental health	Centre for Epidemiologic Studies Depression Scale (CES-D)
		Beck Anxiety Inventory (BAI)
		Combined (depression and anxiety, dichotomised)*
Child/parent relationship factors	Parent type	Parent, grandparent, and foster dummy variables*
	Child/parent gender-matching	Child/parent gender-matching*
Household/community factors	Adult presence	Household Adult:Child ratio (transformed)*
	Urban/rural location	Urban/rural location*
	Poverty	South African Food Consumption Survey
		South African Food Consumption Survey (dichotomised at one day of not having enough food)*
		Economic Asset Index (dichotomised at lowest quintile)
		Indicators of Poverty and Social Exclusion
	Access to healthcare	Travel time to clinic (dichotomised at > 50 minutes)*
		Travel time to clinic (dichotomised at > 30 minutes)
	Visited by home community-based carer	Presence of home community-based carer in previous month*
	Social support	MOS Social Support Survey (dichotomised at 'adequate' score [≥ 70]) *

Chapter 6: Results

This chapter presents the results of multiple regression analyses to identify which parental illness and socio-demographic factors drive child responsibility. *Section 1* discusses the aims of this chapter and briefly covers the significance criteria. *Section 2* presents results of preliminary analyses on the associations between each individual parental illness indicator and responsibility outcomes while controlling for participant demographics (urban/rural location, poverty, child age and gender). *Section 3* describes stepwise regression analyses for each individual responsibility outcome (engagement in intimate care, medical care, childcare, and income-generating activities; total responsibility time) with predictor variables that had either been significantly associated with outcomes in the previous chapter or were theoretically relevant to the analysis. Within the context of research questions, results are summarised in *Section 4*.

1 Chapter aims

The aim of this chapter is to conduct multiple regression analyses addressing the following research questions:

Predictors of children caring for their parents

- Does parental illness predict children's engagement in intimate or medical care?
- What other factors predict children's engagement in intimate or medical care?

Predictors of children's responsibility workload

- Does parental illness predict greater responsibility workloads in children?
- What other factors predict greater responsibility workloads in children?

Due to the large number of analyses conducted in this chapter, significance was set at a conservative $p \leq .01$ to avoid Type I Error, or incorrect rejection of a true null hypothesis.

2 Parental illness and children's responsibilities

In the previous chapter, bivariate analyses found significant associations between parental illness and children's responsibilities. This section determines whether parental health indicators (poor physical health, HIV/AIDS-illness, non-HIV/AIDS chronic illness, and anxiety/depression) are independently associated with children's responsibilities while controlling for socio-demographic factors (child age, child gender, urban/rural location, and poverty as assessed by hunger). All regression models in this section were significant at $p < .001$. Results are presented at the end of this section in *Tables 6.1* to *6.4*.

Children with parents in the poorest physical health quintile were significantly more likely to engage in intimate (OR = 3.42; 99% CI = 2.28-5.12) and medical care (OR = 3.89; 99% CI = 2.83-5.34), and have greater responsibility time burdens ($\beta = .07$; $p = .001$) when controlling for socio-demographic variables. There were no independent associations between parental illness and children's engagement in childcare or income-generating activities. Associations between parental poor physical health and children's responsibility outcomes controlling for socio-demographic variables are presented in *Table 6.1*.

Children with HIV/AIDS-ill parents were more likely to engage in intimate care (OR = 2.16; 99% CI = 1.44-3.24), medical care (OR = 2.64; 99% CI = 1.93-3.61), and childcare (OR = 1.37; 99% CI = 1.04-1.79) when controlling for socio-

demographic variables. They were no more likely to engage in income-generating activities or have greater total responsibility time. Associations between parental HIV/AIDS-illness and children's responsibility outcomes while controlling for socio-demographic variables are presented in *Table 6.2*.

Children whose parents suffered from a non-HIV/AIDS chronic illness were more likely to engage in intimate (OR = 1.62; 99% CI = 1.10-2.38) and medical care (OR = 1.54; 99% CI = 1.14-2.07) when controlling for socio-demographic variables. They were no more likely to engage in childcare or income-generating activities, or to have greater total responsibility times. Associations between parental chronic illness and children's responsibility outcomes controlling for socio-demographic variables are presented in *Table 6.3*.

Children whose parents met cut-offs for either anxiety or depression were more likely to engage in intimate (OR = 2.09; 99% CI = 1.41-3.10) and medical care (OR = 2.19; 99% CI = 1.62-2.95) and income-generating activities (OR = 1.67; 99% CI = 1.03-2.71) when controlling for socio-demographic variables. There was no link between parental depression/anxiety and children's engagement in childcare or total responsibility time. Associations between parental mental health and children's responsibility outcomes controlling for socio-demographic variables are presented in *Table 6.4*.

Table 6.1
Multiple Regressions, Parental illness, and Child Responsibilities (OR 99% CI; Standardised Coefficients)

	Intimate care	Medical care	Childcare	Income-generating activities	Total responsibility time
Parental illness indicator					
Poor physical health	3.42** (2.28-5.12)	3.89** (2.83-5.34)	1.18 (.86-1.61)	1.56 (.91-2.67)	.07**
Household factors					
Rural location	.51** (.34-.76)	.63** (.46-.85)	3.33** (2.59-4.32)	1.34 (.83-2.18)	.18**
Food poverty	1.63 (.99-2.69)	1.84 (1.25-2.71)	1.24 (.88-1.74)	1.42 (.77-2.62)	.11**
Child demographics					
Older	1.12 (.76-1.67)	1.46** (1.08-1.98)	1.30* (1.01-1.67)	2.53** (1.56-4.08)	.14**
Being female	1.66** (1.11-2.48)	1.29 (.95-1.74)	2.30** (1.78-2.97)	.52** (.32-.84)	.20**
Model statistics					
R	-	-	-	-	.34
R^2	-	-	-	-	.12
Adjusted R^2/ Nagelkerke R^2	.09	.11	.14	.05	.12

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

Table 6.2
Multiple Regressions, Parental HIV/AIDS-Illness, and Child Responsibilities (OR 99% CI; Standardised Coefficients)

	Intimate care	Medical care	Childcare	Income-generating activities	Total responsibility time
Parental illness indicator					
HIV/AIDS	2.16** (1.44-3.24)	2.64** (1.93-3.61)	1.37* (1.04-1.79)	1.07 (.63-1.82)	-.01
Household factors					
Rural location	.46** (.30-.69)	.54** (.40-.74)	3.18** (2.44-4.15)	1.32 (.81-2.17)	.18**
Food poverty	1.70* (1.04-2.80)	1.86** (1.27-2.72)	1.20 (.85-1.69)	1.49 (.81-2.75)	.12**
Child demographics					
Older	1.18 (.80-1.74)	1.54** (1.14-2.07)	1.31* (1.01-1.68)	2.55** (1.58-4.12)	.15**
Being female	1.57* (1.06-2.34)	1.21 (.90-1.63)	2.29** (1.77-2.96)	.52** (.32-.84)	.20**
Model statistics					
R	-	-	-	-	.34
R^2	-	-	-	-	.11
Adjusted R^2/ Nagelkerke R^2	.06	.08	.14	.05	.11

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

Table 6.3
Multiple Regressions, Parental Non-HIV/AIDS Chronic Illness and Child Responsibilities (OR 99% CI; Standardised Coefficients)

	Intimate care	Medical care	Childcare	Income-generating activities	Total responsibility time
Parental illness indicator					
Chronic illness (non-HIV/AIDS)	1.62** (1.10-2.38)	1.54** (1.41-2.07)	.97 (.74-1.27)	1.06 (.64-1.74)	.04
Household factors					
Rural location	.57** (.38-.85)	.70* (.51-.94)	3.31** (2.54-4.32)	1.35 (.83-2.21)	.18**
Food poverty	1.97** (1.21-3.21)	2.18** (1.50-3.16)	1.27 (.90-1.77)	1.51 (.82-2.76)	.12**
Child demographics					
Older	1.14 (.77-1.68)	1.46** (1.09-1.96)	1.30* (1.01-1.68)	2.54** (1.57-4.10)	.15**
Being female	1.60* (1.08-2.38)	1.24 (.93-1.67)	2.29** (1.77-2.96)	.52** (.32-.84)	.20**
Model statistics					
R	-	-	-	-	.34
R^2	-	-	-	-	.11
Adjusted R^2/ Nagelkerke R^2	.04	.05	.14	.05	.11

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

Table 6.4
Multiple Regressions, Parental Anxiety/ Depression, and Child Responsibilities (OR 99% CI; Standardised Coefficients)

	Intimate care	Medical care	Childcare	Income-generating activities	Total responsibility time
Parental illness indicator					
Depression or anxiety	2.09** (1.41-3.10)	2.19** (1.62-2.95)	1.12 (.87-1.45)	1.67* (1.03-2.71)	.04
Household factors					
Rural location	.46** (.31-.70)	.57** (.42-.77)	3.27** (2.51-4.26)	1.24 (.76-2.02)	.17**
Food poverty	1.71* (1.04-2.80)	1.90** (1.30-2.77)	1.24 (.88-1.74)	1.37 (.74-2.53)	.11**
Child demographics					
Older	1.16 (.78-1.71)	1.49** (1.11-2.00)	1.30* (1.01-1.67)	2.52** (1.56-4.08)	.15**
Being female	1.60* (1.08-2.38)	1.25 (.93-1.67)	2.29** (1.78-2.96)	.52** (.32-.85)	.20**
Model statistics					
R	-	-	-	-	.34
R^2	-	-	-	-	.11
Adjusted R^2/ Nagelkerke R^2	.06	.07	.14	.06	.11

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

Preliminary regression analyses found that every parental illness indicator was associated with at least two child responsibility outcomes. All four parental illness indicators were associated with children's engagement in intimate and medical care. The only parental illness associated with responsibility time burden was poor physical health. No parental health indicators other than parental HIV/AIDS were associated with children's childcare responsibilities, and only parental anxiety or depression was associated with children's engagement in income-generating activities. To avoid problems from multicollinearity, regressions including either parental HIV/AIDS or chronic illness did not include the poor physical health variable.

3 Parental illness and socio-demographic factors

The following analyses were conducted to determine whether parent type, household/community, and child factors were significant predictors of children's responsibilities and whether they moderated the impact of parental illness.

3.1 Personal care responsibilities

This section presents analyses of the impact of parental illness and socio-demographic factors on children's engagement in personal care outcomes (intimate and medical care) to address the following questions:

Predictors of children caring for their parents

- Does parental illness predict children's engagement in intimate or medical care?
- What other factors predict children's engagement in intimate or medical care?

Multiple logistic regressions were used to identify significant predictor variables. Results are given as odds ratios.

3.1.1 Intimate care

Predictors that were selected for their significant association with children's engagement in intimate care tasks included parental HIV/AIDS-illness, non-HIV/AIDS chronic illness, anxiety/depression, and type, adult:child ratio, urban/rural location, hunger, and child gender. Time to clinic (> 50 min) and home community-based carer presence were not significantly associated with this outcome but were included for theoretical reasons. For one, both factors were indicative of a household's access to healthcare; greater travel time or absence of home community-based carers may each result in greater reliance on internal resources including children to meet its caring needs, or an increase in need if appropriate treatments and medicines are unobtainable. Additionally, potential

confounders may have masked the effect and directionality of both variables in bivariate association analyses. Home community-based carer presence may also indicate other co-resident ill individuals that the child may be caring for. The literature review identified having a home community-based carer as potentially protective against children engaging in intimate care responsibilities, theorising that a carer would reduce a household's illness burden by providing care to the ill person and/or addressing of other domestic needs. Results are presented in *Table 6.5*. Gender-matching was included in separate analyses of boys and girls to avoid the confounding nature of children's gender; the analyses only include children with a parent identified as ill. Results of the follow-up analyses are presented in *Table 6.6*.

Parental HIV/AIDS-illness (Model 4: OR = 4.76; 99% CI = 2.48-9.13) and chronic illness (Model 4: OR = 3.59; 99% CI = 1.90-6.78) were significant predictors of children's engagement in intimate care when controlling for relevant socio-demographic factors, while anxiety/depression approached significance (p = .012) (Model 4: OR = 1.50; 99% CI = .99-2.27). Girls had significantly greater odds of engaging in intimate care (Model 4: OR = 1.60; 99% CI = 1.07-2.39), while adequate social support was protective against it (Model 4: OR = .65; 99% CI = .44-.96). Surprisingly, being from the rural site was also protective against children's engagement in intimate care (Model 4: OR = .45; 99% CI = .28-.73). In the regressions presented in *Table 6.6*, gender-matching was not a significant predictor of either girls' or boys' engagement in intimate care.

Table 6.5
Multiple Regressions Testing Associations of Parental illness, Parent Type, Household/Community, and Child Factors on Children's Engagement in Intimate Care (OR 99% CI)

	Model 1	Model 2	Model 3	Model 4
Parental illness indicator				
HIV/AIDS-illness	4.72** (2.50-8.93)	4.63** (2.45-8.78)	4.78** (2.49-9.15)	4.76** (2.48-9.13)
Chronic illness (non-HIV/AIDS)	4.64** (2.52-8.57)	4.16** (2.22-7.78)	3.62** (1.92-6.83)	3.59** (1.90-6.78)
Anxiety or depression	1.51* (1.01-2.24)	1.47 (.99-2.19)	1.50 (.99-2.27)	1.50 (.99-2.27)
Parent type (constant: biological parent)				
Grandparent	-	1.35 (.85-2.14)	1.23 (.77-1.96)	1.24 (.78-1.99)
Foster parent	-	.74 (.39-1.40)	.70 (.37-1.33)	.68 (.36-1.30)
Household/community factors				
Adult:Child ratio	-	-	1.28 (.79-2.09)	1.30 (.79-2.13)
Rural location	-	-	.45** (.28-.72)	.45** (.28-.73)
Food poverty	-	-	1.42 (.86-2.36)	1.42 (.85-2.35)
Adequate social support	-	-	.65* (.44-.96)	.65* (.44-.96)
Time to clinic (> 50 min)	-	-	.93 (.49-1.75)	.92 (.49-1.74)
Carer presence	-	-	1.51 (.84-2.69)	1.51 (.84-2.70)
Child demographics				
Older	-	-	-	1.19 (.80-1.77)
Being female	-	-	-	1.60* (1.07-2.39)
Model statistics				
Nagelkerke R^2	.08	.08	.11	.12
Overall *p*-value	< .001	*ns*	< .001	.005

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

Table 6.6
Linear Regression Testing Associations of Intimate Care Responsibilities and Child/Parent Gender-Matching by Boys and Girls with Ill Parents (OR 99% CI)

	Boys	Girls
Parent type (constant: biological parent)		
Grandparent	1.22 (.57-2.64)	1.08 (.59-1.95)
Foster parent	.61 (.19-1.99)	.67 (.29-1.58)
Household/community factors		
Adult:Child ratio	1.34 (.58-3.11)	1.29 (.67-2.45)
Rural location	.44* (.19-.98)	.50* (.27-.92)
Food poverty	1.32 (.54-3.24)	1.54 (.81-2.94)
Adequate social support	.57 (.29-1.14)	.59* (.35-.99)
Time to clinic (> 50 min)	.71 (.21-2.36)	1.14 (.53-2.47)
Carer presence	1.93 (.73-5.13)	1.47 (.69-3.12)
Child demographics		
Older	1.21 (.60-2.42)	1.25 (.75-2.10)
Gender-matching	1.25 (.46-3.41)	1.26 (.45-3.49)
Model statistics		
Nagelkerke R^2	.06	.05
Overall *p*-value	.024	.004

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

3.1.2 Medical care

Predictors selected for their significant association with children's engagement in medical care tasks in bivariate analyses included parental HIV/AIDS-illness, non-HIV/AIDS chronic illness, mental health indicators, parent type, urban/rural location, social support, clinic travel time, home community-based carer presence, and child age, gender (approaching significance; $p = .051$), and orphan sta-

tus. Only variables that were significantly associated with children's engagement in medical care in bivariate analyses were included in this regression model. Results of regressions analysis assessing the impact of parental illness on children's engagement in medical care are summarised in *Table 6.7*.

Parental HIV/AIDS-illness (Model 4: OR = 6.01; 99% CI = 3.68-9.82), chronic illness (Model 4: OR = 4.05; 99% CI = 2.50-6.55), and anxiety/depression (Model 4: OR = 1.52; 99% CI = 1.10-2.09) were all significant predictors of children's engagement in medical care responsibilities when controlling for relevant socio-demographic variables. Poverty as measured by hunger (Model 4: OR = 1.56; 99% CI = 1.05-2.32), home community-based carer presence (Model 4: OR = 1.67; 99% CI = 1.07-2.60), and being older (Model 4: OR = 1.52; 99% CI = 1.12-2.08) were also significant predictors. Adequate social support was a significant protective factor (Model 4: OR = .72; 99% CI = .53-.97). Similar to the findings of the regression on children's engagement in intimate care, rural location was a protective factor against children's engagement in medical care (Model 4: OR = .54; 99% CI = .38-.77), and high clinic travel time approached significance as a *protective* factor against children engaging in medical care (p = .012) (Model 4: OR = .61; 99% CI = .37=1.01).

Table 6.7
Multiple Regressions Testing Associations of Parental illness with Parent Type, Household/Community, and Child Factors on Children's Engagement in Medical Care (OR 99% CI)

	Model 1	Model 2	Model 3	Model 4
Parental illness indicator				
HIV/AIDS-illness	5.97** (3.70-9.63)	5.92** (3.67-9.56)	6.06** (3.72-9.87)	6.01** (3.68-9.82)
Chronic illness (non-HIV/AIDS)	4.95** (3.12-7.87)	4.59** (2.86-7.37)	4.16** (2.58-6.72)	4.05** (2.50-6.55)
Anxiety or depression	1.57** (1.16-2.13)	1.54** (1.13-2.09)	1.53** (1.11-2.11)	1.52** (1.10-2.09)
Parent type (constant: biological parent)				
Grandparent	-	1.27 (.88-1.83)	1.19 (.82-1.72)	1.19 (.81-1.74)
Foster parent	-	.87 (.56-1.38)	.85 (.53-1.34)	.76 (.47-1.23)
Household/community factors				
Rural location	-	-	.53** (.38-.75)	.54** (.38-.77)
Food poverty	-	-	1.58* (1.07-2.33)	1.56* (1.05-2.32)
Adequate social support	-	-	.72* (.53-.98)	.72* (.53-.97)
Time to clinic (> 50 min)	-	-	.63 (.38-1.05)	.61 (.37-1.01)
Carer presence	-	-	1.69* (1.09-2.63)	1.67* (1.07-2.60)
Child demographics				
Older	-	-	-	1.52** (1.12-2.08)
Being female	-	-	-	1.23 (.91-1.67)
Orphanhood	-	-	-	1.19 (.85-1.65)
Model statistics				
Nagelkerke R^2	.12	.12	.16	.17
Overall *p*-value	< .001	*ns*	< .001	< .001

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

3.1.3 Urban versus rural

Given the surprising findings regarding the impact of location on children's engagement in personal care responsibilities, follow-up analyses examined each site separately to determine whether there were alternative drivers or patterns at each site. The findings are summarised in *Tables 6.8* and *6.9*.

In the rural site, being female was a significant predictor of children's engagement in intimate care and being older was a significant predictor for medical care, though neither was the case in the urban site. Additionally, parental anxiety/depression was a significant predictor of children's engagement in both personal care responsibilities, but only in the rural site.

Table 6.8
Multiple Regression Model of Children's Engagement in Intimate Care by Urban/Rural Location (OR 99% CI)

	Urban site	Rural site
Parental illness indicator		
HIV/AIDS-illness	5.81** (2.38-14.21)	3.63** (1.40-9.41)
Chronic illness (non-HIV/AIDS)	4.13** (1.80-9.47)	2.82* (1.02-7.78)
Anxiety or depression	1.22 (.71-2.10)	2.07* (1.05-4.08)
Parent type (constant: biological parent)		
Grandparent	1.33 (.74-2.39)	1.07 (.48-2.40)
Foster parent	.72 (.32-1.62)	.65 (.22-1.90)
Household/community factors		
Adult:Child ratio	1.29 (.71-2.34)	1.34 (.56-3.18)
Food poverty	1.49 (.70-3.18)	1.37 (.69-2.74)
Adequate social support	.60 (.36-1.01)	.71 (.38-1.34)
Time to clinic (> 50 min)	.80 (.16-3.97)	.95 (.47-1.93)
Carer presence	1.87 (.62-5.65)	1.37 (.69-2.73)
Child demographics		
Older	1.08 (.64-1.81)	1.40 (.74-2.62)
Being female	1.40 (.84-2.34)	2.00* (1.03-3.87)
Model statistics		
Nagelkerke R^2	.12	.11
Overall *p*-value	< .001	< .001

Note: ***$p \leq .01$, **$p \leq .001$, *ns* = not significant**

Table 6.9
Multiple Regression Model of Children's Engagement in Medical Care by Urban/Rural Location (OR 99% CI)

	Urban site	Rural site
Parental illness indicator		
HIV/AIDS-illness	9.51** (4.40-20.54)	3.87** (2.06-7.30)
Chronic illness (non-HIV/AIDS)	6.49** (3.18-13.23)	2.24* (1.12-4.50)
Anxiety or depression	1.30 (.83-2.07)	1.86** (1.16-3.00)
Parent type (constant: biological parent)		
Grandparent	1.26 (.77-2.07)	1.00 (.53-1.88)
Foster parent	.66 (.34-1.27)	.98 (.49-1.96)
Household/community factors		
Food poverty	1.21 (.62-2.34)	1.93** (1.17-3.20)
Social support	.53 (.35-.81)	.99 (.63-1.56)
Time to clinic (> 50 min)	.66 (.18-2.48)	.61 (.35-1.06)
Carer presence	2.42 (.93-6.31)	1.50 (.90-2.48)
Child demographics		
Older	1.42 (.93-2.18)	1.76** (1.11-2.79)
Being female	1.26 (.83-1.92)	1.20 (.76-1.89)
Orphanhood	1.33 (.85-2.10)	1.06 (.65-1.72)
Model statistics		
Nagelkerke R^2	.20	.15
Overall *p*-value	< .001	< .001

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

3.1.4 Parent type and personal care responsibilities

Whilst controlling for parental illness in the previous analyses, child/parent relationship exhibited no effect on whether a child engaged in either intimate or

medical care. It was suspected that while parental illness may drive caring responsibilities in children, they might have been more common among certain child/parent relationships. Thus, the fourth models of both personal care stepwise regressions were run excluding parental illness indicators. Though this regression may have omitted factors that were the drivers of children's engagement in personal care, these models could identify living situations in which children are most likely to be caring for an unwell parent. However, neither type of child/parent relationship was significantly predictive of children's engagement in either intimate or medical care responsibility. Results are presented in *Table 6.10*.

Table 6.10
Multiple Regression Model of Children's Engagement in Intimate and Medical Care Excluding Health Indicators (OR 99% CI)

	Intimate care	Medical care
Parent type (constant: biological parent)		
Grandparent	1.12 (.70-1.78)	1.12 (.77-1.63)
Foster parent	.64 (.32-1.28)	.70 (.42-1.16)
Household/community factors		
Adult:Child ratio	1.32 (.79-2.20)	-
Rural location	.48** (.29-.78)	.54** (.38-.77)
Food poverty	1.49 (.89-2.51)	1.83** (1.23-2.73)
Adequate social support	.58** (.39-.88)	.62** (.45-.85)
Time to clinic (> 50 min)	.99 (.52-1.89)	.68 (.41-1.13)
Carer presence	1.60 (.88-2.89)	1.72* (1.09-2.70)
Child demographics		
Older	1.24 (.82-1.88)	1.53** (1.11-2.10)
Being female	1.75** (1.14-2.66)	1.30 (.95-1.78)
Orphanhood	-	1.25 (.89-1.75)
Model statistics		
Nagelkerke R^2	.06	.07
Overall *p*-value	.001	< .001

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

3.1.5 Parental anxiety and depression and general physical health

Another surprising finding was that parental anxiety/depression was a significant predictor of children's engagement in medical care and approached significance with intimate care. It was hypothesised that while these regression models controlled for parental HIV/AIDS and chronic illness, the variables did not indi-

cate the state of parents' physical health. Some parents, for instance, may have been HIV-positive or living with another chronic illness yet in relatively good health. Thus, the Physical Component Score of the SF-12, a continuous indicator of parental physical health (which excludes any mental health items in the SF-12 to avoid multicollinearity), was included in the following regression model to gauge whether a common factor, poor parental physical health, was driving both children's caring responsibilities and parental anxiety and depression. The expected outcome was that parental physical health would be a significant predictor of children's caring responsibilities and parental anxiety/depression would no longer be significant.

The findings, summarised in *Table 6.11*, show that parental anxiety/depression was still a significant predictor of children's engagement in both intimate and medical care tasks even when controlling for parental physical health. Additionally, parental physical health was predictive of children's engagement in both types of care. The next chapter contains a discussion of these findings.

Table 6.11
Multiple Regression Model of Children's Engagement in Intimate and Medical Care to Identify Impact of Parental Mental Health Disorder Controlling for Physical Health and Functioning (OR 99% CI)

	Intimate care	Medical care
Parental illness indicator		
General health and functioning (SF-12, Physical Composite Score)	.98** (.98-.99)	.98** (.98-.99)
Anxiety or depression	1.67** (1.11-2.51)	1.73** (1.26-2.37)
Parent type (constant: biological parent)		
Grandparent	.99 (.62-1.58)	.91 (.62-1.33)
Foster parent	.64 (.34-1.22)	.70 (.44-1.12)
Household/community factors		
Adult:Child ratio	1.26 (.76-2.07)	-
Rural location	.46** (.29-.74)	.57** (.40-.80)
Food poverty	1.47 (.88-2.45)	1.66** (1.12-2.47)
Adequate social support	.64* (.43-.96)	.71* (.53-.97)
Time to clinic (> 50 min)	.95 (.50-1.79)	.63 (.38-1.05)
Carer presence	1.47 (.81-2.64)	1.61* (1.03-2.51)
Child demographics		
Older	1.18 (.79-1.76)	1.49** (1.09-2.03)
Being female	1.60* (1.07-2.39)	1.24 (.92-1.69)
Orphanhood	-	1.24 (.89-1.73)
Model statistics		
Nagelkerke R^2	.12	.15
Overall *p*-value	.005	< .001

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

3.2 Total responsibility time

This section presents analysis of the impact of parental illness and socio-demographic factors on children's total responsibility time. Total responsibility time was the sum of time devoted to all responsibilities in the previous week. The following research questions addressed in this section are:

Predictors of children's responsibility workload

- Does parental illness predict greater responsibility workloads in children?
- What other factors predict greater responsibility workloads in children?

Linear multiple regressions were used to identify significant predictors of children's responsibility time burden. Predictors that were selected for statistically significant association with children's total responsibility time included parental poor physical health and anxiety/depression, adult:child ratio, urban/rural location, food poverty, clinic travel time, home community-based carer presence, and child age, gender, and orphanhood. In the literature review, both parent type and completion of compulsory education were suggested to be important factors, however, each was far from statistical significance in bivariate associations in the previous chapter (p = .982 and p = .955). Thus, neither was included in this regression. Results are presented as standardised coefficients in *Table 6.12*.

Significant predictors of children's greater total responsibility time included parental poor physical health (Model 3: β = .06; p = .002), rural location (Model 3: β = .11; p < .001), food poverty (Model 3: β = .10; p < .001), greater clinic travel time (Model 3: β = .14; p < .001), home community-based carer presence (Model 3: β = .06; p = .001), and the child's being older (Model 3: β = .14; p < .001) and

female (Model 3: β = .20; p < .001). Adequate social support approached significance as a predictor of greater responsibility time (Model 3: β = .05; p = .015).

Table 6.12
Linear Regressions Testing Associations of Parental illness Excluding Poor Health Variable, Household/Community, and Child Factors on Children's Total Responsibility Time (Standardised Coefficients)

	Model 1	Model 2	Model 3
Parental illness indicator			
Poor physical health	.07**	.06*	.06*
Anxiety or depression	.07**	.02	.02
Household/community factors			
Adult:Child ratio	-	-.04	-.03
Rural location	-	.10**	.11**
Food poverty	-	.10**	.10**
Adequate social support	-	.05	.05
Time to clinic (> 50 min)	-	.14**	.14**
Carer presence	-	.07**	.06**
Child demographics			
Older	-	-	.14**
Being female	-	-	.20**
Orphanhood	-	-	.01
Model statistics			
R	.11	.28	.38
Adjusted R^2	.01	.08	.14
Overall p-value	< .001	< .001	< .001

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

3.2.1 Personal and domestic responsibility time burdens

Follow-up analyses were conducted to evaluate the impact of parental illness and socio-demographic factors on children's engagement in personal care and domestic responsibility time burdens. There was an expectation that having an ill parent would increase a child's personal care time burden, though it was unclear whether this would correspond with an increase in domestic responsibility

time burdens as found in the UK in Warren (2007), a decrease as children realign their responsibilities within finite time constraints as suggested in Robson, Ansell, Huber, Gould, and Van Blerk (2006), or no change if children added personal care responsibilities without any corresponding impact in domestic responsibility time burden. The results, which indicate that parental health only affects children's personal care responsibility time burdens, are presented in *Table 6.13*.

Table 6.13
Linear Regressions Testing Associations of Parental illness, Household/Community, and Child Factors on Children's Personal Care and Domestic Responsibility Time (Standardised Coefficients)

	Responsibility time	
	Caring	**Domestic**
Parental illness indicator		
Poor physical health	.15**	.02
Anxiety or depression	.03	.02
Household/community factors		
Adult:Child ratio	-.01	-.05
Rural location	-.05	.15**
Food poverty	.08**	.09**
Adequate social support	.00	.04
Time to clinic (> 50 min)	.00	.16**
Carer presence	.07**	.05*
Child demographics		
Older	.01	.16**
Female	.04	.21**
Orphanhood	.02	.00
Model statistics		
R	.21	.42
Adjusted R^2	.04	.17
Overall *p*-value	< .001	< .001

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

3.2.2 Gender and total responsibility time

A second follow-up was conducted to evaluate the differences in how socio-demographic factors affect boys' and girls' responsibility time burdens. Findings from bivariate and multiple regression analyses indicate that girls engage in significantly more responsibilities than boys. Additionally, qualitative evidence from the literature review suggests alternative pathways for responsibility between boys and girls due to cultural reluctance to remove boys from school to provide help and traditional ideas about the stereotypically gendered nature of most responsibilities (see *Chapter 2*, *Section 3.3.3*). This analysis included all variables controlled for in the above section. Results are presented in *Table 6.14*.

Poor parental physical health was significantly predictive of boys' responsibility time burden (β = .12; p < .001) but not girls. Home community-based carer presence was significantly predictive of girls' responsibility time burden (β = .09; p = .001), but not boys. The remaining significant predictive factors of rural location, poverty as assessed by hunger, time to the local clinic, and being older, were the same for both genders.

Table 6.14
Linear Regressions on Children's Total Responsibility Time, Separated by Gender (Standardised Coefficients)

	Total responsibility time	
	Boys	**Girls**
Parental illness indicator		
Poor physical health	.12**	.03
Anxiety or depression	.01	.04
Household/community factors		
Adult:Child ratio	-.01	-.04
Rural location	.15**	.09*
Food poverty	.08*	.11**
Adequate social support	.03	.06
Time to clinic (> 50 min)	.13**	.15**
Carer presence	.02	.09**
Child demographics		
Older	.09*	.17**
Orphanhood	.00	.02
Model statistics		
R	.30	.35
Adjusted R^2	.09	.12
Overall *p*-value	< .001	< .001

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

3.3 Domestic maintenance responsibilities

This section presents analyses of the impact of parental illness and socio-demographic factors on children's engagement in non-personal care responsibilities (childcare and income-generating responsibilities). Housework responsibilities were not included for reasons discussed in the previous chapter (*Section 4*). The analyses address the following research questions:

- Does parental illness predict greater responsibility workloads in children?
- What other factors predict greater responsibility workloads in children?

Logistic multiple regressions were used to identify significant parental health and socio-demographic predictor variables, and results are presented as odds ratios.

3.3.1 Childcare

Predictors that were selected for their significant association with children's engagement in childcare included parental poor physical health and anxiety/depression, child/parent relationship type, adult:child ratio, rural location, food poverty, adequate social support, clinic travel time, and home community-based carer presence, as well as child age, gender, orphanhood, and completion of compulsory education. Child/parent gender-matching was also significantly associated with engagement in childcare, though it was likely due to its close association with the child being a girl and was therefore not included in this regression due to the risk of multicollinearity and a lack of any theoretical rationale for association. Dichotomised child age and children's completion of compulsory education were not included in the same regression due to the risk of multicollinearity. *Table 6.15* presents the results of the regression including child age and excluding the completion of compulsory education variable. The regression analysis including children's completion of compulsory education in lieu of their age was not significant (p = .278) and as such is neither presented nor interpreted.

Parental HIV/AIDS-illness was significantly predictive of children's childcare responsibility for Models 1 and 2, but only approached significance in Model 3 with the inclusion of household/community factors; in Model 4, it approached significance (p = .011). Significant socio-demographic predictors of children's engagement in childcare included a lower household adult:child ratio (Model 4: OR = .28; 99% CI = .19-.42), rural location (Model 4: OR = 2.33; 99% CI = 1.74-3.13), and the child being older (Model 4: OR = 1.41; 99% CI = 1.08-1.83) and female (Model 4: OR = 2.27; 99% CI = 1.75-2.94). Interestingly, orphanhood was significantly protective against children engaging in childcare (Model 4: OR = .71; 99% CI = .53-.95).

Table 6.15
Logistic Regression Testing Associations of Parental illness, Parent Type, Household/Community and Child Factors on Children's Engagement in Childcare (OR 99% CI)

	Model 1	Model 2	Model 3	Model 4
Parental illness indicator				
HIV/AIDS-illness	1.61** (1.24-2.09)	1.54** (1.18-2.00)	1.29 (.97-1.70)	1.33 (1.00-1.77)
Anxiety or depression	1.21 (.95-1.56)	1.24 (.96-1.59)	1.04 (.80-1.36)	1.06 (.81-1.39)
Parent type (constant: biological parent)				
Grandparent	-	.70* (.51-.97)	.86 (.61-1.21)	.93 (.65-1.32)
Foster parent	-	.79 (.56-1.10)	.89 (.63-1.27)	.96 (.66-1.39)
Household/community factors				
Adult:Child ratio	-	-	.29** (.19-.42)	.28** (.19-.42)
Rural location	-	-	2.22** (1.67-2.96)	2.33** (1.74-3.13)
Food poverty	-	-	1.11 (.79-1.57)	1.13 (.79-1.60)
Adequate social support	-	-	.81 (.63-1.04)	.80 (.62-1.03)
Time to clinic (> 50 min)	-	-	1.08 (.77-1.51)	1.11 (.79-1.57)
Carer presence	-	-	1.33 (.93-1.90)	1.31 (.90-1.89)
Child demographics				
Older (15-17 years)	-	-	-	1.41** (1.08-1.83)
Being female	-	-	-	2.27** (1.75-2.94)
Orphanhood	-	-	-	.71* (.53-.95)
Model statistics				
Nagelkerke R^2	.02	.03	.14	.19
Overall *p*-value	< .001	.006	< .001	< .001

***Note:* *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

3.3.2 Income-generating activities

Predictors that were selected for their significant association with children's engagement in income-generating activities included parental poor physical health and anxiety/depression, clinic travel time, home community-based carer presence, child age, gender, and orphanhood. Food poverty approached significance in bivariate analysis (p = .063) and was included to test whether children took on income-generating activities to supplement poor households' income. Results are presented in *Table 6.16*.

Three variables were predictive of children's engagement in income-generating activities: presence of a home community-based carer (Model 3: OR = 2.06; 99% CI = 1.14-3.72), being older (Model 3: OR = 2.43; 99% CI = 1.50-3.95), and being male (Model 3: OR = .52; 99% CI = .32-.85). Interestingly, poverty as assessed by hunger was not a significant predictor of children's engagement in income-generating activities.

Table 6.16
Logistic Regressions Testing Associations of Parental illness, Household/Community, and Child Factors on Children's Engagement in Income-Generating Activities (OR 99% CI)

	Model 1	Model 2	Model 3
Parental illness indicator			
Poor physical health	.1.49 (.86-2.55)	1.40 (.81-2.43)	1.34 (.77-2.34)
Anxiety or depression	1.68* (1.04-2.72)	1.54 (.94-2.52)	1.52 (.93-2.50)
Household/community factors			
Food poverty	-	1.23 (.66-2.27)	1.26 (.68-2.34)
Carer presence	-	1.98* (1.11-3.54)	2.06* (1.14-3.72)
Child demographics			
Older	-	-	2.43** (1.50-3.95)
Being female	-	-	.52** (.32-.85)
Orphanhood	-	-	1.22 (.74-1.99)
Model statistics			
Nagelkerke R^2	.02	.03	.07
Overall *p*-value	.001	.009	< .001

***Note*: *$p \leq .01$, **$p \leq .001$, *ns* = not significant**

4 Chapter summary

This chapter is summarised with responses to each of the research questions presented at the beginning of this chapter:

Predictors of children caring for their parents

- Does parental illness predict children's engagement in intimate or medical care?
- What other factors predict children's engagement in intimate or medical care?

Both parental HIV/AIDS and non-HIV/AIDS chronic illness were significant predictors of children's engagement in intimate and medical care when controlling

for socio-demographic variables. Parental anxiety/depression was also predictive of children's engagement in medical care and approached significance as a predictor of children's engagement in intimate care. Further analyses that controlled for parental health using a continuous indicator of physical health indicated the relationship between parental mental health disorders and children's caring responsibilities was independent of other health problems.

Child/parent relationship type was not predictive of children's caring responsibilities, even in regressions that excluded parental illness.

Controlling for parental illness and poverty among other socio-demographic variables, children from the urban site were significantly more likely to engage in both types of personal care. Separate analysis found only three differences in significant predictors between the urban and rural site: parental anxiety/depression and children's being older or female were only predictive in the rural site.

Travel time to the local clinic approached significance as a protective factor against children engaging in medical care. Girls were more likely to provide intimate care. Separate analyses indicated being gender-matched with a sick parent was not a significant predictor of children's engagement in intimate care. Older children were more likely to provide medical care.

Predictors of children's responsibility workload

- Does parental illness predict greater responsibility workloads in children?
- What other factors predict greater responsibility workloads in children?

Parental poor physical health was predictive of greater responsibility time burden in children when controlling for socio-demographic variables, though further analysis found this was only true of caring responsibility time burden, and only in boys. Other factors that were predictive of children's greater responsibility time burden were rural location, food poverty, greater distance to the clinic, presence of a home community-based carer, and the child being older and female.

Parental HIV/AIDS-illness approached significance as a predictor of children's engagement in childcare. Lower adult:child ratios, rural location, and the child being older and female were also predictive of children's engagement in childcare, while orphanhood was protective.

No parental health indicator was predictive of children's engagement in income-generating activities when controlling for socio-demographic factors. Predictive socio-demographic factors included being visited by a home community-based carer and the child being older and male. This was the only child responsibility that was more common among boys. Surprisingly, poverty as measured by child hunger was not a significant predictor.

Chapter 7: Discussion and conclusion

The research and findings presented within this thesis explore the relationship between parental illness and child responsibility in South Africa. The first phase of research was a literature review that summarised what was known about the interaction between parental illness and child responsibility in sub-Saharan Africa and highlighted substantial research gaps. The most notable gaps were a limited amount of quantitative evidence exploring how parental illness affects child responsibilities and the moderating influence of socio-demographic factors such as child gender and poverty. Additionally, it was noted that all of the existing tools used to assess child responsibility had either not been adapted to the South African context or did not include caring responsibilities. The second phase of research was an exploratory study that collected data from children living with an ill parent to identify their range of responsibilities. These data were used to create the Child Responsibility Measure, designed to assess the range and time burden of responsibilities among children in deprived South African communities. The third phase of this research was a cross-sectional quantitative survey, which collected data from a large and representative sample of children and their parents regarding responsibility, parental illness, and socio-demographic factors. The resulting data were analysed first to find associations between these factors, then with multiple regressions to determine drivers of child responsibility.

This thesis's findings are discussed within the context of existing literature in *Section 1*. *Section 2* lists strengths and limitations of the research within this thesis. *Section 3* covers implications for policy and practice, and suggestions for fu-

ture research are presented in *Section 4*. The thesis ends with a conclusion in *Section 5*.

1 Key findings and interpretation

Parental illness was found to be a key determinant of children's engagement in personal care and responsibility time burdens. However, many socio-demographic factors were found to influence children's responsibility range and burden, including gender, urban/rural location, and social support. Some findings, including the link between urban location and caring responsibility, were unexpected. This section interprets the meaning of findings within the context of existing research.

1.1 Parental illness and children as care providers

Parental HIV/AIDS-illness and non-HIV chronic illness were significant predictors of children's engagement in caring responsibilities. Parental mental health disorder (anxiety or depression) was predictive of children's caring responsibilities, even when controlling for physical health indicators (parental HIV/AIDS-illness, non-HIV chronic illness, and in separate set of regression analyses, general physical health).

The relationship between parental illness and children's caring responsibilities was expected; qualitative evidence from the literature review and exploratory study had previously linked these factors. The significance of this finding relates to the types of parental illness that are predictive of children's caring responsibilities. Children with HIV/AIDS-ill parents had the greatest odds of engaging in both intimate and medical care responsibilities. The latter was expected given

the increasing availability of ART in South Africa (WHO/UNAIDS/UNICEF, 2011) and their complex adherence regimes that may benefit from child assistance. However, as parental HIV/AIDS-illness was the strongest health predictor of children's engagement in intimate care, it appears that many remain severely affected by the virus and that there is clearly still a need for greater access to effective treatment. Also noteworthy was the association between parental chronic illness and children's caring responsibilities, highlighting the importance of non-HIV/AIDS illnesses. As argued in the introduction, the prevalence of HIV/AIDS and its impact on public health and demographics make it the most prominent illness in the country, which can divert attention from other health problems. Certainly the magnitude of parental HIV/AIDS-illness was greater than that of chronic illnesses, though it is possible a more focused analysis of specific health problems would reveal those most likely to result in the burden of care falling to children. Among illnesses assessed in the survey, bivariate analyses indicate parental tuberculosis, cancer, and diabetes have strong links to children's caring responsibilities.

The relationship between parental anxiety/depression and children's personal care responsibilities was unexpected. Research presented in the literature review suggested that children provide care for parents with mental health disorders, though mainly in the form of emotional support (Abebe, 2007; Evans & Becker, 2007, 2009; Robson, 2000, 2004; Robson & Ansell, 2000). The Child Responsibility Measure, which was used to assess children's responsibility in this thesis's quantitative study, did not include any emotional support tasks; all personal care tasks involved some form of physical engagement. Additionally, there

were no indications from the exploratory study that children were providing any sort of intimate or medical care to address an adult's mental health disorder specifically. Associations between parental anxiety/depression and children's caring responsibilities found in the bivariate analysis section were presumed to be the result of a third factor (e.g., parental physical illness, poverty, or a lack of social support) driving both parent's mental health disorders and children's caring. For instance, mental health disorders often accompany physical illness as a result of physical health problems associated with severe illnesses like cancer or HIV/AIDS-related stigma (Bird, Bogart, & Delahanty, 2004; Lee, Kochman, & Sikkema, 2002; A. L. Pillay, 2001; Simbayi et al., 2007). Regardless, regression analyses found that independent of physical health, parental anxiety/depression drove children's caring responsibility. However, given the limited evidence linking the two, it remains unclear how parental mental health disorders would drive children's caring. For instance, while it was possible that children administered medication to address a parent's mental health disorder, only one child in the quantitative study described doing so.

An alternative explanation lies in reversing the direction of this relationship. Research from the literature review suggests ambivalence concerning children who provided care for their ill parents. Expectations appear to be rooted in times prior to the HIV/AIDS-epidemic, though children are now required to go beyond cleaning the household and helping with cooking to bathing and feeding a parent (Skovdal, 2009a; Skovdal & Andreouli, 2011). While often praised for helping in the abstract, children in Martin (2006) reported being chastised by community members for providing care to their parents, while home community-based car-

ers in Kang'ethe (2010) were openly hostile to the idea of children providing care. In the latter article, carers' stated reasoning was that children were not capable of providing proper care, though Akintola (2004) describes children being sent away during home community-based carers' demonstrations of proper care even though it was often the child who provided the care. Parents, as members of these communities, may also harbour negative feelings about children providing care (in addition to positive perceptions in the abstract), and find it difficult to cope with being cared for by a child. Thus, it may not be that parental mental health disorders drive children's caring responsibilities, but rather the reverse.

1.2 Parental illness and domestic responsibilities

Poor physical health was the only parental illness indicator that was significantly predictive of children's total responsibility time; however, further analyses found the effect was with personal care time burden but not domestic responsibility time burden. Stepwise regression analyses found parental HIV/AIDS-illness to be predictive of children's engagement in childcare prior to the inclusion of household/community factors. No parental illness indicator was predictive of children's engagement in income-generating activities.

Existing research suggested that parental illness would not only create a need for care but also domestic maintenance, as an ill adult would no longer be able to meet his or her household obligations. Robson et al. (2006) argue that children have finite capacities, shifting or dropping existing responsibilities to adopt new and more immediately necessary tasks; if this were the case there would have been an appreciable and significant drop in domestic responsibility time burden in accordance with the increase in personal care time burden, of which multiple

regression analyses in this thesis found no evidence. While personal care time burden increased with parental illness, domestic responsibility time burden was not affected, suggesting that responsibilities are added to what children already do; however, evidence from the literature review and the exploratory study suggests that responsibilities may be taken on at the expense of social or educational activities. Further, parental illness was associated with an overall increase in children's responsibility time burdens. The relationship may be more nuanced, however, as children from the rural site, who had significantly larger time burdens, were less likely to engage in personal care responsibilities. Differences between children from the urban and rural sites are discussed in greater detail in the next section under the heading Urban/rural location.

Also noteworthy is the lack of association between parental illness and children's engagement in either childcare or income-generating activities when controlling for socio-demographic factors. Prior to the inclusion of household/community factors in stepwise regression models, parental HIV/AIDS was a significant predictor of children's engagement in childcare. In terms of children's engagement in income-generating activities, the lack of association with other factors such as poverty indicates that the responsibility is impervious to household need, children are sent away to reduce household burden or earn remittances in times of financial stress, or that the measures of poverty were inadequate. Potential explanations for this finding are presented in the next section under the subtitle Poverty.

1.3 Moderating effects of socio-demographic factors

Child gender

In regression analyses, girls were significantly more likely to engage in intimate care and childcare and have greater responsibility time burdens. However, further analysis found that the association with intimate care responsibilities was only significant at the rural site, and the association with time burdens only applied to domestic responsibilities. Further analyses also found that parental illness only affected boys' total responsibility time burdens. Boys were significantly more likely to engage in income-generating activities. Gender-matching was not a significant predictor of children's intimate care responsibilities.

Findings regarding the impact of gender on intimate care were in line with existing research, excluding Bauman et al. (2006); however, there were limitations to this study, which are described in detail in *Chapter 2*, *Section 3.4.1*. However, it was unexpected that this association would only be significant at the rural site. Possibly, this is related to the relative strengths of traditional cultural values between the study sites, which existing research suggests dictate a gendered division of labour (Abebe, 2007; Abebe & Skovdal, 2010; Evans, 2010c; Evans & Becker, 2009; Robson & Ansell, 2000; Wittenberg, 2009). Many aspects of the rural site were indicative of more traditional values, from the prevalence of polygamous homesteads to the prominence of tribal power structure.

Girls were also expected to have greater responsibility time burdens, though unexpectedly regression analyses showed this only applied to domestic responsibilities. It is likely that the caring and household needs introduced by parental illness demand child's labours without preference of gender, supported by the

lack of relationship between intimate care and gender-matching. Similar to a point presented in *Section 1.2* of this chapter concerning children's finite capacity for responsibility, girls may already be engaged in the maximum amount of responsibility possible, and it is only when an adult becomes ill that boys' time burdens, significantly lower than girls', begin to increase. Separate analysis of boys' and girls' time burdens found that parental illness only affected boys' responsibility time burdens. This analysis also found that home community-based carer presence increased time burdens in girls only. Possibly, carers impart skills on girls, who are already socialised to be carers and have more responsibility, thus increasing households' reliance on them. The relationship between carers and children's responsibilities is discussed in greater detail under the Home community-based carer heading later in this section.

The one area in which boys had more responsibility was income-generating activities, which much of the existing literature suggested was reflective of gendered divisions of labour. Interestingly, poverty was not a significant predictor, though as Bray (2003) notes, when boys perform tasks, it is often only for their own benefit. It is possible that when boys earn money, they are earning cash to meet their own wants and needs. The relationship between poverty and income-generating activities is discussed in greater detail in this section under the heading Poverty.

Child age

Older children were significantly more likely to engage in medical care and childcare, and to have greater responsibility time burdens. There was no associa-

tion between child age and children's engagement in intimate care in either bivariate or multiple regression analyses.

The findings are mostly consistent with existing research, which suggest that older children are given more responsibility due to their greater intellectual, emotional, and physical capacities, and the primacy of birth order in supervision of other children. Though qualitative evidence indicated that many responsibilities start young, the intensity and prevalence appear skewed towards older children.

The one exception is the lack of association between intimate care and child age, which was unexpected given that some intimate care responsibilities require substantial physical strength that younger children often lack. Bauman et al. (2006) report a similar lack of association; however, given the problems with measurement tools and sampling, the similarity in findings may be due to a contextually inappropriate tools and a lack of statistical power (see *Chapter 2*, *Section 3.4.1* for a more detailed discussion). The lack of association may be the result of a phenomenon suggested elsewhere in this chapter, that households with caring needs are desperate for help and turn to whatever resources are available with limited opportunities to exercise preferences regarding age-appropriateness.

Parent type and orphanhood

While parent type was significantly associated with children's engagement in intimate care, medical care, and childcare in bivariate analyses, there were no significant associations in regression analyses. Orphanhood, which was significantly associated with children's engagement in medical care, childcare, income-

generating activities, and total responsibility time in bivariate analyses, was only significantly associated with childcare in regression analyses, in this case as a protective factor.

The lack of relationship was unexpected for two reasons. First, qualitative research suggests grandparents frequently require care due to poorer health and illness, which would normally be provided by their healthy, working age children. With the interruption of the 'generational bargain,' however, orphaned children, in lieu of their deceased parents, become responsible for their adoptive grandparents' care. Indeed, greater parental age was significantly associated with poorer health generally and all illnesses aside from HIV/AIDS (which was more common among younger parents), and bivariate analyses found children with grandparent 'primary caregivers' were providing more personal care. As such, it was thought that a regression excluding parental illness variables would find an association, though this was not the case.

The second reason the findings regarding parent type were unexpected was that research suggested adoptive parents become carers for orphaned children to gain their potential labours, or that the strain of new additions to the home necessitated adopted children to contribute for household survival. Yet this association was not seen in either bivariate or regression analyses. Interestingly, these findings were consistent with those of a longitudinal study in Parikh et al. (2007), which found no support for the 'Cinderella myth' of intra-household labour differences between co-resident orphaned and non-orphaned children.

A possible explanation for the above findings is that the extended family household is more common in South Africa, and the notion of a distinct 'primary care-

giver' may not be as strong. Generalised care by all adults for all children within a household may limit the importance of 'primary caregivers,' or make this categorisation irrelevant in many households. Granted, data from the cross-sectional survey found near unanimity in identifying the interviewed adult as the child's primary caregiver; however, this may have reflected the pre-interview selection and priming of a child to endorse the relationship rather than an elicitation of a genuine response. The questionnaire, therefore, may have forced children to place an artificial paradigm on the relationship they had with the interviewed adult.

The one significant finding in the realm of parent type/orphanhood was that being an orphan was significantly protective against children engaging in childcare. Research on young carers and child-headed households indicates that older children often become surrogate parents to their younger siblings following parental incapacity or death; but while older children took on greater amounts of childcare, orphaned children were significantly less likely. There was nothing in the literature or in either the findings presented in this thesis to offer insight into this association.

Children's educational attainment

Children's educational attainment was not associated with any responsibility outcome in multiple regression analyses. This finding was not in line with suggestions from existing research suggesting that independent of child age, having reached an educational milestone would increase the likelihood that a child would be removed from school to provide care or become responsible for the home (Robson, 2000, 2004).

Adult presence

In multiple regression analyses, the ratio of adults to children was only predictive of children's engagement in childcare, with more adults per children being a protective factor. Bivariate analyses found associations between adult:child ratio and intimate care and greater responsibility time burdens as well.

The association between reduced adult presence and children's engagement in childcare was consistent with findings in existing research (Evans & Becker, 2009; Steinberg et al., 2002). Though greater responsibility time burden was associated with reduced adult presence in bivariate associations, it was not significant when controlling for socio-demographic variables in regression analysis. What is surprising about this finding is that while children in rural households were expected to have greater responsibility time burdens, it was suspected this was partially a function of reduced adult presence and the a resulting need to rely on children to provide for domestic needs. However, when controlling for rural location, adult:child ratio was not a significant predictor of children's responsibility time burdens, which suggests that some aspect of rural location other than adult presence is responsible for children's increased household contributions.

Urban/rural location

In both bivariate and multiple regression analyses, children from the urban site were much more likely to engage in caring responsibilities than their rural counterparts. Conversely, rural children had greater responsibility time burdens and were more likely to engage in childcare.

The finding that urban children were much more likely to engage in personal care responsibilities was unexpected and inconsistent with existing research. Despite most risk factors being far more prevalent in the rural site, both bivariate and multiple regression analyses that did and did not control for such factors found the same association. Such findings suggest that another unmeasured aspect of the urban setting drives children to engage in personal care for ill people, or of the rural site preventing children from doing so. Evans and Becker (2009) argue that the typically nuclear makeup of urban households disconnects them from extended family and kin networks, resulting in fewer internal and external resources to rely on. However, adequate social support was more prevalent in the urban, though the scale did not differentiate between internal and external sources of support. Another possibility is found within the extent to which children are relied upon in their homes for domestic maintenance. Children in the rural site spent nearly 11½ hours per week on responsibilities, almost six and a half more hours than their urban counterparts. As noted elsewhere in this section, Robson et al. (2006) write that children have finite capacities to provide for the home, especially when attending schooling, and that it is less the addition of caring tasks than the shifting of other responsibilities. This explanation is also problematic, however. A separate analysis of personal care and domestic responsibility time burdens found that while parental illness increased personal care time burdens, there was no reciprocal effect on domestic responsibility time burdens. If children did shift around their responsibilities to meet their immediate household and caring needs, one would expect a significant reduction in domestic responsibility time burdens.

For intimate care specifically, a third possibility is that traditional values, which were likely more prominent in the rural field site, strongly discourage intimate contact between children and parents. For instance, Skovdal and Andreouli (2011) suggest differences between impoverished rural and middle class urban households in terms of expectations of children and the perceived appropriateness of certain responsibilities. If such attitudes were less pronounced in the urban site, families would have fewer barriers to allowing their children to care for an ill parent.

In terms of medical care, rural children's engagement may have been limited by the availability of healthcare options. All of the medical care tasks involved basic assistance with formal healthcare provision: collecting, administering, or reminding an ill person to take medicines, or accompanying the ill person to the clinic or hospital. Where those services are unavailable, children cannot assist in them. Thus the greater prevalence of medical care responsibilities in the urban site may have been indicative of greater availability and use of public healthcare services. However, the reliance on medical care tasks based on engagement with formal healthcare systems highlights a potential bias of the Child Responsibility Measure against the role of traditional medicine. While in the introduction it is argued that traditional medicine can be detrimental to community- and individual-level health, engagement with traditional medical care tasks would nevertheless be considered a responsibility.

Associations between rural location and greater responsibility time burden and engagement in childcare were consistent with the existing research. Interestingly, this did not appear to be a function of poverty or long clinic travel times, both

of which were controlled for in multiple regression analysis. Rural location was predictive of greater domestic responsibility time burden, but not of personal care time burden, supporting arguments that rural households are more difficult to maintain and require more work (Bray, 2003). Also of note is that rural location was predictive of children's engagement in childcare even when controlling for adult:child ratio, which was thought to be the primary driver of this responsibility. If not related to adult presence, the greater propensity for rural children to engage in childcare may be another reflection of stronger traditional values; caring for younger siblings has been identified as an important part of socialisation in African cultures (Cicirelli, 1994; Evans, 2010c; R. A. LeVine et al., 1996; Weisner, 1982).

Differences between urban and rural settings must be interpreted with caution, however. As noted in *Chapter 5*, there were variations in recruitment strategies between the urban and rural sites. There are few obvious explanations for how the difference in sampling methods could have confounded analyses, though given a skew towards high-visibility, easily accessible areas within the rural site, the rural sample may have been biased towards areas with better access to services. However, experience on the field and quantitative analyses suggested that households in the urban site generally had better access to services.

Poverty

Poverty was a significant predictor of children's engagement in medical care, though further analysis found that the relationship was only present in the rural field site. Poverty was also predictive of greater responsibility time burdens, both caring and domestic and for boys and girls. There were no associations be-

tween poverty and children's engagement in intimate care, childcare, and, most surprisingly, income-generating activities in regression analyses.

Associations between poverty and children's engagement in medical care were mostly consistent with the literature. As noted in Evans and Becker (2009) and Harms et al. (2010), poverty can restrict access to medical care, while those with pre-existing yet treatable conditions such as HIV/AIDS, tuberculosis, or asthma may avoid treatment until absolutely necessary. In impoverished settings, sicker parents would present a greater need for children to provide care. Interestingly, this only applied at the rural field site. Poverty may not have presented as large a barrier to healthcare access in the urban site, where due to higher population density, travelling to the clinic is not as dependent on paying for transport.

Contrary to research presented in the literature review, which hypothesised that poverty would result in poorer health among the ill and fewer options for care (Bray, 2003; Evans & Becker, 2009; Lalloo et al., 2004; Steinberg et al., 2002), poverty was not predictive of children's intimate care responsibilities. A potential explanation may lie in the decision to use child hunger as an indicator of poverty, which was selected for its association with child responsibility outcomes in bivariate analyses and its potential to identify extremes within a setting of generalised poverty. Indeed, bivariate analyses found hunger to be associated with the greatest number of child responsibility outcomes (one exception was income-generating activities, which was only associated with Indicators of Poverty and Social Exclusion; the implications of this relationship are discussed below). However, differences in intra-household food allocation may have limited the validity of this indicator. Existing research, which identifies demographic dif-

ferences (i.e., age and gender) in household food allocation, conflicts about who is favoured (Berti, 2012). As the child questionnaire only collected data concerning hunger and responsibility from one child, it is possible that households facing hunger engaged in strategic resource allocation, prioritising the nutritional needs of children most essential to household survival. Thus, a household may have been experiencing hunger, though only data from a caring or working child was collected, missing other indicators of a household's limited resources.

There were no theoretical reasons to suspect that poverty would increase a household's reliance on children for childcare other than a highly significant relationship in bivariate analyses. For this reason, poverty was included in regression analyses of children's childcare responsibilities, where it was found not to be a significant predictor. The most likely explanation for the significant relationship in bivariate analyses that was absent in regression analyses is the degree to which poverty was associated with other factors predictive of children's childcare responsibilities. Notably, in the childcare regression, both adult:child ratio and urban/rural location were controlled for and significantly predictive, suggesting they rather than poverty were the drivers of this responsibility among children.

The most surprising finding concerning poverty was that it was not predictive of children's engagement in income-generating activities. Evidence from the literature review and anecdotal experiences from the exploratory study suggested that children earn money to help alleviate household poverty (Barnard, 2002; Bray, 2003, 2009; Evans & Becker, 2009; Skovdal, 2009a). This may be partially explained by the reason given above concerning the use of child hunger as an in-

dicator of poverty and strategic resource allocation, which may mean working children are more likely to have their nutritional needs met. Another potential explanation is that children in the quantitative study were not working to alleviate household income but rather to meet or supplement their own material wants and needs. For one, the Economic Asset Index, which assessed household material wealth, was not significantly associated with children's income-generating activities in bivariate analyses and child hunger only approached significance, while scores on the Indicators of Poverty and Social Exclusion were significant. What is interesting about the latter scales is that they are more reflective of the children's material wealth/deprivation than the household's; hunger was only based on the interviewed child, and Indicators of Poverty and Social Exclusion were mostly composed of items concerning the child's own school supplies and clothing. Furthermore, income-generation was more common among boys, who, as noted under the subheading Gender, are suggested to perform tasks mainly for their own benefit. Thus, when children earn money, they may be directing much of it towards their own material wants and needs.

Another potential explanation lies in how children were recruited. Though attempts were made to randomly select an eligible child within a home, it is likely that the recruitment strategy missed many children who worked long hours, especially considering fieldwork was scheduled to avoid conflicts with school; Skovdal (2009a) notes that children's responsibility time burden increased almost fourfold during weekends when they were out of school. Further, the quantitative survey may have excluded economically viable children with its focus on co-resident child/parent dyads; qualitative evidence and the literature review

documented cases of (usually older) children leaving home to earn money for remittances (Skovdal, 2009b; Skovdal et al., 2009).

Healthcare access

Greater distance to the local clinic was not predictive of children's engagement in either type of personal care, though it approached significance as a *protective* factor against children engaging in medical care and was predictive of total responsibility time burden.

The lack of association between distance to the local clinic and children's engagement in intimate care was inconsistent with existing research, which had found greater travel times were a significant barrier to clinic utilisation (Tanser et al., 2006). This was suggested to exacerbate poor health and increase the need for children to provide care. However, the finding of greater clinic travel time's protective nature against children engaging in medical care contains a counterintuitive logic. The further a household is from a clinic, the fewer opportunities children have to interact with clinic-based medical care. In cases where the child's parent is ill, he or she may be in greater need for care, though extensive travel times (and their associated monetary costs) still present a substantial barrier.

Though long clinic travel times were thought to be indicative of greater responsibility time, it was unexpected that this would be correlated with only domestic tasks. However, the results are consistent with those described above: if a child is not more likely to engage in intimate care, and possibly even less likely to engage in medical care, any increase in responsibilities would be among domestic responsibilities. Additionally, long clinic travel times are likely indicative of

greater household isolation, and children may have to spend more time traveling to shops or collecting water, two domestic tasks essential for survival.

Home community-based care

Home community-based carer presence was not a protective factor against children engaging in intimate care, though it was predictive of their engagement in medical care and total responsibility time burden. Further analysis found the association with responsibility time burden was only significant with girls.

The findings of the regression analyses ran contrary to existing literature, which had suggested that carers would alleviate caring and household burdens and reduce reliance on children (Akintola, 2004; Bray, 2009; Evans & Becker, 2009; Thomas, 2006). A possible explanation for the associations with children's engagement in medical care is that carer presence increases a household's medical care options. For one, carers could inform ill individuals and their households about the types of treatment available to them and how to acquire them. Additionally, while Akintola (2004) writes that children were often sent away while carers demonstrated proper methods of care, this likely applied to intimate care, which is often cited as culturally inappropriate between children and adults. Lacking intimate contact, medical care would not violate social norms and carers would be more likely to teach a child the appropriate means of acquiring and administering treatment, leading them to be relied on for future medical care needs.

The association between carer presence and children's greater responsibility time burdens were also contrary to the expectations of the literature, though an explanation may lie in the finding that this applied only to girls. As noted under

the heading Child gender, carers may be imparting skills on household members during their visits. Research suggests that girls are socialised to take on caring and domestic responsibility, and thus carers may be teaching girls the appropriate means to provide care. This is further evidenced by the fact that carer presence increased the time burdens of personal care but not domestic responsibility.

Alternatively, the presence of a carer may otherwise be an indicator of greater caring and domestic needs. Bivariate analyses found that parents in households visited by a home community-based carer were in poorer health and their homes were poorer, further from a clinic, and had fewer adults per children.

Social support

Adequate social support was significantly protective against children's engagement in personal care responsibilities. Unexpectedly, adequate social support approached significance as a predictor of greater responsibility time burdens in children.

The finding that social support was protective against children engaging in personal care responsibilities was consistent with existing research, which suggested adequate social support would be a source of necessary material goods like food, school fees, and medicine, in addition permitting caring and domestic burdens to be distributed among a larger number and more culturally acceptable demographic (i.e., adults) of people (Bray, 2009; Evans, 2010b; Evans & Becker, 2009; Withell, 2009). However, the association with greater time burdens may be reflective of the expectations of reciprocity within social support networks rather than its function as a protective factor. Thomas (2006) and Skovdal

(2009a, 2009b) argue that social support networks require individuals to contribute in order to receive its benefits. Children who are busy providing care would be less able to contribute to support networks, and would therefore receive fewer of the benefits of social support. Interestingly, adequate social support approached significance as a predictor of children's greater domestic responsibility time burden. This suggests that children with adequate support networks are in general contributing more in terms of domestic responsibility, whether to their own household or people within the kin network, but in times of need they are less likely to be given more domestic tasks than new caring responsibilities.

2 Study strengths and limitations

There were several limitations in the methods of this thesis. First, the large number of analyses conducted in the quantitative study could have resulted in a Type II error, whereby false associations were reported as statistically valid. The risk was partially mitigated by the use of a conservative *p*-value in multiple regression analyses ($p \leq .01$). Another limitation was the use of cross-sectional rather than longitudinal data, which do not provide any information on the temporal order of associations. Several questions remain regarding the use of tools used in the quantitative survey. For one, despite a rigorous translation process (see *Chapter 4*, *Section 4.4* for a more detailed description) there were issues noted with isiXhosa and isiZulu versions of questionnaires; several errors were brought to project managers' attention weeks or months into fieldwork. In other cases, translations of tools designed in Western settings may not have captured conceptually similar themes or concepts in the target population (Kuo, 2010).

Additionally, the fieldwork experience presented the author of this thesis with some questions regarding the numeracy skills of both children and parents, particularly in the rural site. Frequently, children had difficulty telling interviewers how old they were, referring them to birth certificates to calculate their age. Interviewers described cases where children had difficulty differentiating between small and large units of time. To counter this, the Child Responsibility Measure would have done well to incorporate the three-point frequency scale (0 = 'never'; 1 = 'some of the time'; 2 = 'a lot of the time') used in the MACA-YC18 (Joseph et al., 2009) to determine responsibility burden, which was significantly correlated with hours spent on responsibilities. Nevertheless, analysis of rural sample data was mostly consistent with hypotheses regarding responsibility time burdens.

The focus on the child/parent dyad in the quantitative study excluded many other aspects of South African family life that would influence children's responsibilities. For one, the average household size was six members, meaning that the health and responsibility data for roughly four people per household were not collected. The findings of this thesis indicate that responsibilities are not bound by the child/parent dynamic, as children were caring for other children and were likely assisted in their own responsibilities by siblings or other adults.

Aside from the unintended exclusion of the 'feed/help an adult to eat' variable, there remain questions about the validity of the Child Responsibility Measure, which had been created using data from the literature review and the exploratory study. Though efforts were made to include relevant items based on the settings, very little of the data had been collected from among isiZulu-speaking populations in the KwaZulu-Natal province. There were differences between re-

gional and ethnic groups in the studies, most notably the apparent absence of subsistence agriculture in Western Cape populations and the prominence of traditional medicine in KwaZulu-Natal. Efforts were made to include participants from deprived and rural communities and to use data from the literature review, which included research in more agrarian communities, in creating items in the Child Responsibility Measure.

The studies within this thesis had considerable strengths as well, one of which was the use of mixed methods in addressing the research topic; these include a literature review to identify research gaps, an exploratory study to collect data on the range and type of responsibilities among children with unwell parents, and a cross-sectional quantitative survey that collected and analysed data from a large and representative sample. The quantitative survey also used paired data to analyse the relationship between parental illness and child responsibility, which reduced reliance on less accurate second hand accounts. While there were weakness in the Child Responsibility Measure noted above, it nevertheless firmly rooted the research in the South African context by creating a tool based on data collected in South Africa and elsewhere in the subcontinent. Finally, to the author's knowledge this is the largest study on children's responsibilities as related to parental illness, and of paired data, ever conducted in sub-Saharan Africa.

3 Implications for policy and practice

This thesis addresses a substantial gap in existing research regarding quantitative data on the relationship between parental illness and child responsibility in South Africa and identifies potential areas in which to focus interventions. However, the author of this thesis stresses the limitations of its findings. First, while

the majority of literature on children's caring roles portrays such responsibilities as inherently negative, several researchers note this may not be the case (Evans & Becker, 2007, 2009; Olsen, 1996; Skovdal, 2009b). Prior to the development of any interventions aimed at limiting children's caring responsibilities, there needs be rigorous quantitative research into their impact on children. As of this writing such evidence is limited (e.g., Gwandure, 2007). On the other hand, there appears to be a substantial amount of research indicating exaggerated responsibility time burdens are detrimental to children's educational attendance and performance (Barnard, 2002; Bray, 2009; Evans, 2010b, 2010c; Evans & Becker, 2009; Harms et al., 2010; Lindsey et al., 2003; Martin, 2006; Robson, 2000; Robson et al., 2006; Skovdal, 2010; Skovdal et al., 2009; Thomas, 2006; Wood et al., 2006). In this case, the thesis identifies children most at risk for exaggerated responsibility time burdens: poorer, older, and female children in rural settings who travel more than 50 minutes to reach their local clinic whose parents are in relatively poor physical health. Interestingly, children with the greatest responsibility time burdens are also more likely to be visited by a home community-based carer, which can provide a useful means of access to this population.

Another reason to resist the temptation to label children's caring responsibilities as inherently harmful is the way in which they may benefit their parents, families, and communities. Indeed, some factors that are protective against children engaging in medical care may be indicative of limited healthcare access, resulting in worse health outcomes in parents and other family members. Several articles argue that child carers are a last resort for resource-deprived households (Martin, 2006; Robson, 2000, 2004; Robson et al., 2006; Skovdal, 2009a, 2009b;

Van Blerk & Ansell, 2002), suggesting that children may be the only source of support for some ill parents. With the detrimental impact of the HIV/AIDS epidemic on the public health sector (Oramasionwu et al., 2011; Shisana et al., 2003) and government endorsement of home-based care (DOH, 2001), it is unlikely that a reliance on children to provide care will change any time soon. Alternatives may include expanding home community-based carer programmes, education programmes to teach children proper care techniques, or some combination of the two. Such programmes would have to acknowledge the reality of public healthcare problems in deprived South African communities while also imparting skills on children and improving the health of ill parents.

Another implication of this study pertains to AIDS exceptionalism. While parental HIV/AIDS-illness was the most important health predictor of children's engagement in personal care responsibility, non-HIV/AIDS chronic illness and anxiety/depression were both significant to a high degree of magnitude. Non-communicable diseases are a source of considerable burden in South Africa, as evidenced in both this thesis and existing research (Bradshaw et al., 2003; Bradshaw et al., 2007; Mayosi et al., 2009; Norman et al., 2007; M. Schneider et al., 2009; Tollman et al., 2008; WHO, 2009), though HIV/AIDS still receives what some argue is a disproportionate amount of attention and funding (England, 2007, 2008; R. Levine & Oomman, 2009; Shiffman, Berlan, & Hafner, 2009). Additionally, AIDS-focused interventions ignore children burdened by other parental health problems, and can stigmatise a programme and its beneficiaries (Kuo, 2010). This is not to downplay the negative impact of HIV/AIDS on public and family health in South Africa, only to recognise that in terms of children's care

provision and accumulated responsibilities, a substantial amount of the burden is attributable to other types of parental health problems.

4 Directions for future research

The findings of this thesis address an important gap in research on the impact of parental illness on children's responsibilities. However, these findings should only represent the beginning of quantitative study on this topic. This section provides several suggestions for future research.

4.1 Longitudinal research

Some associations raised questions about the causal relationship between predictors and child responsibility outcomes. Specifically, the link between parental anxiety/depression and children's caring tasks was especially surprising given that it appeared independent of parent's physical health. Some hypotheses were suggested to explain this finding, though the directionality of this relationship remains unclear (i.e., whether parental mental health disorders result in children's caring, or children's caring results in parental distress that manifests as mental health disorder), a longitudinal study would be the most appropriate means of disentangling the pathways in this association.

Another finding that would benefit from a longitudinal study is the relationship between home community-based carer presence and children's medical care responsibilities, which was unexpected as carers were imagined to alleviate household care burdens resulting from parental illness. Some possibilities were offered to explain this finding including carers teaching children how to provide care or introducing households to previously unavailable and/or unknown types of treatment, thus opening a new range of responsibilities to children. Alterna-

tively, carer presence may be a more accurate indicator of greater care needs than dichotomous parental illness variables. A longitudinal study would be helpful in disentangling the temporal order of these relationships.

4.2 Risks and impacts of responsibilities

Impacts of providing care were beyond the scope of this thesis, however, it is the next step in research on the relationship between parental illness and child responsibility.

With regards to caring responsibilities, there is evidence that children whose parents are in home-based care programmes have poorer mental health outcomes (Akintola, 2006; Gwandure, 2007; Lindsey et al., 2003), though the research is limited and has not yet linked the provision of care to such outcomes. Given the paucity of skills and appropriate equipment, several articles note the inherent risk of infection in providing care (Akintola, 2004, 2006; Bray, 2009; Kidman, Hanley, Subramanian, Foster, & Heymann, 2010; Nnko et al., 2000; Skovdal, 2009b; Steinberg et al., 2002; Thomas, 2006); tuberculosis in particular presents substantial risks of infection, especially among carers with HIV/AIDS or otherwise compromised immune systems (Cluver et al., 2013; Shisana et al., 2003). Further, Lindsey et al. (2003) and Akintola (2004) note risks of sexual abuse among girls who provide care, which carries with it the risk of exposure to HIV.

Large time burdens, especially those resulting from domestic responsibilities, have been noted to negatively impact children's education (Barnard, 2002; Evans, 2010b, 2010c; Evans & Becker, 2009; Harms et al., 2010; Lindsey et al., 2003; Martin, 2006; Robson, 2000; Skovdal, 2010; Skovdal et al., 2009; Thomas,

2006; Wittenberg, 2005; Wood et al., 2006). The impact appears mostly to affect school attendance and performance rather than forcing children to withdraw, though children with full time caring responsibilities have been known to drop out entirely (Barnard, 2002; Bray, 2003; Robson et al., 2006). The extent to which responsibilities negatively affect schooling needs to be investigated to determine the point at children's education begins to suffer and the ways in which this can be remedied. Furthermore, research in China has linked large amounts of domestic responsibility to depressive symptoms in children (Yu et al., 2012). Future research could investigate the relationship between chores and children's mental health outcomes in sub-Saharan Africa. One potential measure of outcomes is the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) in Joseph et al. (2009), though it must first be adapted to and validated in the sub-Saharan Africa (or more specific) context.

Another possible direction for future research is the impact on adults of being cared for by a child. Home-community based carers in Kang'ethe (2010) raised the issue of parents receiving inadequate care as a result of it being provided by children. One stated 'we do not expect any good care productivity from children caregivers,' while another said, 'the government and [home community-based care programme] authorities should not allow the sick to be taken care of by children. It takes away the clients' rights to good care,' (p. 198).

4.2.1 Interventions

If future research links responsibilities to negative outcomes, the focus can then move to interventions. This thesis provides quantitative data identifying the conditions under which children are likely to engage in specific types of responsibilities and have greater time burdens, which may be used to identify children

who are at greatest risk of negative outcomes. For instance, if intimate care responsibilities produce negative health outcomes in children, interventions would do well to focus on urban environments and female children with ill parents.

Importantly, interventions should not focus solely on the child or children providing care or maintaining the household but the entire family unit. For one, neither the literature nor this thesis explores the quality of care children are providing other than to comment on children's potential health risks. Potential interventions may focus on improving the quality of care children provide, which may not only improve parental illness but also improve general household living conditions. This strategy is not without its risks, however. For one, if interventions target children as care providers, some children, particularly girls, may be viewed as natural carers and burdened with an even greater degree of responsibility. This could lead to some children being overburdened with caring responsibilities at the expense of their education and possibly mental health.

4.3 Familial response to household illness

As noted elsewhere in this chapter, one of the limitations of this thesis was the focus on a child/parent dyad, which ignored interactions between different individuals in response to household need. Evidence from the literature review and children in the exploratory study suggest that in the face of familial illness, children often serve as 'secondary' carers to adults, or work with other children to address both caring and domestic needs (Akintola, 2004, 2006; Harris, 2008; Harris & Stuart, 2006; Lindsey et al., 2003; Robson, 2000, 2004; Skovdal, 2009a, 2009b). It would be interesting to explore the allocation of responsibilities within the household; for one, findings from the exploratory study, the quantitative

survey, and other research (Akintola, 2004, 2006; Martin, 2006; Ruiz-Casares, 2009; Skovdal et al., 2009) indicate that responsibilities between household members are divided according to age (or birth order) and gender. Additionally, future studies could further explore the acquisition of and obstacles to external resources, be they from the neighbourhood, community, or kin network. One potential area is whether and how older children are sent or leave home for economic centres to provide remittances in response to financial need.

4.4 Validity and utility of the Child Responsibility Measure

Many of the quantitative survey findings were consistent with hypotheses, suggesting the Child Responsibility Measure was a valid measure of child responsibility in South Africa, in spite of the error resulting in the exclusion of 'feed/help an adult to eat' noted in *Chapter 4*, *Section 4.3*. Regardless, future research may increase the validity of this measure and its adaptability to other cultures within South Africa and the subcontinent as a whole. For one, much of the data used to create this measure were derived from a study in the Western Cape province, which is very different in terms of demography and economics from the rest of the subcontinent. One specific area of concern is the breadth of items in medical care responsibilities. The unexpected finding that children from the rural site were significantly less likely to engage in medical care may have reflected the relatively well-established dominance of Western medicine in the Western Cape province in which data for the Child Responsibility Measure had been collected; *Chapter 3*, *Section 3.2* notes that no child mentioned providing traditional medicines. Had some of the data been collected in other provinces such as KwaZulu-Natal or the Eastern Cape, medical care items may have reflected the more prominent role of traditional medicine found elsewhere in the country.

4.5 The past and future of home-based care

The findings of this thesis indicate a tension between cultural expectations and the reality of child caring responsibilities. While on the one hand children are expected to contribute to their households and help their parents in times of need, there also appear to be strong cultural proscriptions against tasks such as providing care for an adult. However, such attitudes were shaped prior to the HIV/AIDS-epidemic, putting strains on traditional and public means of care and likely challenging traditional notions about the appropriateness of child-provided care, forcing them to adapt to present needs and limitations.

There is evidence that cultural expectations have changed since the beginning of the HIV/AIDS-epidemic. Evans and Becker (2007, 2009), Robson (2000, 2004), and Skovdal (2009a, 2009b) argue that preferences for gender-matching between children who provide intimate care for their ill parents are dependent on adequate availability of children who meet a gendered criteria, and that the strains of the HIV/AIDS-epidemic have reduced the importance of such preferences. Unfortunately, findings in this thesis reflect only one moment in time and cannot be used in comparison to a previous era. However, one could argue that the urban site, located within the Durban/eThekwini area, is subject to more influence from international, particularly Western, notions of childhood, and attitudes would thus drift away from 'traditional' beliefs. Indeed, some of the differences found between the urban and rural cohorts may be attributable to the greater prominence of 'traditional' beliefs in the rural site. In particular, the greater propensity for children in the urban site to engage in intimate care suggests that restrictions against intimate care contact between children and adults have eroded.

Changes in the HIV/AIDS-epidemic, whether perceived or real, will also impact how care is provided in the future. Akintola (2004, 2006) argues the creation of home-based care programmes in southern Africa were a response to the sudden crisis of overwhelming demand for care and diminished capacity to provide it resulting from the onset of the epidemic. Many of these organisations are dependent on international funding, which itself is strongly rooted in perceptions of the continuing detrimental effects of HIV/AIDS in the subcontinent and may be reduced if attention is to shift away (Kates, Wexler, Lief, Avila, & Gobet, 2011; Lynch & Maclean, 2009). There are already signs that the global financial crisis has threatened HIV/AIDS funding (Izazola-Licea et al., 2009; UNAIDS, 2009). These issues are especially pertinent when considering that a reduction in AIDS-related death will lead to a rise in people suffering from and dying of other illnesses (Mayosi et al., 2009; Tollman et al., 2008; WHO, 2009), and the long-term detrimental impact of HIV/AIDS will leave demographic challenges for generations to come (Heuveline, 2004; Porter & Zaba, 2004). All of this leads to the conclusion that with strained resources, home-based care is likely to continue as a low-cost alternative to hospice care, and that research and policy will need to acknowledge the role of children as important contributors to adult care. Additionally, traditional and formal care mechanisms will need to work with children to provide the most efficient, low-cost, and effective care for both ill parents and their children.

5 Conclusion

In the introduction, this thesis set out a problem, noting the lack of research and policy concerning young carers in sub-Saharan Africa (Becker, 2007; Skovdal,

2009b). Much of the existing research originated in the United Kingdom, a wealthy nation with low disease burden and a comprehensive public healthcare service. This was contrasted with South Africa, a nation with little research on this subject, yet numerous indications that many children were at risk for a wide range of caring and domestic responsibility. Among these were huge degrees of inequality and deprivation, high disease burden including but not limited to HIV/AIDS, limited public healthcare, and cultural values that emphasise children's duty to their parents and family. Some aspects of the limited research included the lack of a tool adapted or designed for the South African context and quantitative evidence linking not only parental illness to child caring but also to other types of responsibility and the impact of socio-demographic factors.

This thesis addresses these gaps, first in producing a contextually-specific tool to capture the range and time burden of children's responsibilities, then by collecting and analysing data from a large, representative sample of children living within deprived South African communities. The results support many of the findings and suggestions of qualitative research: there is indeed a phenomenon of children caring for ill parents; children do more when their parents are unwell; and girls are generally doing more than boys. Other findings challenge existing research, such as the greater prevalence of intimate care responsibilities among children in the urban site and the lack of evidence that adoptive carers take in foster children in exchange for their labours. Other findings lead to even more questions, like the link between parental mental health disorders and children's caring responsibilities and the ability of home community-based carers to address household caring needs adequately.

Nevertheless, this is the first study to quantitatively analyse the relationship between parental illness and child responsibility using a large, representative sample of deprived communities in South Africa. The use of multiple regression analyses disentangled related causes including parental illness and household poverty to produce clearer ideas about the drivers of children's responsibility. Finally, this thesis sought to broaden the scope of research on the effect of illness in sub-Saharan Africa beyond the immediate impacts of HIV/AIDS. It is the hope of this author that the findings presented in this thesis will be used to direct future research and to inform interventions focusing not only on reducing children's responsibility burden, but also ways to improve the quality of care they provide.

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Appendix

The following documents are contained in the following order in the appendix:

1) Exploratory study
    a. Ethics approval forms
        i. Department of Social Policy and Social Work Research Ethics Committee, University of Oxford
        ii. Health Sciences Faculty Research Ethics Committee, University of Cape Town
    b. English language girl version of questionnaire with information sheet and consent form
    c. Certificate of participation
2) Cross-sectional quantitative survey
    a. Ethics approval forms
        i. Department of Social Policy and Social Work Research Ethics Committee, University of Oxford
        ii. Inter-divisional Research Ethics Committee, University of Oxford
        iii. Humanities and Social Sciences Ethics Committee, University of KwaZulu-Natal
        iv. KwaZulu-Natal provincial Department of Health
        v. KwaZulu-Natal provincial Department of Education
    b. Blank referral report sheet
    c. Example referral
    d. Example training schedule
    e. Fieldwork protocol manual
    f. Training certificate for staff in rural site
    g. Questionnaires
        i. Sampling sheet with eligibility screening flowchart
        ii. Bilingual (English and isiZulu) version of adult questionnaire
        iii. English language version of child (*Teen Talk*) questionnaire
    h. Child certificate of participation with important contact information

DEPARTMENT OF SOCIAL POLICY AND SOCIAL WORK

Barnett House, 32 Wellington Square, Oxford OX1 2ER
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UNIVERSITY OF OXFORD

Department of Social Policy and Social Work
University of Oxford
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32 Wellington Square
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England

Tyler Lane
Department of Social Policy and Social Work

Dear Tyler

2007-08-073

Young carers for AIDS-unwell parents: mental health, physical health, social health and educational outcomes

Your application for research ethics approval in connection with your MPhil thesis has been scrutinised and approved by the Departmental Research Ethics Committee.

Yours sincerely

Department of Social Policy and Social Work
University of Oxford
Barnett House
32 Wellington Square
Oxford OX1 2ER
England

Ceridwen Roberts
Chair of DREC

cc. Lucie Cluver

UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: lamees.emjedi@uct.ac.za

28 August 2008

REC REF: 365/2008

Dr L Cluver
Social Policy and Social Work
Oxford University

Dear Dr Cluver

PROJECT TITLE: YOUNG CARERS FOR AIDS-UNWELL PARENTS: MENTAL HEALTH, PHYSICAL HEALTH, SOCIAL AND EDUCATIONAL OUTCOMES: THE 'KIDS WHO CARE' PROJECT

Thank you for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 31st August 2009.

Please submit an annual progress report if the research continues beyond the expiry date. Please submit a brief summary of findings if you complete the study within the approval period so that we can close our file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

Ashley Henley

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

PP

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

lemjedi

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

(To be filled in by interviewer)

Name	_____	DOB	_____
Address	_____	School	_____
	_____	Grade	_____
Phone #	_____	Date	_____
Interviewer	_____	Questionnaire #	_____



Please draw your picture in this box, and personalise this page!

Hello! My name is:

I am a __ year old girl
Let me tell you about myself!

Welcome to your book! Please fill in the sections the best you can. You can draw or write your responses.
Make your voices heard, but don't forget to have fun with this book!
-the 'kids who care' researchers

Tic this box if you'd like to have a copy of this workbook returned to you ☐

Department of Social Policy and Social Work | *Cape Town Child Welfare* | *Department of Social Development*

'kids who care' information sheet

You are being invited to take part in a research study. Before you decide, it is important for you to know why the research is being done and what will happen. Please take time to read this sheet carefully. Ask the research team if there is anything that is not clear or if you have questions. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is this study about? This study is about the care and help that families give to each other. The government wants to know more about this so they can plan how to help families better.

Do I have to take part? Not at all. It is up to you to decide whether or not to take part. If you do not want to, this will not affect any help you may be getting from anyone. You will not get in any trouble if you do not want to take part.

If you decide to take part, you are still free to stop taking part at any time and without giving a reason. Again, this will not affect any help or support you are getting from anyone.

What would I have to do? If you decide to take part, you will first sign a consent form (on the next page), and then take a few minutes to complete this workbook with a researcher.

What if the questions upset me? You can leave the activities at any point, and you do not have to give a reason. You can also contact the research team at any point after the group, and say that you want your answers about certain questions to be destroyed, which we will do without hesitation. If you want to talk to someone about anything that has been raised in the group session, you can tell one of the facilitators or contact Lucie Cluver or Tyler Lane at Cape Town Child Welfare (021 638 3127).

Why should I take part in this study? This study may help us to know more about what kind of things families in South Africa need to support each other. The things we learn from you during the focus groups and interviews will be used to inform future government policy for families, and the children who help out.

What if I have a complaint? If there is anything to do with this research which you are unhappy with, you can complain to Dr. Lucie Cluver at the University of Oxford (lucie.cluver@socres.ox.ac.uk).

Would my taking part in this study be kept confidential? All information you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name and address removed so that you cannot be recognised from it.

During this study, it may become clear that you are suffering from serious difficulties. If so, the interviewer will explain to you some possibilities for further help. If there is a safety issue, we may contact a welfare organisation for you. All this will be talked over with you first.

What will happen to the results of the research study? The results of this study will be used to help the government to make policies regarding kids and families in situations much like yours.

Who is organising and reviewing the research? The research is being organised by the University of Oxford in England and the Department of Social Development in Pretoria. Ethics groups in both countries have approved the research.

Contact for further information:

Tyler Lane
Cape Town Child Welfare
Lower Klipfontein Road
Gatesville, Athlone
South Africa 8000
+21 (0)71 087 4557
tyler.lane@socres.ox.ac.uk

Thank you for reading this sheet. If you feel comfortable with everything, you

can then check the boxes, and sign and date this sheet:

Consent for participation *Please tick boxes*

1. I have read and understand the information sheet for this study and have had the chance to ask questions ☐
2. I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting ☐
3. I agree that any words I may say during the interview can be used, without giving my name, in the presentation of the research. I agree to take part in the study ☐

_____	_____	_____
Name of Participant	Signature	Date

_____
Name of Researcher



The Story of Winnie

Winnie is a girl much like you. She lives with two of her brothers, a girl cousin, her grandmother and her mother. Winnie loves to go to school where she can see her friends and learn maths. Her favourite singer is Beyoncé, and one day she would like to go to France. When she grows up, she wants to be a teacher.

Recently, Winnie's mother has become sick. She hasn't been able to walk Winnie's brothers to school like she used to, and Winnie has had to cook meals for the family. The other day, she even had to clean up her mother's bed after she had been sick in it. Her grandmother helps out where she can, but Winnie has found herself busy all the time.

Winnie is worried that she won't have time to do her homework, or even go to school anymore. She finds that she is tired all the time, and not as happy as she once was. She is proud that she is able to handle so much responsibility, but she is afraid that she'll miss a lot of important things at school. It also upsets her to see her mother be so sick.

Throughout this book, Winnie has written about her experience to help you write about yours. Though her story may be like yours, her experiences may not be the same.

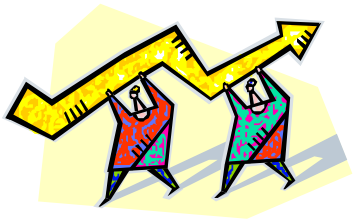
My home



Can you list everyone who lives in your home on this page? Draw your house, show where they sleep, and include their ages and how they are related to you:

Can you circle who is sick in your house?

Life Changing Moments



Can you write about the most important moments in your life, including how old you were when it happened, and how it made you feel? This could be anything like the birth of a new brother or sister, a parent getting sick, or the death of someone you cared about. Winnie has already written in one of his milestones for you. (You don't have to fill in all the boxes)

Life changing moment:	How old I was:	How it made me feel:
Ex: my father died	Nine years old	I was very sad when my father died



Helping When Someone is sick

Listed below are a few examples of things kids do when someone in their home is sick. Do you have do of these, or do anything else not listed here? Please circle those you do, and add in those that we missed. Then, tell us who is sick in the home, and draw them:

Cooking

Shopping

Waking up brothers/sisters in the morning

Cleaning up around the house

Washing clothes

Feeding an adult

Giving medication

Watching brothers or sisters

Can you tell us why you help when someone is sick?



My day

On this page you can tell us about a typical day. List any of your daily tasks, at what time you do them and how long you spend doing each, and then write down how each makes you feel. Winnie has already provided a few examples for you. (You don't have to fill in all the boxes)

Time:	What I do:	How long I do it:	How I feel:
Example: 7am	I change my mother's sheets	Half an hour	I am proud that I am able to help mom, but it makes sad to see her so sick



Changes

Here we want you to tell us about how things have changed since an adult in your house got sick. Write about any new responsibilities that you have had to take on, or of any things you have had to give up.

School:

Relationships with others:

Health and sickness:

Things I feel:

Other:



Support

Here, we'd like you to tell us about the ways people outside your home help you and the people you live with. It could come from a sibling who has moved away, or from a government programme.

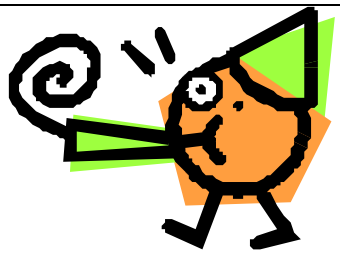
Emotional:

Medical:

Money and things:

Other:

Now that you've told us about the types of support you and the people in your home receive, what other types of support would you like to receive? Winnie has already written about the support he would like to receive.



Open page!!

On this page, we'd like you to write whatever you'd like about the study. Is there anything you'd like to tell us about the study that you particularly liked? Anything you wish we had done differently? Is there anything else you'd like to tell us about the responsibilities you take on? Then put it all down here!



Other Kids

On this last page, we'd like you to recommend three other young people who also live in a house where there is a sick adult.

Full Name	Phone Number	Age
	School	Grade
Address		

Full Name	Phone Number	Age
	School	Grade
Address		

Full Name	Phone Number	Age
	School	Grade
Address		

This Certificate Recognizes

for Their Participation in

'kids who care'

on this date:





DEPARTMENT OF SOCIAL POLICY AND SOCIAL WORK

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UNIVERSITY OF OXFORD

18th May 2009

Dr L Cluver
Department of Social Policy and Social Work

Dear Dr Cluver,

2008-09-027

Young Carers for AIDS-ill family members in South Africa: predictors for providing care and psychological, health and educational outcomes.

Your application for research ethics approval in connection with your research has been considered by the Departmental Research Ethics Committee in accordance with the procedures laid down by the University for ethical approval.

I am pleased to inform you that, on the basis of the information provided, the proposed research has been judged as meeting appropriate ethical standards and DREC approval has been granted.

Yours sincerely

Ceridwen Roberts
Chair of DREC

Department of Social Policy and Social Work
University of Oxford
Barnett House
32 Wellington Square
Oxford OX1 2ER
England

SOCIAL SCIENCES & HUMANITIES
INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE

Hayes House, 75 George Street, Oxford. OX1 2BQ
Tel: +44(0)1865 614871 Fax: +44(0)1865 614855
ethics@socsci.ox.ac.uk www.socsci.ox.ac.uk

Co-ordinator of the IDREC
Social Sciences Divisional Office

Ref. SSD/2/3/IDREC

08.12.09

Dr. Lucie Cluver
Department of Social Policy and Social Work,
Barnett House
32 Wellington Square
Oxford
OX1 2ER

Dear Dr. Lucie Cluver,

Application for research ethics approval

Ref No.: SSD/CUREC2/09 – 52

Title: Young Carers for AIDS-ill family members in South Africa: Predictors for providing care and psychological, health, and educational outcomes

The above application has been considered on behalf of the 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 proposed research has been judged as meeting appropriate ethical standards, and accordingly approval has been granted.

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,

Chris. Ballinger

Dr Chris. Ballinger

cc: Elaine Evers, Department of Social Policy and Social Work

HBP/CAJB

UNIVERSITY OF
KWAZULU-NATAL

RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL: ximbap@ukzn.ac.za

14 JULY 2009

DR. L CLUVER
HEARD

Dear Dr. Cluver

ETHICAL CLEARANCE: "THE CARER-CHILD WELLBEING PROJECT: KWAZULU NATAL UKUNAKEKELA PROJECT"

I wish to confirm that ethical clearance has been granted for the above project, subject to independent contact information being included on the information sheet:

This approval is granted provisionally and the final clearance for this project will be given once the above condition has been met. Your Ethical Clearance Number is HSS/0254/09

Kindly forward your response to the undersigned as soon as possible

Yours faithfully

MS. PHUMELELE XIMBA
ADMINISTRATOR
HUMANITIES & SOCIAL SCIENCES ETHICS COMMITTEE

cc. Prof. D Operario
cc. Ms. C Kuo
cc. Casale Marisa

HEALTH
KwaZulu-Natal

Health Research & Knowledge Management sub-component
10 – 103 Natalia Building, 330 Langalibalele Street
Private Bag x9051
Pietermaritzburg
3200
Tel.: 033 – 3953189
Fax.: 033 – 394 3782
Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference : HRKM091/09
Enquiries : Mrs G Khumalo
Telephone : 033 – 3953189

05 August 2009

Dear Dr Cluver

Subject: Approval of a Research Proposal

1. The research proposal titled **'Young Cares for AIDS-ill family members in South Africa: Predictors for providing care and psychological, health and educational outcomes'** was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken at **KwaZulu-Natal amongst the Durban community.**

2. You are requested to undertake the following:
   a. Make the necessary arrangement with the identified community before commencing with your research project.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mrs G Khumalo on 033-3953189.

Yours Sincerely

Dr S.S.S. Buthelezi
Chairperson, Health Research Committee
KwaZulu-Natal Department of Health

PROVINCE OF KWAZULU-NATAL
ISIFUNDAZWE SAKWAZULU-NATALI

DEPARTMENT OF EDUCATION
UMNYANGO WEMFUNDO

Tel: 033 341 8610
Fax: 033 341 8612
Private Bag X9137
Pietermaritzburg
3200

228 Pietermaritz Street
PIETERMARITZBURG

INHLOKOHOVISI	PIETERMARITZBURG	HEAD OFFICE
Imibuzo: Enquiries: Sibusiso Alwar	Reference: Inkomba: 0048/2009	Date: Usuku: 30 July 2009

MR T LANE
DEPARTMENT OF SOCIAL POLICY
AND SOCIAL WORK BARNETT HOUSE
32 WELLING SQUARE
OXFORD OX1 2ER
UK

RESEARCH PROPOSAL: YOUNG CARERS OF AIDS-UNWELL CAREGIVERS IN SOUTH AFRICA RESEARCH PROPOSAL.

Your application to conduct the above-mentioned research in schools in the attached list has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educator programmes are not to be interrupted.
5. The investigation is to be conducted from 30 July 2009 to 30 July 2010.
6. Should you wish to extend the period of your survey at the school(s) please contact Mr Sibusiso Alwar at the contact numbers above.
7. A photocopy of this letter is submitted to the principal of the school where the intended research is to be conducted.
8. Your research will be limited to the schools submitted.
9. A brief summary of the content, findings and recommendations is provided to the Director: Resource Planning.

10. The Department receives a copy of the completed report/dissertation/thesis addressed to

The Director: Resource Planning
Private Bag X9137
Pietermaritzburg
3200

We wish you success in your research.

Kind regards

R. Cassius Lubisi (PhD)
Superintendent-General

PROVINCE OF KWAZULU-NATAL
ISIFUNDAZWE SAKWAZULU-NATALI

DEPARTMENT OF EDUCATION
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INHLOKOHOVISI | PIETERMARITZBURG | HEAD OFFICE

Imibuzo: Enquiries: Sibusiso Alwar
Reference: Inkomba: 0048/2009
Date: Usuku: 30 July 2009

MR T LANE
DEPARTMENT OF SOCIAL POLICY
AND SOCIAL WORK BARNETT HOUSE
32 WELLING SQUARE
OXFORD OX1 2ER
UK

PERMISSION TO INTERVIEW LEARNERS AND EDUCATORS

The above matter refers.

Permission is hereby granted to interview Departmental Officials, learners and educators in selected schools of the Province of KwaZulu-Natal subject to the following conditions:

1. **You make all the arrangements concerning your interviews.**
2. **Educators' programmes are not interrupted.**
3. **Interviews are not conducted during the time of writing examinations in schools.**
4. **Learners, educators and schools are not identifiable in any way from the results of the interviews.**
5. **Your interviews are limited only to targeted schools.**
6. **A brief summary of the interview content, findings and recommendations is provided to my office.**
7. **A copy of this letter is submitted to District Managers and principals of schools where the intended interviews are to be conducted.**

The KZN Department of education fully supports your commitment to research: **Young carers of AIDS-unwell caregivers in South Africa research proposal**

It is hoped that you will find the above in order.

Best Wishes

R Cassius Lubisi, (PhD)
Superintendent-General

PROVINCE OF KWAZULU-NATAL
ISIFUNDAZWE SAKWAZULU-NATALI

DEPARTMENT OF EDUCATION
UMNYANGO WEMFUNDO

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228 Pietermaritz Street
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INHLOKOHOVISI PIETERMARITZBURG HEAD OFFICE

Imibuzo: Reference: Date:
Enquiries: Sibusiso Alwar Inkomba: 0048/2009 Usuku: 30 July 2009

MR T LANE
DEPARTMENT OF SOCIAL POLICY
AND SOCIAL WORK BARNETT HOUSE
32 WELLING SQUARE
OXFORD OX1 2ER
UK

LIST OF SCHOOLS

1. Bonela Secondary School
2. Bonela Primary School
3. Ukukhanya Kwelanga Primary School
4. Chesterville Secondary School
5. Christopher Nxumalo Primary
6. Mayville Primary School
7. Wiggins Secondary School
8. Wiggins Primary School
9. Mayville Secondary School
10. Chesterville Extension Secondary School
11. HP Ngwenya Public Primary
12. Cato Crest Primary School
13. Nsimbini Primary School
14. Hillview Primary Secondary
15. Westville Boys High School
16. Westville Girls High School
17. Westville Junior Primary School
18. Westville Senior Primary School
19. Berea West Senior Primary School
20. Berea West Preparatory School
21. Bulwer Primary School
22. Kikizani Primary School
23. Madulini Priamry School
24. Pholela Secondary School

Kind regards

R Cassius Lubisi, (PhD)
Superintendent-General

Referral report sheet

Field worker name:

Date:

Referee details:

Full name:

Date of birth:

Address:

Contact number:

Description of incident:

Date of incident:

Name of perpetrator if known:

Other information:

School name:

School principal:

School contact number:

School address

RA signature:

Project manager signature:

DEPARTMENT OF SOCIAL POLICY AND SOCIAL WORK

Barnett House, 32 Wellington Square, Oxford OX1 2ER
Tel: +44(0)1865 270325 Fax: +44(0)1865 270324
www.spsw.ox.ac.uk



To Whom It May Concern:

My name is Tyler Lane, and I am visiting University of KwaZulu-Natal from the University of Oxford in the UK. I am a Project Manager on a research project on children and their caregivers, investigating how they help each other and how the well being of one affects the other. In the course of this project we occasionally come across incidents that require a referral.

In this case a respondent, Mr XXXX XXXX (DOB: 00/00/0000; address: 00 XXXXXXX Street; ID# XXXXXXXXX; contact # XXX XXXX XXX)) who is currently staying with two of his younger sibling brothers. XXXX's mother, XXXX XXXX (ID# XXXXXXXXX) has mental health problems, which has resulted in XXXX taking on responsibility for the children.

The house has no source of income or grant money due to problems that arose in January 2010 and is struggling in steep poverty. Additionally, XXXX reported the need of a social worker, as the mother is unstable, one of the younger children has quit school and steals from his mother.

This child headed household finds it very difficult to survive while their mother suffers from mental health problems compounded with the lack of any source of income. They would greatly appreciate a visit from social services.

Thank you for taking the time to read this letter.

Kind regards

Tyler Lane

DPhil candidate
Department of Social Policy and Social Work
University of Oxford

Project Manager
Young Carers/Ukunakekela Project
Health Economics and HIV/AIDS Research Division
University of KwaZulu-Natal

Email: tyler.lane@socres.ox.ac.uk

Date	Topics	Team members
1/9/09 – 2/9/09	Introduction -Team introduction (activity) -Context and project background -General project description -Project timeline -Brief overview of survey methods -Ethics -HIV/AIDS discussion and activities	Field team; data team
3/9/09	Recruitment -Introducing oneself -Describing the project -Acquiring consent -Who to interview and how to select them -Answering questions about the project	Field team
4/9/09 – 5/9/09	Back-translation of questionnaires	Selected RAs
7/9/09 – 9/9/09	Charlotte Ritchie (consider breaking into teams for this activity) -Disclosure -Referrals Continue back-translation if need be	Field team, research managers
10/9/09	Child questionnaire -Go over questionnaire -Team identifies translation errors, general errors and difficult questions -Group discussion	Field team; data team
11/9/09	Carer questionnaire -Go over questionnaire -Team identifies translation errors, general errors and difficult questions -Group discussion	Field team; data team
Week of 14/9/09	GIS training -Technical training for research managers, field managers, data manager -Fieldwork team training on using GPS devices	Research managers, field team, data manager
15/9/09 & 16/9/09; or 16/9/09 & 17/9/09	Data training (Mike Rogan)	Data team (avoid overlap with GIS training for research managers and data manager)

Fieldwork Pack

Young Carers Project

HEARD, University of KwaZulu-Natal

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Project summary

In this section you will find a brief summary of the project that you can refer to when describing the project to people in the community.

Background

In many households in South Africa, children help adults with their care and take on other responsibilities. Sometimes when there is an illness in the family, children take on even more responsibility.

The South African government wishes to inform policies regarding children and their carers based with research. This national project will interview children and their carers to find their wellbeing and how they help each other out.

What we're doing

The research team will be interviewing a child-caregiver pair from every eligible home in

Purposes

This project will consist of interviews with caregivers and their children to find:

- Health outcomes of caregivers and their children when living with someone who is unwell
- How children help
- Types of support families receive

Collaboration

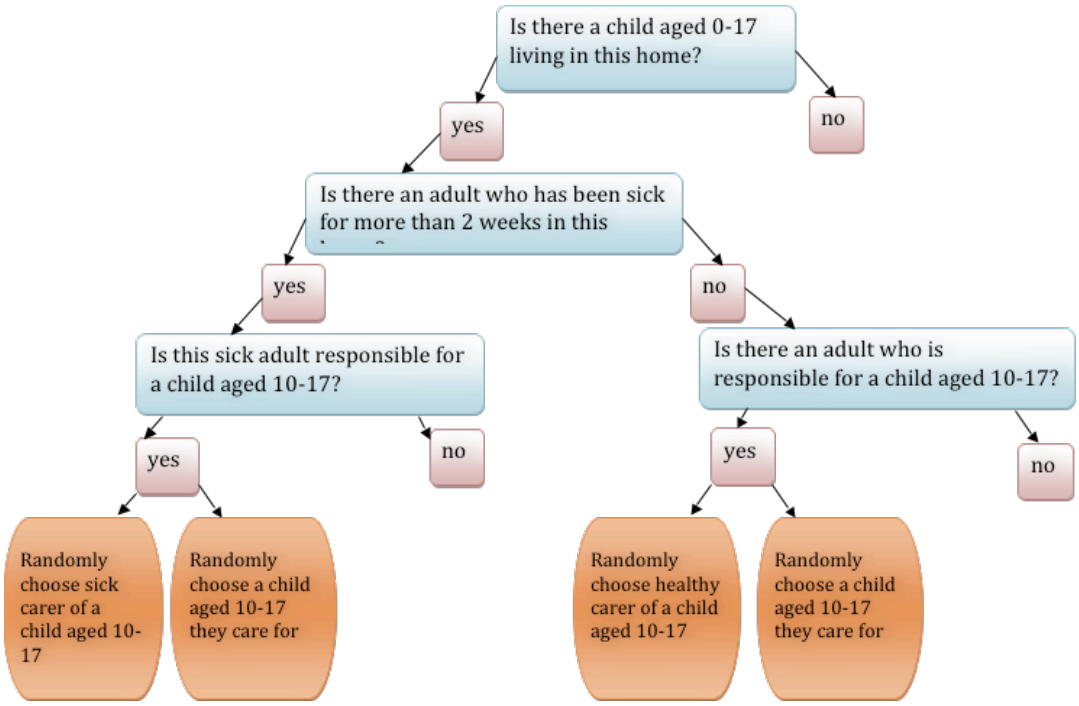
This project is a collaboration between several national government departments (Health, Education, Social Development, Agriculture and Fisheries), universities (KwaZulu-Natal, Cape Town, Witwatersrand, Oxford, Brown), and NGOs (Cape Town Child Welfare, HEARD). Many people around the world will see the results of this study in addition to the South African government.

Logistics

In this section you will find helpful guides on fieldwork logistics.

Recruitment

After appropriate introductions have been made and the project introduced, RAs will then proceed to acquire the following information:



If there is more than child/caregiver pair, randomly select one pair per household.

Remember: INFORMATION FROM EVERY HOME MUST BE RECORDED!! It is required that each house in the enumeration area has been approached and documented, even if no one in the house is interviewed, or the homeowners refuse to participate. If we find there is no data on a home, the RA responsible for that home will be sent back to collect this information! This information includes:

- Date
- GPS device number
- GIS latitude
- GIS longitude
- Waypoint

What is a 'household'?

For this project a household is defined as a place where someone sleeps for four or more nights a week for the past four weeks, and where everyone shares from the

Privacy code

RAs will be responsible for assigning a privacy code to each interview. It is composed of the RAs initials, the date, and the number of questionnaires for that day.

Interviewing

Each RA will be responsible for the child/caregiver pair of interviews. Each participant will be interviewed one at a time and in as private a setting as possible.

Ex. Nelson Mandela, 17 September, third interview of the day = NM-17-09-03

Informed Consent

Before beginning interviews, RAs will need to acquire informed consent from caregivers, and informed consent plus parent/caregiver consent for each child.

Handling data and quality checking

Everyone from RAs to project managers is responsible for handling questionnaires. At every handoff a record will be made of date of the handoff and that questionnaire's privacy code. They will first be handed from RAs to field coordinators, then coordinators to the data manager. At each stage the questionnaires will be quality checked (QC).

- RAs
    - Check for completeness before leaving home
    - QC at home
    - Hand in to field coordinator next morning
- Field coordinators
    - QC a portion interviews during the day
    - Hand in to data manager before going into field the next morning
- Data manager
    - Have data team capture data and note any errors

Correcting mistakes

If a mistake is found in a questionnaire, such as a missing answer, the RA who conducted the interview will be responsible for fixing the mistake. If the mistake is caught before leaving the home, the RA can easily refer back to the question. If the mistake is found after leaving the home, such as by the RA, the coordinator, data manager or project manager, the RA will be required to go back to the house and complete that questionnaire.[1]

[1] Exception: a participant withdraws during an interview. You will not be penalised for this, nor will you need to return to the home to complete the questionnaire.

Protocols

In the field we may come across incidents that are difficult or impossible to resolve by ourselves. We have set up a list of protocols for your and our protection when dealing with these incidents.

Incident book

Every member of the field team will have an incident book to carry with them while they're in the field. Any time they come across an incident that requires reporting, they are required to make a note of it. Incident books will be filled out as follow:

Date	Time	Address	Type of incident	Who it was reported to

Referrals

During our research we are likely to come across families where we suspect abuse. In cases where we have reason to suspect abuse, it is our responsibility to report the incident.

Questions about an incident:

1) Has the participant disclosed some type of abuse (e.g., rape, child abuse, domestic violence, neglect) that requires referral?
2) Is there evidence that the abuse is ongoing?
3) Is the person currently in danger?

If it appears that the people in question are in immediate danger, make a referral as soon as you can. Incidents that require immediate attention include:

- When a person's life or health is in danger
- Cases of rape that happened less than three days prior

Next step:

1) Speak to your field coordinator about the incident. Report everything you found.
2) RA to phone project manager
3) RA and field manager to make a note in their Incident Book

Safety

In addition to watching for the safety of the people we speak to, we also have to be concerned for our own wellbeing. Here are some guidelines for staying safe in the field:

- Wear your team t-shirt at all times
- Wear good walking shoes
- Have your panic alarm
- Make sure your mobile is always charged
- Stay within eyesight of other members of the team
- Don't stay in the field after dark
    - On weekends, be out before the afternoon
- Always have a black male present
- Don't have any items of value
- Don't resist if you're not in physical danger
- Use your panic alarm if you are in danger

Health

We also have to be mindful of our own health. Fieldwork can be tiring, dirty, and strenuous. It is important you consider your own health when you are in the field. Following these strategies should keep you well:

- Avoid long sun exposure
- Make sure you get enough food and water
- Avoid conducting interviews in a home where someone is coughing; take the interview outside
- Wash hands or use hand sanitizer frequently

Emergency

Sometimes in the field we may come across an incident that requires emergency attention. If there appears to be an emergency in the field, follow these steps:

1. What type of emergency
    a. Medical (heart attack, car accident, etc.)
    b. Criminal (robbery, assault, threat, etc.)
    c. Other (fire, storm, etc.)
2. Decide seriousness of emergency
    a. Is this a matter of life or death?
    b. Is someone seriously hurt?
    c. Is there potential for either death or injury (such as during a crime or storm)?
3. Ensure own safety
4. Ensure the safety of others if possible
5. Contact relevant emergency services first, then field coordinators and project managers

Do not:

- Administer medical care unless you are qualified to do so

Appendix

Emergency contacts

These numbers should be in your mobile already, but if not they are listed here:

Services

Cell phone emergency number:	112
Police emergency number:	10111
Ambulance/fire:	10177

Team

Reggie:	082 431 7845
Thokozisiwe:	082 224 5738
Marisa:	082 909 0276
Tyler:	083 342 8957

HEARD

(Health, Economics, and HIV/AIDS Research Division, University of KwaZulu-Natal)

in conjunction with

Tholulwazi Uzivikele

Would like to present

with a

Certificate of Attendance

for training in research, ethics, GPS technology, HIV/AIDS and health knowledge

_____ _____

Manager signature Date

social development
Department: Social Development
REPUBLIC OF SOUTH AFRICA

health
Department: Health
REPUBLIC OF SOUTH AFRICA

education
Department: Education
REPUBLIC OF SOUTH AFRICA

agriculture, forestry & fisheries
Department: Agriculture, Forestry and Fisheries
REPUBLIC OF SOUTH AFRICA

UNIVERSITY OF OXFORD

HEARD

UNIVERSITY OF KWAZULU-NATAL

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

BROWN

Cape Town Child Welfare

IDENTIFICATION OF DWELLING AND FIELD STAFF INFORMATION

Complete this page for ALL HOUSES!

A

1:

Enumeration Area Number .....

GPS lattitude: ..... **GPS longitude:** .....

Address:

(dwelling number / inombolo yomuzi) .....

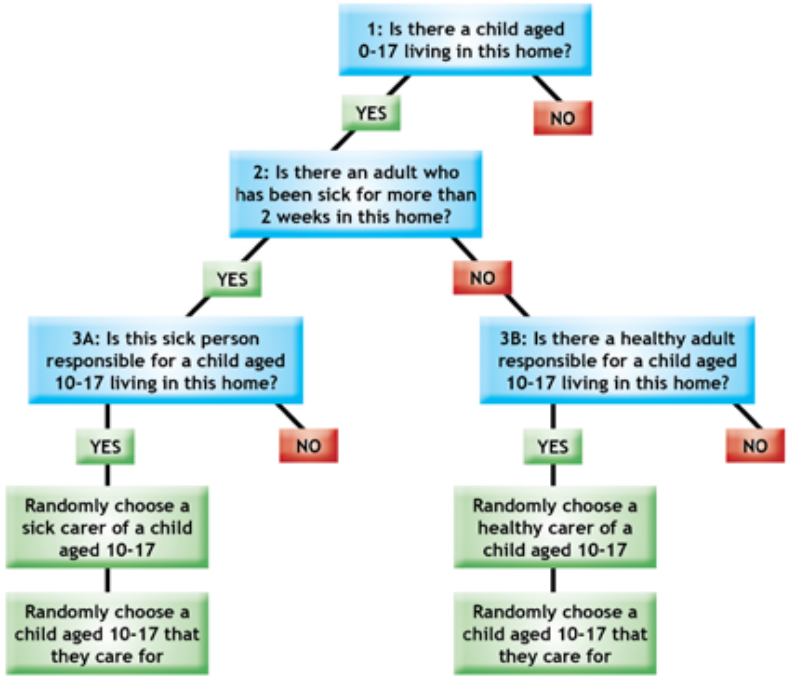
(street name) .....

(village, suburb, locality) .....

(postal code) .....

Date: .....

2:



3: **ELIGIBLE?**

YES | NO *(STOP)*

4: *COMPLETE*

Result Code	*Circle type of response if eligible:*	**Details of Non-response**
1	Completed	
2	Partly complete	
3	No children in household	
4	Refusal	
5	Referral(s) made	
6	Child carer	
7	Visited 3 times and no one home	

PRIVACY CODE:

ADULT CARERS SURVEY

KWA-ZULU/NATAL - 2009/10

UNIQUE ID NUMBER:	PRIVACY CODE:

MAIN SURVEY QUESTIONS / IMIBUZO YOCWANINGO
SECTION 1: HOUSEHOLD INFORMATION AND DEMOGRAPHIC INFORMATION / ISIGABA 1: IMININGWANE NGOMUZI NANGESIMO SABAHLALA KUWONA

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 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 and Occupants (Extra Page)". You will need to refer to the drawing as the survey progresses.

/ Ngicela ukuthola imininingwane ngalomuzi nabantu abahlala kuwona. Ngicela ukuyidweba kanye nawelemininingwane. Ngicela ukukukhombisa ukuthi leminingwane izokuba njani.

Abasebenzi bocwaningo mababheke lokhu: Bheka isibonelo somdwebo omakiwe, "Isigaba sokuqala 1: Imininingwane yomuzi nezinhlobonhlobo zabantu kanye nezigaba zabo, Isibonelo somdwebo womuzi nabahlala kuwo". Sebenzisana nomnakeleli wengane ukudweba lomininnngwane elandelayo nisebenzise amakhasi amaphepha angeziwe futhi amakiwe, " Isigaba 1: Imininingwane yomuzi nezinhlobonhlobo zabantu kanye nezigaba zabo - nokudweba indlu, abahlala kuyo, nokudweba indlu nabahlala kuyo (Iphepha elingeziwe)". Kuzofanele umane ubheka kulomdwebo ngesikhathi uqhubeka nocwaningo.

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.*
/ Ungakwazi ukungilekelela ukuthi ngidwebe amagumbi akhona kulendlu? *Izindlu zifake omaka. Faka indlu yangasese neyokugezela. Ungakhohlwa izindlu ezakhiwe ngaphandle uma zikhona egcekeni.*

Note to Survey Staff: Fill in questions 1.2-1.4 using your own observation. Do not ask the participant to answer these questions. / Abasizi bocwaningo ababheke lokhu: Gcwalisa imibuzo kusuka ku 1.2 kuya ku 1.4 ngokusebenzisa lokho ozibonela khona wena. Ungambuzi umuntu ophendulayo lemibuzo.

1.2(G): *Dwelling Type: (circle one answer choice) / Uhlobo lwendawo yokuhlala: (kokelezela impendulo eyodwa)*
1 = dwelling/house or brick structure on a separate stand or yard / indlu yezitini ezimele esizeni sayo
2 = town/cluster/semi-detached house (simplex, duplex, triplex) / izindlu ezingamadabuli
3 = dwelling/house/flat/room in backyard / indlu noma ifulethi noma ikamelo elakhiwe ngemuva ebaleni
4 = informal dwelling/shack in backyard / indlu esebaleni engumjondolo
5= informal dwelling/shack not in backyard, e.g. in an informal/squatter settlement / indlu engumjondolo endaweni engenazo zonke izidingo
6 = room/flatlet on a property or a larger dwelling / ikamelo noma ifulethi elincane elisebaleni noma endlini enkulu
7 = caravan/tent / indlu edonswa yizimoto ikharavan noma itende
8 = other (specify) / okunye (cacisa): .....

1.3(SADH): *What is the main material of the floor? (circle one answer choice) / Iphansi lendlu lakhiwe ngani? (kokelezela impendulo eyodwa)*
1 = earth/sand/dung / umhlabathi/isihlabathi/ubulongwe
2 = bare wood planks / amapulangwe nje angenalutho
3 = cement / usimende
4 = vinyl / umata
5 = carpet / ukhaphethi
6 = ceramic tiles / kufakwel ama-tiles
7 = parquet or polished wood / amapulangwe afakwe upholishi
8 = other (specify) / okunye (cacisa): .....

1.4(SADH): *What is the main material of the walls? (circle one answer choice) / Izindonga zakhiwe ngani? (kokelezela impendulo eyodwa)*

1 = plastic/cardboard / amapulasitiki noma amakhalibothi
2 = mud / udaka
3 = mud and cement / udaka kanye nosimende
4 = corrugated iron/zinc / uthayela
5 = prefab / isakhiwo esithengwayo sesilungisiwe
6 = bare brick / cement block / izitini noma amabhulokisi angafikiwe usimende
7 = plaster / finished / kufakwe usimende noma kupalusteliwe kwaqedwa
8 = other (specify) / okunye (cacisa): .....

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. /* **Ulala kuphi?** *Sebenzisa umdwebo womuntu wesilisa noma wesifazane utshengise ebusweni bawo ukuthi umnakekeli ungumuntu ongunombolo "1".*

1.6(M): **How old are you?** *Write age in years, for example "58 Y". /* **Uneminyaka emingaki?** *Bhala iminyaka, njengokuthi "58 Y".*

1.7(G&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". /* **Iliphi ibanga lemfundo oliqedile?** *Faka ikhodi efanele lapha ngezansi kwegama nesibongo, njengokuthi uthi "1 edu".*

1 edu= No Schooling / Angiyanga esikoleni
2 edu = Grade R/0 / Ibanga lokulungiselela ukungena isikole
3 edu = Grade 1/Sub A / Ufestiye
5 edu = Grade 3/Standard 1 / Ibanga lokuqala
6 edu = Grade 4/Standard 2 / Ibanga lesibili
7 edu = Grade 5/Standard 3 / Ibanga lesithathu
8 edu = Grade 6/Standard 4 / Ibanga lesine
9 edu = Grade 7/Standard 5 / Ibanga lesihlanu
10 edu = Grade 8/Standard 6/Form 1 / Ibanga lesithupha
11 edu = Grade 9/Standard 7/Form 2 / Ibanga lesikhombisa
12 edu = Grade 10/Standard 8/Form 3 / Ibanga lesishiyagalombili
13 edu = Grade 11/Standard 9/Form 4 / Ibanga lesishiyagalolunye
14 edu = Certificate with less than Grade 12/Standard 10; Diploma with less than Grade 12/Standard 10 / Isitifiketi noma idipuloma ngaphandle kwebanga leshumi
15 edu = Grade 12/Standard 10/Form 5/Matric / Ibanga leshumi
16 edu = Certificate with Grade 12/Standard 10; Diploma with Grade 12/Standard 10 / Isitifiketi noma idipuloma ehambisana nebanga Leshumi
17 edu = NTC I / Isigaba sokuqala ekolishi lamakhono
18 edu = NTC II / Isigaba sesibili ekolishi lamakhono
19 edu = NTC III / Isigaba sesithathu ekolishi lamakhono
20 edu = Bachelors Degree; Honours Degree / Imfundo yejazi lasenyuvesi; ijazi lesibili
21 edu = Higher Degree (Masters, Doctorate) / Ijazi lasenyuvesi ephezulu (iMaster, ubudokotela)
22 edu = Other (specify) / Okunye (cacisa): .....
23 edu = Don't know / Angazi

1.8: **What population group do you belong to?** *Fill in the correct codes below the name, for example, "1 P". /* **Ongowaluphi uhlanga?** *Faka uphawu okuyilonalona ngezansi kwegama, isibonelo, " 1 P".*

1 P = African/Black / Umafrika/Omnyama
2 P = Coloured / Ikhaladi
3 P = Indian/Asian / Umndiya
4 P = White / Omhlophe
5 P = Other (specify in drawing) / Okunye (cacisa)

1.9(G): **What is your native language?** *Fill in the correct code below for the language group, for example, "1 L". /* **Yiluphi ulwimi owaluncela ebeleni olikhulumayo?** *Faka uphawu okuyilonalona ngezansi kwegama, isibonelo, "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 / Isibhunu
11 L = English / Isingisi
12 L = Other (specify) / Okunye (cacisa): .....

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 1.13 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.*
Manje ngicela ukwazi ngabanye abantu asebeke bahlala kulomuzi bachitha okungenani ubusuku obune ngeviki kula maviki amane edlule. *Abasizi bocwaningo ababheke lokhu: Buza imibuzo 1.10 kuya ku 1.13 ngomuntu ngamunye lapha ekhaya osehlale ubusuku obune okungenani emasontweni amane edlule. Ningakhohlwa izingane ezincane.*

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. /* **Ngobani abanye abalala kwamanye amagumbi alomuzi?** *Sebenzisa imidwebo yezingane nabantu abadala ubhale izinombolo ebusweni babo zokuthi umuntu "2", "3", "4", njalo njalo.*

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". /* **Uneminyaka emingaki u . . . .?** *Bhala iminyaka njengokuthi "58 Y" kuthi uma kuyingane engaphansi konyaka ubhale izinyanga njengokuthi "8 M".*

1.12(M): **What is . . .'s first name?** *Write their first name underneath the age. If there are people in the household with the same first name, also include the initial of the surname. /* **Ubani lgama lakho?** *Bhala igama ngaphansi kweminyaka. Uma kukhona abanye abantu kulelikhaya abane gama elifanayo, jobelela izinhlamvu zokuqala zesibongo sakhe.*

1.13 (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". /* **Kungabe wena no . . . . . nihlobene kanjani** *(mnakekeli - ngumuntu ongunombolo "1")***?** *Faka ikhodi efanele ngezansi kwebanga lemfundo noma uhlobo lohlanga noma ulimi uma kufanele. Njengokuthi "12 rel".*

1 rel = husband/wife/partner / umyeni/unkosikazi/umuntu othandana naye
2 rel = father/mother/step father/step mother / ubaba/umama/ubaba ngoba eganwe umama ongizalayo/ umama ngoba egane ubaba ongizalayo
3 rel = grandparent/great grandparent / ugogo noma umkhulu/ ukhokho
4 rel = parent in-laws / abasekhweni noma abasemzini
5 rel = brother or sister in-laws / usibali
6 rel = aunt/uncle / umalumekazi/umalume
7 rel = biological or step son/daughter / indodana/indodakazi yakho oyizalayo noma ongayizali
8 rel = brother/sister/step brother/step sister / umfowenu/udadewenu enizalwa ndawonye noma eningazalwa ndawonye naye
9 rel = grandchild / umzukulu
10 rel = great grandchild / umzukulwana
11 rel = niece or nephew/ umshana (wesifazane) noma umshana (wesilisa)
12 rel = non-related child who was a neighbour's child / ingane esingahlobene nayo ekwakungeka makhelwane
13 rel = non-related child who was a friend's child / ingane esingahlobene nayo ekwakungeka mngane
14 rel = non-related foster child that you previously did not know through a neighbour or friend / ingane esingahlobene nayo engangingayazi ngomakhelwane noma umngane
15 rel = cousin / umzala
16 rel = other (specify in drawing) / okunye (cacisa kumdwebo)

Note to Survey Staff: Return to question 1.10. Repeat questions 1.10 to 1.13 for every person in the household. / Kubacwaningi: Buyela kumbuzo 1.10. Phinda ubuze imibuzo ka 1.10 kuya ku 1.13 ngamuntu ngamunye kulelikhaya.

SECTION 2: CAREGIVER STRAIN AND HEALTH
/ ISIGABA 2: UKUHLUKUMEZEKA KOMNAKEKELI NESIMO SEMPILO

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.

/ Ingxenye ebaluleke kakhulu kulolucwaningo ukuzwa ngezinselelo ohlangabezana nazo njengomunakekeli. Imibuzo elandelayo izozama ukuzwa ngezinselelo obhekana nazo ngesimo sakho sempilo okungenzeka zigcine ziphazamise umsebenzi wakho wokunakekela izingane. Lemibuzo elandelayo, ibuza ngovo lwakho nangempilo yakho. Lolulwazi luzosiza uhlale wazi ukuthi uzizwa unjani nokuthi uyenza kahle kangakanani imisebenzi yakho ojwayele ukuyenza.

2.1(LC): Would you say getting out of bed is ..... / Ungasho uthi ukuphuma embhedeni ku	
1 = Not at all difficult? / Akulukhuni neze?	1
2 = A little difficult? / Kulukhunyana, kancane?	2
3 = Very difficult? / Kulukhuni kakhulu?	3
4 = You are not able to do it? / Akuvukeki nhlobo, awukwazi ukukwenza?	4

2.2(SF): In general, would you say your health is ..... / Ngokwejwayelekile, ungasho ukuthi isimo sempilo yakho si	
1 = Excellent? / Ngiphila saka?	1
2 = Very good? / Sihle kakhulu?	2
3 = Good? / Sihle?	3
4 = Fair? / Asisihle kakhulu?	4
5 = Poor? / Sibi?	5

Question Number / Inombolo yombuzo	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? / Le mibuzo elandelayo imayelana nezinto ongazenza njengenhlalayenza osukwini. Kungabe isimo sakho sempilo sesiyakuvimbela yini ukuba wenze le misebenzi? uma kunjalo, uvimbeleka kangakanani?	Would you say ..... / Ungathini kulokhu		
		1 = Yes, limited a lot? / Yebo, kakhulu?	2 = Yes, limited a little? / Yebo, kancane?	3 = No, not limited at all? / Cha, lutho?
2.3a(SF)	Moderate activities, such as moving a table, or pushing around boxes in the home. / Imisebenzi elukhunyana njengokugudluza itafula, ukuphusha umshini wokuhlanza, ukushanela phansi noma ukugoba.	1	2	3
2.3b(SF)	Climbing several steep hills / Ukukhuphuka izintaba.	1	2	3

Question Number / Inombolo yombuzo	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? / Emasontweni amane adlule, isikhathi esingakanani lapho uke waba nenye yalezi zinkinga ezilandelayo ngomsebenzi wakho noma ngenye yezinto ojwayele ukuzenza nsukuzonke ngenxa yokungaphatheki kahle komzimba?	Would you say ..... / Ungathini kulokhu				
		1 = All of the time? / Sonke isikhathi?	2 = Most of the time? / Isikhathi esiningi?	3 = Some of the time? / Kwesinye isikhathi?	4 = A little of the time? / Isikhashana?	5 = None of the time? / Nhlobo?
2.4a(SF)	Accomplished less than you would like. / Ufeze ngaphansi kokufisa kwakho.	1	2	3	4	5
2.4b(SF)	Were limited in the kind of work or other activities. / Uvimbelekile ukwenza uhlobo oluthile lomsebenzi noma ezinye izinto.	1	2	3	4	5

Question Number / Inombolo yombuzo	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)? / Emasontweni amane adlule, isikhathi esingakanani lapho uke waba nenye yalezi zinkinga ezilandelayo ngomsebenzi wakho noma enye yezinto ozenza nsukuzonke ngenxa yokungaphatheki kahle emoyeni? (njengokuzizwa uphansi noma uvalo/ivuso)?	Would you say ..... / Ungathini kulokhu				
		1 = All of the time? / Sonke isikhathi?	2 = Most of the time? / Isikhathi esiningi?	3 = Some of the time? / Kwesinye isikhathi?	4 = A little of the time? / Isikha-shana?	5 = None of the time? / Nhlobo?
2.5a(SF)	Accomplished less than you would like. / Ufeze ngaphansi kokufisa kwakho.	1	2	3	4	5
2.5b(SF)	Did work or other activities less carefully than usual. / Awuwenzanga umsebenzi noma em-inye imisebenzi ngokuqikelela njengokwe jwayelekile?	1	2	3	4	5

2.6(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 ..... / Emasontweni amane adlule, zikuphazamise kangakanani izinhlungu emsebenzini wakho ojwayelekile (owenza ekhaya nangaphandle)? Ungathini kulokhu	
1 = Not at all? / Azingiphazamisanga nhlobo?	1
2 = Slightly? / Zingiphazamise kancane nje?	2
3 = Moderately? / Ziphazamisile?	3
4 = Quite a bit? / Zithe ukuphazamisa impela?	4
5 = Extremely? / Ziphazamiseke kakhulu?	5

Question Number / Inombolo yombuzo	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..... / Le mibuzo imayelana nokuthi uzizwa unjani nokuthi izinto bezinjani emasontweni amane adlule. Embuzweni nga-munye, nikeza impendulo eshaya emhloleni ngobukuzwa. Isikhathi esingakanani emasont-weni amane adlule	Would you say ..... / Ungathini kulokhu				
		1 = All of the time?/ Sonke isikhathi?	2 = Most of the time? / Isikhathi esiningi?	3 = Some of the time? / Kwesinye isikhathi?	4 = A little of the time? / Isikha-shana?	5 = None of the time? / Nhlobo?
2.7a(SF)	Have you felt calm and peaceful? / Uke wazizwa unokuthula noxolo?	1	2	3	4	5
2.7b(SF)	Did you have a lot of energy? / Uke waba nomdlandla omningi?	1	2	3	4	5
2.7c(SF)	Have you felt downhearted and depressed? / Uke wazizwa udabukile futhi udangele?	1	2	3	4	5

2.8(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 ..... / Emasontweni amane adlule, izinkinga zokukhathazeka kwakho emzimbeni noma emoyeni zikuphazamise kangakanani ekuphilisaneni kwakho nabanye abantu (njen-gokuvakasha nabangani, nezihlobo njll)? Ungathini kulokhu	
1 = All of the time? / Sonke isikhathi?	1
2 = Most of the time? / Isikhathi esiningi?	2
3 = Some of the time? / Kwesinye isikhathi?	3
4 = A little of the time? / Isikhashana?	4
5 = None of the time? / Nhlobo?	5

We all get sick sometimes. We would like to ask about your illnesses. These questions may be personal but this information will be valuable for government who wants to better understand the health of carers and support them. Therefore these questions are especially important for our survey. If you want to answer these questions in private, we will pull out these pages out and you can store your answers in a sealed, unnamed envelope. If you become uncomfortable, remember you can always ask us to stop at any time.

/ Sonke sinakho ukuhlaselwa ukugula ngezinye izikhathi. Singathanda ukukubuza ngezifo zakho. Lemibuzo ingahle ingene kakhulu ezintweni ezithinta wena kodwa imininingwane izoba usizo kakhulu kuhulumeni ozama ukuqonda isimo sempilo yabanakekeli nokusekelwa kwabo. Ngakhoke lemibuzo ibaluleke kakhulu kulo-lucwaningo. Uma ufisa ukuphendula lemibuzo ngasese, singakwazi ukukhipha lamakhasi anezimpendulo zakho futhi siwabeke emvilophini evaliwe nqi engenagama lamuntu. Uma uzizwa ungasazizwa kahle, khumbula ukuthi ungasimisa noma yinini.

(Chronic Conditions / Izimo Ezikuxhwalisayo)		No / Cha	Yes / Yebo
2.9	**Do you have asthma? / Unaso isifuba somoya?**	0	1
2.9a	**How many asthma attacks have you had in the last month? ..... attacks / Sikuhlasele ngakaki isfuba somoya kulenyanga edlulile? ..... ukuhlaselwa**		
2.9b	**When you have an attack, do you have a puffer spray you can take? / Uma uhlaselwa yilokhukugula, unaso yini isifutho somlomo ongasithatha?**	0	1
2.10	**Do you have epilepsy? / Unaso yini isifo sokuwa?**	0	1
2.10a	**How many seizures have you had in the last month? ..... seizures / Uwe waba nokudlikiza komzimba kangaki kulenyanga edlulile? ..... ukudlikiza**		
2.10b	**Are you taking your treatment every day? / Ingabe uthatha imithi yakho nsuku zonke?**	0	1
2.11	**Do you have diabetes? / Unaso Isifo sikashukela?**	0	1
2.11a	**How many times have you been sick in the past month? ..... times / Ugule kangaki kulenyanga edlulile? ..... izikhathi**		
2.11b	**Are you taking your injections or pills every day? / Ingabe uyayithatha imijovo yakho noma amaphilisi nsukuzonke?**	0	1
2.12	**Do you have hypertension? / Unaso isifo sengcindezi eyenza inhliziyo ishaye ngamawala uphelelwe nawumoya?**	0	1
2.12a	**Do you have medication for this? / Unayo imithi yalesisifo?**	0	1
2.12b	**Do you take your medication every day? / Uyayidla lemithi yakho zonke izinsuku?**	0	1
2.13	**Do you have high or low blood pressure? / Unaso isifo somfutho wegazi ophakeme noma ophansi?**	0	1
2.13a	**Do you have medication for this? / Unemithi oyithathayo yalesosifo?**	0	1
2.13b	**Do you take your medication every day? / Uyayidla lemithi yakho zonke izinsuku?**	0	1
2.14	**Do you have arthritis? / Unaso isifo samathambo namalungu omzimba?**	0	1

(Physical disability / Ukukhubazeka ngokomzimba)		No / Cha	Yes / Yebo
2.15	**I have problems seeing properly / Nginezinkinga zokubona kahle**	0	1
2.16	**I have another kind of disability** *(what kind?)* ..... **/ Nginolunye uhlobo lokukhubazeka** *(hloboluni?)*	0	1

(Communicable TB) **Have you had ..... /** *(Izifo sofuba esithelelanayo)* **Uke waba no…….**		No / Cha	Yes / Yebo
2.17a	**A cough where you spit up green or yellow stuff / Ukukhwehlela lapho ukhipha into eluhlaza noma ephuzi**	0	1
2.17b	**A bad cough lasting 3 weeks or longer / Ukukhwehlela okunzima okuhlale amaviki amathathu nesikhashana esingaphezulu kwalokho**	0	1
2.17c	**Pains in your chest / Izinhlungu esifubeni sakho**	0	1
2.17d	**Tiredness and weakness / Ukukhathala nokuba buthaka**	0	1
2.17e	**Have you lost weight without meaning to? / Ngabe wehlile emzimbeni ube ungaqondanga ukwenza lokho?**	0	1
2.17f	**Do you have night sweats? / Ngabe uyajuluka ebusuku?**	0	1
2.17g	**Are you coughing up blood? / Ingabe ukhwehlela igazi?**	0	1
2.17h	**Are you having a fever? / Ingabe unomkhuhlane imfiva?**	0	1
2.17i	**Has a nurse or doctor asked you to cough sputum into a little bottle' test? / Ngabe umhlengikazi noma udokotela uke wakucela ukuba ukhiphele isikhwehlela sakho ebhodleleni elincane na?**	0	1
2.17j	*Ask if the participant answered "Yes" to Q2.17i. If the participant answered "No", skip to Q2.17k.* **Do you know if the test was positive for TB?** */ Buza lombuzo kuphela uma lowo obuzwayo ephendule "Yebo" ku Q2.17i. Uma obuzwayo ephendule "Cha", yeqela ku Q2.17k.* **Uyazi noma ukuhlolwa kwakho kwesifo sofuba kwaqinisekisa ukuthi unaso?**	0	1
2.17k	**Have you had TB in the past 2 years? / Uke waba naso isifo sofuba kuleminyaka emibili edlulile?**	0	1
2.17l	*Ask if the participant answered "Yes" to Q2.17k. If the participant answered "No", skip to Q2.18a.* **Were you given pills to take every day for TB?** */ Buza lombuzo kuphela uma lowo obuzwayo ephendule "Yebo" ku Q2.17k. . Uma obuzwayo ephendule "Cha", yeqela ku Q2.18a.* **Wanikwa yini amaphilisi esifo sofuba ozowadla nsukuzonke?**	0	1
2.17m	**If yes, how long did you take pills for? ..... months** **/ Uma uvuma, wawathatha isikhathi esingakanani amaphilisi? ..... izinyanga**		

(Other general health questions) **Have you had any of these symptoms?** */ (Eminye imibuzo eyejwayelekile ngesimo sakho sempilo)* **Uke waba nalezizimpawu ezinjengalezi?**		No / Cha	Yes / Yebo
2.18a	**Have you had moderate or severe weight loss? / Uke wehlelwa umzimba ngokungekubi kangako noma wehle kakhulu?**	0	1
2.18b	**Have you had wasting which is moderate or severe weight loss with at least four of the following symptoms: paleness, changing hair colour, swelling of legs, burning feelings in feet, or dry scaly skin? / Uke wehlelwa umzimba ngokungekubi kangako noma wehle kakhulu ube nalez-impawu ongenani ezine kwezilandelayo: ukuphaphatheka, ukushintshelwa umbala wezinwele, ukuvuvuka kwezinyawo, ukushisa okukhulu ezinyaweni, isikhumba esomile esikhekhebukayo?**	0	1
2.18c	**Have you had jaudince where the whites of your eyes are yellow and no history of alcohol abuse? / Uke waba nejondisi isifo esibangwa ukuchitheka kwenyongo amehlo akho aphenduke abe phuzi kodwa unganamlando wokuphuza utshwala kakhulu?**	0	1
2.18d	**Have you had shingles or a rash on one side of your body that is like a belt? / Uke waba nalo ibhande noma utwayi olwakuvela engxenyeni eyodwa yecele lomzimba wakho?**	0	1
2.18e	**Have you had a cold or the flu? / Uke waba nomkhuhlane noma influwenza?**	0	1

.....2.18 continued from above / ….2.18 uqhuntswa okusukela phezulu		No / Cha	Yes / Yebo
2.18f	**Have you had abscesses or sores on your body? / Uke wabanamathumba noma izilonda emzimbeni wakho?**	0	1
2.18g	**Have you had oral candidasis where you have two or three of the following: ulcers in your mouth, difficulty swallowing, or white patches in your mouth? / Uke waba nenkwethu emlonyeni ikwenze waba nokubili noma okuthathu kwalokhu okulandelayo: izilonda emlonyeni, ungakwazi ukugwinya, amabala amhlophe emlonyeni?**	0	1
2.18h	**Do you have cancer? Where is the cancer?..... / Unaso isifo somdlavuza? Sikuphi isifo sakho somdlavuza? .....**	0	1
2.18i	**Have you had general body pain (headaches, backaches etc)? / Uke waba nobuhlungu emzimbeni wonke (ikhanda elinkenkethayo, iqolo elibuhlungu)?**	0	1
2.18j	**Do you use antiretrovirals or ARVs? / Uyayisebenzisa imishanguzo yokwelapha ingculazi?**	0	1
2.18k	**Have you had pneumonia or bronchitis (really sick with cough, chest pain and yellow spit for at least 1 week)? / Uke waba nesifo sokushisa nokuba namanzi emaphashini (ugule kakhulu futhi ukhwehlele, ubenobuhlungu esifubeni futhi ukhiphe uketshezi oluphuzi mhlawumbe iviki elilodwa)?**	0	1
2.18l	**Have you had trouble breathing, or a cough for more than 2 days with fever? / Uke waba nenkinga yokuphefumula, noma ukhwehlele kuzekube ngaphezulu kwezinsuku ezimbili unomkhuhlane?**	0	1
2.18m	**Last time you went to the doctor, did they tell you your CD4 count? What was it? ..... / Ngesikhathi ugcina ukuya kwadokotela wokutshela yini ngezinga lamasosha omzimba wakho? Lalingubani izinga? .....**	0	1
2.18n	*Ask only if the respondent is female:* **Do you have vaginal tumors where there was a vaginal tumour for at least one month with or without bleeding? /** *Buza kuphela uma aphendulayo kungo wesifazane:* **Ingabe unakho okusamathumba esithweni sakho sangasese, lapho wake waba nawo amathumba esithweni sangasese okungenani inyanga eyodwa wopha noma ungophi?**	0	1
2.18o	**Have you been bewitched? / Uke wathakathwa?**	0	1
2.18p	**Have you had any injury or burn? / Uke waba nokulimala noma ukusha?**	0	1
2.18q	**Have you had constant diarrhea or a runny tummy? / Uke waba nesifo sohudo olungapheli noma isisu esikuhambisayo?**	0	1
2.18q(i)	*Ask if the participant answered "Yes" to Q2.18q. If the participant answered "No", skip to Q2.18r.* **How many days has this lasted? ..... days** */ Uma obuzwayo ephendule "Yebo" ku Q2.18q. Uma obuzwayo ephendule "Cha" dlulela ku Q2.18r.* **Sithathe izinsuku ezingaki? ..... izinsuku**		
2.18r	**Do you have anything else we haven't asked about? / Unakho yini okunye okuthile esingakakubuzi khona?**	0	1
2.18r(i)	*Ask if the participant answered "Yes" to Q2.18r. If the participant answered "No", skip to Q2.19.* **If yes, what do you have?** *(specify):* ..... */ Uma obuzwayo ephendule "Yebo" ku Q2.18r. Uma obuzwayo ephendule "Cha" dlulela ku Q2.19.* **Uma yebo/uvuma, Kuyini lokho onakho?** *(cacisa):*		

Directions: If the carer answered yes to any questions 2.10 through 2.19, ask these questions. / Indlela: Uma umnakekeli ephendule wathi "yebo" kunoma imuphi umbuzo 2.10 kuya ku 2.19, buza lemibuzo.		
2.19	*(WHO Clinical Staging)* **Are you able to do activities that you would normally do at work, at home, etc? / Ingabe uyakwazi ukwenza lmisebenzi yakho ejwayelekile emsebenzini, ekhaya, nakewzinye lzindawo?**	
	0 = No → *Go to Q2.20* / 0 = Cha → *Yiya ku Q2.20*	0
	1 = Yes (Stage 2) → *Go to Q2.22* / 1 = Yebo (Isigaba 2) → *Yiya ku Q2.22*	1
2.20	**Do you spend time in bed during the day? / Uchitha isikhathi embhedeni naphakathi nosuku?**	
	0 = No → *Go to Q2.22/* 0 = Cha → *Yiya ku Q2.22*	0
	1 = Yes → *Go to Q2.21* / 1= Yebo → *Yiya ku Q2.21*	1
2.21	*(WHO Clinical Staging)* **How much time do you spend in bed? / Uchitha isikhathi esingakanani embhedeni?**	
	1 = Half of the day or less (Stage 3) / **1 = Uhafu wosuku/isigamu sosuku noma ngaphansi** *(Isigaba 3)*	1
	2 = More than half of the day (Stage 4) / **2 = Ngaphezulu kohafu wosuku** *(Isigaba 4)*	2

Could you tell me whether you used these kinds of healthcare in the past two years? / Ungangitshela ukuthi uke wazisebenzisa yini lezinhlobo zezindawo zokuthola impilo kuleminyaka emibili edlule?		**0 = No, I didn't need to** → *Go to Q2.27* / **0 = Cha, Ngangingakud-ingi ukuya** → *Yiya ku Q2.27*	**1 = No, I needed to but I couldn't** → *Go to Q2.25* / **1 = Cha, Ngan-gidinga kodwa angikwazanga** → *Yiya ku Q2.25*	**2 = Yes** → *Go to Q2.24* / **2 = Yebo** → *Yiya ku Q2.24*
2.22a	**Chemist/pharmacy / Ikhemisi**	0	1	2
2.22b	**A public clinic / Umtholampilo womphakathi**	0	1	2
2.22c	**A private doctor / Udokotela ozimele**	0	1	2
2.22d	**A traditional healer / Umelaphi wendabuko**	0	1	2
2.22e	**A healer at a church or medicines from the church / Umthandazi enkozweni noma ukwelashwa enkozweni**	0	1	2
2.22f	**Dentist / Udokotela wamazinyo**	0	1	2
2.22g	**A public hospital / Isibhedlela somphakathi**	0	1	2
2.22h	**A private hospital / Isibhedlela esizimele**	0	1	2
2.22i	**Community Health Worker / Unompilo womphakathi**	0	1	2
2.22j	**Other / Okunye** *(Specify / Cacisa):*	0	1	2

....2.22 continued from above / ….2.22 uqhuntswa okusukela phezulu		**0 = No, I didn't need to** → *Go to Q2.27* / **0 = Cha, Ngangingakud-ingi ukuya** → *Yiya ku Q2.27*	**1 = No, I needed to but I couldn't** → *Go to Q2.25* / **1 = Cha, Ngan-gidinga kodwa angikwazanga** → *Yiya ku Q2.25*	**2 = Yes** → *Go to Q2.24* / **2 = Yebo** → *Yiya ku Q2.24*
2.22k	**Home Based Care Worker** → *Go to Q2.23* / **Unompilo okunakelela ekhaya** → *Yiya ku Q2.23*	0	1	2
	2.23a: **How many times did the Home based carer visit you in the last month? / Unompilo wasekhaya wakuvakashela izikhathi ezingaki enyangeni edlule?** ..... times / izikhathi			
	2.23b: **Did the home based carer give you: / Ingabe unompilo wasekhaya wakunika:**	**No / Cha**	**Yes / Yebo**	
	(i) Emotional support / Ukusekelwa ngokomphefumulo	0	1	
	(ii) Cared for you / Wakunakelela kahle	0	1	
	(iii) Cared for children in the home / Wanakelela abantwana abasekhaya	0	1	
	(iv) Spent time talking to you about your health / Wachitha isikhathi nami ekhuluma ngempilo yami	0	1	
	(v) Brought food parcels / Waletha ukudla ngezijumbane	0	1	
	(vi) Assisted with domestic duties / Wasiza kumisebenzi yasendlini	0	1	

2.24: *Ask only if the participant answered "Yes" to any question from Q2.22.* **If you had an appointment to see a health care provider, were you able to keep your appointments?** */ Buza kuphela uma lowo obuzwayo ephendule "Yebo" kunoma imuphi umbuzo kusuka ku Q2.22.* **Uma wawunikezwe ithuba nesikhathi sokubona owezempilo, wakwazi yini ukufinyelela ugcine nesikhathi?**

- ❑ **1 = Always / 1 = Ngasosonke isikhathi**
- ❑ **2 = Sometimes** → *go on to Q2.25.* / **2 = Ngesinye isikhathi** → *qhubekela ku Q2.25.*
- ❑ **3 = Never** → *go on to Q2.25.* / **3 = Angikaze neze** → *qhubekela ku Q2.25.*

Note to Survey Staff: Ask Q2.25 only if participant answered "No, I needed to but Couldn't" to any question from Q2.22. / Abasebenzi bocwaningo ababheke lokhu: Buza u Q2.25 kuphela uma obuzwayo ephendule "Cha, ngangidinga ukuya kodwa angikwazanga" kunoma umuphi umbuzo kusuka Q2.22.

2.25 (G,M&K): **Why did you not see any health worker during the past two years?** *(circle all that apply)* / **Kungani ungayanga ukuyobona noyedwa umsebenzi wezempilo eminyakeni emibili eyedlule?** *(zungeleza konke okushiwo)*	
1 = shortage of money for consultation or medicine / Ibingekho imali yokukhokha noma ukuthenga imithi	1
2 = shortage of money for transport / Ibingekho imali yokugibela	2
3 = sick person too busy / Isiguli besixakekile asilitholanga ithuba	3
4 = no one available to go with him/her / Akekho obezophelezela isiguli	4
5 = health facility too far away / Isizinda sezempilo sikude kakhulu	5
6 = queues/waits too long / Kumiwa isikhathi eside kakhu noma kuya gcwala	6
7 = staff unhelpful or lack skills to help / abasebenzi abakwazi ukusiza noma abanawo amakhona okwelapha lenkinga yami	7
8 = no medicine at the facility / ayikho imithi kule sizinda	8
9 = could not decide what to do / ngigcine ngingakwazanga ukuthatha isinqumo sokuthi ngenzenjani	9
10 = religious reason / yizizathu zenkolo	10
11 = fear/embarrassment / ukusaba nokwesaba ukuhlekwa ngabanye abantu	11
12 = other *(specify)* / okunye *(cacisa)*:	12
13 = don't know / angazi	13

2.26a(M): **Is this place where you get help for your health a .....** *(Circle all that apply)* / **Ngabe iyona lendawo othola khona usizo lwezempilo e .....** *(kekelezela konke ovumelana nakho)*		2.26b(G): **How long in minutes does it take or would it take, from home to reach the nearest place to get help when you are sick?** *(in minutes)* / **Kuthatha imizuzu emingaki Uma ukusuka ekhaya ukufinyelele endaweni eseduze yomtholampilo nxashana ugula?** *(ngemizuzu)*	2.26c(G and M): **What means of transport do you typically use to get to the nearest place where you can get help for your health?** *If more than one means of transport, take the one used over the longest distance.* / **Usebenzisa uhlobo olunjani lwezinto zokuhamba ukufinyelela kumtholampilo oseduze nawe?** *Uma ingaphezulu kweyodwa that leyo esisethenziswe ibanga elide.*
1 = public hospital / Isibhedlela somphakathi	1		
2 = private hospital / isibhedlela esizimele	2		
3 = public clinic / umtholampilo womphakathi	3		
4 = private clinic / umtholampilo ozimele	4		
5 = traditional healer / umelaphi wendabuko	5		
6 = other *(specify)* / **okunye** *(cacisa)*	6		

2.27: **Did you talk to the following people or use any of these services in the past two years because you were feeling sad or stressed?** *(Circle all that apply.)* / **Wake wakhuluma nalababantu abalandelayo noma usebenzise lezizizinda zosiso kuleminyaka emibili edlulile ngenxa yokuthi wawuzizwa unomunyu nengcindezi?** *(kekelezela konke ovumelana nakho)*	**0 = No, I didn't need to** → *Go to Q2.29* / **0 = Cha, Ngangingakudingi ukuya** → *Yiya ku Q2.29*	**1 = No, I needed to but I couldn't** → *Go to Q2.28* / **1 = Cha, Ngangidinga ukuya kodwa angikwazanga** → *Yiya ku Q2.28*	**2 = Yes / 2 = Yebo**
a) friend /family member / umngani noma ilungu lomndeni	0	1	2
b) priest/pastor / umfundisi	0	1	2
c) traditional/faith healer / umelaphi wendabuko noma umthandazi	0	1	2
d) nurse / umhlengikazi	0	1	2
e) psychiatrist / udokotela wezengqondo	0	1	2
f) doctor that is not a psychiatrist / udokotela ongasiye owezengqondo	0	1	2
g) support group / inhlangano yokwesekelana	0	1	2
h) telephone hotline / ucingo oluphuthumayo lokwaluleka	0	1	2
i) other / okunye *(Specify / Cacisa)*	0	1	2

2.28: **Why did you not talk to or use services when you were feeling sad or stressed?** *(Circle all that apply.)* / **Kungani ungakhulumanga noma usebenzise izinsiza ngesikhathi uzizwa unomunyu noma ingcindezi?** *(Zungeleza konke okushiwo)*	
1 = shortage of money for consultation or medicine / Ibingekho imali yokukhokha noma ukuthenga imithi	1
2 = shortage of money for transport / Ibingekho imali yokugibela	2
3 = sick person too busy / Isiguli besixakekile asilitholanga ithuba	3
4 = no one available to go with him/her / Akekho obezophelezela isiguli	4
5 = health facility too far away / Isizinda sezempilo sikude kakhulu	5
6 = queues/waits too long / Kumiwa isikhathi eside kakhu noma kuya gcwala	6
7 = staff unhelpful or lack skills to help / abasebenzi abakwazi ukusiza noma abanawo amakhona okwelapha lenkinga yami	7
8 = no medicine at the facility / ayikho imithi kule sizinda	8
9 = could not decide what to do / ngigcine ngingakwazanga ukuthatha isinqumo sokuthi ngenzenjani	9
10 = religious reason / yizizathu zenkolo	10
11 = fear/embarrassment / ukusaba/ukuphoxeka	11
12 = other *(specify)* / okunye *(cacisa):*	12
13= don't know / angazi	13

2.29: **If you ever needed to get help for feeling sad or stressed, which of these people or services would you go to?** *(Circle all that apply.)* / **Uma kwenzeka udinga usizo ngenxa yokuzizwa unomunyu noma unengcindezi, yibaphi abantu noma izizinda zosizo ongazisebenzisa?** *(kekelezela konke ovumelana nakho)*	**No / Cha**	**Yes / Yebo**
a) friend /family member / umngani noma ilungu lomndeni	0	1
b) priest/pastor / umfundisi	0	1
c) traditional/faith healer / umelaphi wendabuko noma umthandazi	0	1
d) nurse / umhlengikazi	0	1
e) psychiatrist / udokotela wezengqondo	0	1
f) doctor that is not a psychiatrist / udokotela ongasiye owezengqondo	0	1
g) support group / inhlangano yokwesekelana	0	1
h) telephone hotline / ucingo oluphuthumayo yokwalulekwa	0	1
i) other / okunye *(Specify / Cacisa)*	0	1

Now I want to learn about who helps you when you are sick. / Manje ngifisa ukwazi ukuthi ubani okusizayo uma ugula.

2.30: **Are you sick now? / Uyagula njengamanje?**

❑ 0 = No / Cha

❑ 1 = Yes / Yebo

2.31: **When we're sick, often our children help look after us. Does a child in your home help care for you when you are sick? / Kaningi masigula abantwana bethu bayasiza ukusinakelela. Ingabe umtwana okhona ekhaya lakho uyasiza akunakekele mawugula?**

❑ 0 = No → *Go on to Q2.32 /* Cha → *Dlulela ku Q2.32*

❑ 1 = Yes → **Which child is this?** *(specify person number) /* Yebo → **Yimuphi lowo mtwana?** *(cacisa inombolo yakhe)* ..... → *Go on to Q2.32 and Q2.33. / → dlulela ku Q2.32 no Q2.33*

2.32: **Does a child help with domestic work when you are sick? / Ingabe umtwana uyasiza ngemisebenzi yasendlini mawugula?**

❑ 0 = No → *Go on to Q2.34 /* 0 = Cha → *Dlulela ku Q2.34*

❑ 1 = Yes → **Which child is this?** *(specify person number)* ..... → *Go on to Q2.33 /* Yebo → **Yimuphi ke lomtwana?** *(cacisa inombolo yakhe)* ..... → *Dlulela ku Q2.33*

2.33: **When a child or young person helps look after us, it can sometimes make us feel good, and sometimes bad. Could you tell us a bit about what it's like when a young person helps look after you or helps with domestic work when you are sick? / Uma umtwana noma umuntu omusha esinakekela, kwezinye lzikhathi kusenza sizizwe sithokozile noma siphatheke kabi. Ungake usichazele kancanyana ukuthi kukuphatha kanjani uma unakekelwa umuntu omusha aphinde abheke okwasendlini uma ugula?**

.....

.....

2.34: **When you have to go to a clinic or hospital, does a child go with you for assistance or company? / Uma kufanele uye emtholampilo noma esibhedlela, umtwana uyaye ahambe nawe yini ukukuphelezela nokukusiza?**

❑ 0 = No / Cha

❑ 1 = Yes → **Which child is this?** *(specify person number)* / Yebo → **Yimuphi ke lomtwana?** *(cacisa inombolo yakhe)* .....

2.35: **When you are sick, is there someone who has been helping care for your child(ren)? / Uma ugula, ukhona yini obekulekelela ukunakelela abantwana?**

❑ 0 = No / Cha

❑ 1 = Yes → *go to Q2.36 /* Yebo → *yiya ku Q2.36*

2.36: How is this person in 2.35 related to you? / Umuntu omshilo kumbuzo 2.35 uhlobene kanjani nawe?			How old is this person in years? / Uneminyaka emingaki lowomuntu?
Relative / Isihlobo	1 = husband/wife/partner / umyeni/unkosikazi/ othandana naye	1	
	2 = parent or step-parent / umzali noma umzali ongangizali kodwa ongibhekayo	2	
	3 = aunt/uncle / umalumekazi/umalume	3	
	4 = sibling or step-sibling / umtwana wakithi noma owakithi ongazalwa umzali wami	4	
	5 = child / Ingane	5	
	6 = grandchild or great-grandchild / umzukulu noma umzukulwana	6	
	7 = other relative *(specify) /* esinye isihlobo *(cacisa):*	7	
Non-relative / Okungahl-obene	8 = friend / umngani	8	
	9 = neighbour / umakhelwane	9	
	10 = child not related through kinship / umtwana ongahlobene naye ngokobundeni	10	
	11 = other non-relative *(specify) / okunye okungahlangene nobuhlobo (cacisa):*	11	

SECTION 3: PSYCHOSOCIAL MEASURE / ISIGABA 3: IZINYATHELO NGOKWENGQONDO NESIMO SENHLALO

Now, I want to learn more about how you have been feeling emotionally and mentally. / Manje, ngicela ukuzwa ngokuthi uphatheke kanjani emoyeni nasengqondweni.

Question Number / Inom-bolo yombuzo	Below is a list of common symptoms of anxiety. Indicate how much you have been bothered by that symptom during the past month, including today. / Lapha ezansi kunohla lwezimpawu ezijwayelekile ezihambisana novalo. Sicacisele ukuthi zike zakuhlupha kangakanani kulenyanga edlulile, kufaka namhlanje.	0 = Not At All / Azikaze zingih-luphe nhlobo	1 = Mildly but it didn't bother me much. / Zike zangihlupha kan-canyana, azangikhat-haza kangako	2 = Moderately - it wasn't pleasant at times / Zingihluphah-luphile, bekuy-isikhathi esingem-nandi	3 = Severely - it bothered me a lot / Kakhulu impela, kwangikhathaza kakhulu impela
3.1a	**Numbness or tingling / Ukungabi nemizwa/ukukitazeka**	0	1	2	3
3.1b	**Feeling hot / Ukushiselwa**	0	1	2	3
3.1c	**Wobbliness in legs / Ukuxegelwa imilenze**	0	1	2	3
3.1d	**Unable to relax / Ukungakwazi ukuphumula ngokukhululekile**	0	1	2	3
3.1e	**Fear of worst happening / Uvalo lokuthi kungenzeka into embi kakhulu**	0	1	2	3
3.1f	**Dizzy or lightheaded / Isiyezi nokuzulelwa ikhanda**	0	1	2	3
3.1g	**Heart pounding/racing / Inhliziyo eshayayo, igijime kakhulu**	0	1	2	3
3.1h	**Unsteady / Ukungaqini gnqi noma ukushikashikeka**	0	1	2	3

Question Number / Inombolo yombuzo	...3.1 continued from above / ....3.1 uqhuntswa okusukela phezulu	0 = Not At All / Azikaze zingihluphe nhlobo	1 = Mildly but it didn't bother me much. / Zike zangihlupha kancanyana, azangikhathaza kangako	2 = Moderately - it wasn't pleasant at times / Zingihluphaluphile, bekuyisikhathi esingemnandi	3 = Severely - it bothered me a lot / Kakhulu impela, kwangikhathaza kakhulu impela
3.1i	Terrified or afraid / Ukwesaba okukhulu	0	1	2	3
3.1j	Nervous / Ukuba nemizwa ephezulu ngenxa yovalo	0	1	2	3
3.1k	Feeling of choking / Uzizwa uklinyeka	0	1	2	3
3.1l	Hands trembling / Izandla ziyaqhaqhazela	0	1	2	3
3.1m	Shaky/unsteady / Uyaqhaqhazela/ uyashikashikeka	0	1	2	3
3.1n	Fear of losing control / Uvalo lokulahlekelwa ukuzibamba	0	1	2	3
3.1o	Difficulty in breathing / Ukuba nenkinga yokuphefumula	0	1	2	3
3.1p	Fear of dying / Ukusaba ukufa	0	1	2	3
3.1q	Scared / Ukuthuka	0	1	2	3
3.1r	Indigestion / Ukuqumbelana	0	1	2	3
3.1s	Faint/lightheaded / Uzizwa ufuna ukuquleka	0	1	2	3
3.1t	Face flushed / Ubuso buhwabhekile	0	1	2	3
3.1u	Hot/cold sweats / Imijuluko eshisayo nebandayo	0	1	2	3

Question Number / Inombolo yombuzo	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 ..... / Ngizo kufundela uhla lwezi tatimende ngokuthi uzizwe noma waziphatha kanjani kulelisonto elidlulile .Ngifuna ukwazi ukuthi uzizwe kangaki kanje kuleliviki eledlule	Would you say ..... / Ungathini kulokhu			
		1 = Rarely or none of the time (Less than 1 day)? / Akuvamile noma akwenzeki nhlobo (Alupheli usuku)?	2 = Some of the time (1-2 days)? / Kunezikhathi ekwenzeka ngazo (Usuku olulodwa noma izinsuku ezimbili)?	3 = Occasionally or Moderately (3-4 days)? / Kuvamile noma ngezikhashana (izinsuku ezintathu kuya kwezine)?	4 = Most of the time (5-7 days)? / Isikhathi esiningi (izinsuku ezinhlanu kuya kweziyisikhombisa)?
3.2a	I have been bothered by things that don't usually bother me / Uke waphazanyiswa yinto engavamile ukukuphazamisa	1	2	3	4
3.2b	I did not feel like eating, my appetite was poor / Uke wezwa ukudla kungangeni ngoba ungayizwa indlala	1	2	3	4
3.2c	I felt that I could not shake off the blues (sadness) even with help from my family or friends / Kungavumi ukuthi uyeke ukubhocobala noma umndeni wakho nabangani bakho bezama ukukwenza ngcono?	1	2	3	4
3.2d	I felt that I was not as good as other people / Uzizwe engathi izinto zakho azihambi kahle njengezabanye abantu	1	2	3	4

Question Number / Inombolo yombuzo	...3.2 continued from above / ....3.2 uqhuntswa okusukela phezulu.	Would you say ..... / Ungathini kulokhu			
		1 = Rarely or none of the time (Less than 1 day)? / Akuvamile noma akwenzeki nhlobo (Alupheli usuku)?	2 = Some of the time (1-2 days)? / Kunezikhathi ekwenzeka ngazo (Usuku olulodwa noma izinsuku ezimbili)?	3 = Occasionally or Moderately (3-4 days)? / Kuvamile noma ngezikha-shana (izinsuku ezintathu kuya kwezine)?	4 = Most of the time (5-7 days)? / Isikhathi esiningi (izinsuku ezinhlanu kuya kweziyisik-hombisa)?
3.2e	I had trouble keeping my mind on what I was doing (concentration) / Kuke kwenzeka ukuthi uthole ubunzima ekubekeni umqondo wakho entweni oyenzayo	1	2	3	4
3.2f	I felt depressed or sad / Uzizwa ukhahlamezekile noma uphatheke kabi emoyeni	1	2	3	4
3.2g	I felt that everything I did was an effort. Kuke kwenzeka ukuthi yonke into oyenzayo uyenza ngokuzikhandla	1	2	3	4
3.2h	I have no hope for the future / Ulahle ithemba ngekusasa	1	2	3	4
3.2i	I thought my life has been a failure / Uke ucabange ukuthi impilo yakho ayinayo impumelelo	1	2	3	4
3.2j	I felt fearful or afraid / Uzizwa unovalo noma wesaba	1	2	3	4
3.2k	My sleep was restless / Ulala ubuthongo benyoni	1	2	3	4
3.2l	I was unhappy / Ungajabule neze	1	2	3	4
3.2m	I talked less than usual / Ukhuluma izikhathi ezimbalwa kunokujwalekile	1	2	3	4
3.2n	I felt lonely / Uzizwa unesizungu	1	2	3	4
3.2o	People were unfriendly / Abantu bengenabungani	1	2	3	4
3.2p	I did not enjoy life / Ungayithokozeli impilo	1	2	3	4
3.2q	I cried frequently for no reason / Nganginokukhala izikhashana eziningi kungenasizathu	1	2	3	4
3.2r	I felt sad / Uzizwe uphatheke kabi	1	2	3	4
3.2s	I felt that people disliked me / Uzwa ukuthi abantubakuthandi	1	2	3	4
3.2t	I could not get “going” during the day / Angikwazanga ukuqhubeka ngokosuku	1	2	3	4

We are now going to talk about a number of difficult or stressful events that sometimes happen to people. / Manje sesizoxoxa ngezehlakalo ezinzima noma ezihlukumeza umuntu uma zenzeka.

Question Number / Inombolo yombuzo	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? *(Circle all that apply)* / Awusho, kuke kwenzeka ukuba uhlanga bezane nezinye zalezimo ezilandelayo, noma uzibone zenzeka komunye umuntu, noma uzwe ngokuthi lezi zehlakalo zenzeke kumuntu omaziyo? *(kekelezela konke ovumelana nakho)*	Happened to care provider / Yenzeka kuyena umnakekeli	Witnessed event happening to someone they know / umnakeleli wabona isehlo senzeka kumuntu amaziyo	Heard about event happening to someone they know / Ngezwa ngezehlakalo senzeka kumuntu engimaziyo	Never Happened / Akukaze kwenzeke
3.3a	Natural disaster (such as a flood, earthquake, or severe drought? / Umonakalo odalwa yimvelo (njengezi khukhula, ukuzamazama komhlaba, isomiso)?	0	1	2	3
3.3b	Fire or explosion? / Umlilo noma ukuqhuma?	0	1	2	3
3.3c	Transport accident (taxi, train, car, plane or boat)? / Ingozi yezinto zokuthutha (itekisi, isitimela, imoto, ibhanoyi, isikebhe)?	0	1	2	3
3.3d	Serious accident at work, home or when playing sports or having fun? / Ingozi enkulu ekhaya, emsebenzini noma kudlalwa umdlalo othize noma nje kungcebelekiwe?	0	1	2	3
3.3e	Physical assault (being attacked, beaten, slapped, kicked)? / Ukulinyazwa emzimbeni (ukuhlaselwa, ukushaywa, izimpama, ukukhahlelwa)?	0	1	2	3
3.3f	Assaulted with a weapon (being shot, stabbed, threatened with a knife, gun or bomb)? / Ukulinyazwa ngesikhali (ukudutshulwa, ukugwazwa, ukwesatshiswa ngomummese noma isibhamu noma ibhomu)?	0	1	2	3
3.3g	Sexual assault (rape, attempted rape, forced to perform sexual acts or threats of harm)? / Ukuhlukunyezwa ngokocansi (ukudlwengulwa, ukuzama ukudlwengulwa, ukuphoqelelwa ukwenza izinto ezithile zangokocansi noma ukusatshiswa ukuthi uzolinyazwa)?	0	1	2	3
3.3h	Other unwanted or uncomfortable sexual experience? / Ezinye izinhlobo zokuhlukunyezwa ngokocansi ezingamukelekile?	0	1	2	3
3.3k	Life-threatening illness or injury? / Isifo noma ukulimala engagcina idlule nomphefumulo?	0	1	2	3
3.3l	Exposed to sudden or violent death (murder or suicide)? / Ukuba sengcupheni yokufa ngokuzuma noma ngodlame (ukubulawa noma ukuzi bulala)?	0	1	2	3
3.3m	Sudden, unexpected death of someone close to you? / Ukufa ngokuzuma,kungazelele komuntu osondelene naye?	0	1	2	3
3.3n	Exposure in a war-zone (in combat or as civilian), captivity (being kidnapped, abducted, held hostage or prisoner of war), serious injury, harm or death you caused to someone else, another life-threatening experience not mentioned here? / Ukuba sempini (uyisosha noma uyilunga lomphakathi), ukudunwa (ukuthunjwa noma ukuvalelwa njengesiboshwa sezempi), ukulimala, ukuhlukumezeka okukhulu noma ukufa okudalwe nguwe komunye umuntu, olunye uhlobo lwesimo esingadlula nomphefumulo womuntu esingabaliwe lapha?	0	1	2	3

Note to Survey Staff: IIf the care provider experienced, witnessed, or heard about any of the events above, move on to Q3.4 and Q3.5. Otherwise, skip ahead to Q4.1 / Uma um-nakekeli eke wambandakanyeka, ebone noma ezwe ngesehlakalo esingenhla, qhubekela kumbuzo Q3.4 naku Q3.5. Ngaphandle kwalokho, bhala ukuthi "Not applicable" kumbuzo Q3.4 bese udlulela kumbuzo Q4.1.

3.4(HTS): **Please specify the event(s) that you feel is most upsetting and still bothering you. / Sicela ucacise ngesehlakalo(ize) ozwa ukuthi yisona esikuphethe kabi futhi esisakuhlukumeza namanje.**

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Question Number / Inombolo yombuzo	Sometimes, people experience symptoms after a traumatic experience. Have you experienced any of the following during the past week? / Ngesinye isikhathi abantu bayaye bezwe izinto ezenzeka kubona uma behlangabezane nesehlakalo esibahlukumezile. Usuke wahlangabe-zana nalezihlakalo ngesonto eledlule?	Would you say ..... / Ungathini kulokhu			
		Not at all?/ Akwenziki nhlobo?	A little?/ Kwenzeka mahlayeni nje?	Quite a bit?/ Kuvamile ukwenzeka?	Extremely?/ Kwenzeka njalo?
3.5a	Thoughts or memories that keep coming back of that event/s you specified / Imicabango noma izinto olokhu uzikhumbula ngalesi sehlakalo okhulume ngaso	1	2	3	4
3.5b	Feeling as though the event is happening again / Ukuzwa ngathi lesise sehlakalo siyaphinda siyenzeka	1	2	3	4
3.5c	Nightmares about the event/s that keep coming back / Uke waphupha yini isehlakalo esake senzeka/esiloklu sibuya	1	2	3	4
3.5d	Feeling detached or withdrawn from people / Akuvumi ukuthi uhlale nabanye abantu	1	2	3	4
3.5e	Unable to feel emotions / Uke wazizwa ungenayo imizwa yakho	1	2	3	4
3.5f	Feeling jumpy, easily startled / Uthuswa wubala	1	2	3	4
3.5g	Difficulty concentrating (focus your mind on tasks) / Awukwazi ukubeka umqondo wakho entweni osuke ubhekene nayo	1	2	3	4
3.5h	Trouble sleeping / Unenkinga yokufikelwa ubuthongo	1	2	3	4
3.5i	Feeling on guard (mistrusting others)/ Uhlezi uhlahle amehlo (awethembi muntu)	1	2	3	4
3.5j	Having outbursts of anger / Uvele ubhoke ngolaka	1	2	3	4
3.5k	Avoiding activities that remind you of the traumatic or hurtful event / Uyakubalekela ukwenza izinto ezikukhumbuza isehlakalo esenzeka	1	2	3	4
3.5l	Inability to remember parts of the most traumatic or hurtful events / Awukwazi ukukhumbula yonke into eyenzeka noma uyazikhohlwa izingxenye ezibuhlungu kakhulu	1	2	3	4
3.5m	Feeling less interested in daily activities / Awunalo ugqozi ngezinto ezenzeka nsuku zonke	1	2	3	4
3.5n	Feeling as if you don't have a future / Uzwa engathi awunalo nhlobo ikusasa	1	2	3	4

Question Number / Inombolo yombuzo	...3.5 continued from above / ….3.5 uqhuntswa okusukela phezulu.	Would you say ..... / Ungathini kulokhu			
		Not at all?/ Akwenziki nhlobo?	A little?/ Kwenzeka mahlayeni nje?	Quite a bit?/ Kuvamile ukwenzeka?	Extremely?/ Kwenzeka njalo?
3.5o	**Avoiding thoughts and feelings associated with the traumatic or hurtful events / Uyayibalekela imicabango nemizwa ehambisana nesehlakalo esihlukumezayo noma esibuhlungu**	1	2	3	4
3.5p	**Sudden emotional or physical reaction when reminded of the most hurtful part of the traumatic event / Uma ukhumbula ingxenye ebuhlungu kakhulu ngesehlakalo uvele uthinteke ngamawala emoyeni nasemzimbeni**	1	2	3	4

SECTION 4: CHILDREN IN HOUSEHOLD / ISIGABA 4: IZINGANE EZIKHONA KULOMUZI

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. / Manje ngicela ukuthola imininingwane ngezingane ezineminyaka eyishumi nesikhombisa nanga phansi ezihlala kulomuzi. Okokuqala ngizobuza ngezesikole

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. / Abasizi bocwaningo babheke lokhu: Uma isikhala singaneli ungaqhubeka usebenzise enye ifomuengabhaliwe. Gcwalisa imininingwane yezingane ezineminyaka ewu 17nangaphansi kuphela. Qondanisa inombolo yomuntu maqondana nengane edwetshiwe.

Question Number / Inombolo yombuzo	What is the highest level of education that.....has successfully completed? / Iliphi ibanga eliphakeme kwezemfundo aliqedile u.....?	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.1(G)	1 edu= No Schooling / Angiyanga esikoleni		1	1	1	1	1	1	1	1	1	1	1	1	1	1
	2 edu = Grade R/0 / Ibanga lokulungiselela ukungena isikol		2	2	2	2	2	2	2	2	2	2	2	2	2	2
	3 edu = Grade 1/Sub A / Ufestiye		3	3	3	3	3	3	3	3	3	3	3	3	3	3
	4 edu = Grade 2/Sub B / Usekhondiye		4	4	4	4	4	4	4	4	4	4	4	4	4	4
	5 edu = Grade 3/Standard 1 / Ibanga lokuqala		5	5	5	5	5	5	5	5	5	5	5	5	5	5
	6 edu = Grade 4/Standard 2 /Ibanga lesibili		6	6	6	6	6	6	6	6	6	6	6	6	6	6
	7 edu = Grade 5/Standard 3 / Ibanga lesithathu		7	7	7	7	7	7	7	7	7	7	7	7	7	7
	8 edu = Grade 6/Standard 4 / Ibanga lesine		8	8	8	8	8	8	8	8	8	8	8	8	8	8
	9 edu = Grade 7/Standard 5 / Ibanga lesihlanu		9	9	9	9	9	9	9	9	9	9	9	9	9	9
	10 edu = Grade 8/Standard 6/Form 1 / Ibanga lesithupha		10	10	10	10	10	10	10	10	10	10	10	10	10	10
	11 edu = Grade 9/7/Form 2 / Ibanga lesikhombisa		11	11	11	11	11	11	11	11	11	11	11	11	11	11
	12 edu = Grade 10/Standard 8/Form 3 / Ibanga lesishiyagalombili		12	12	12	12	12	12	12	12	12	12	12	12	12	12
	13 edu = Grade 11/Standard 9/Form 4 / Ibanga lesishiyagalolunye		13	13	13	13	13	13	13	13	13	13	13	13	13	13

Question Number / Inombolo yombuzo	...4.1 continued from above / ….4.1 uqhuntswa okusukela phezulu.	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.1(G)	14 edu = Grade 12/Standard 10; Diploma with less than Grade 12/Standard 10 / Isitifiketi noma idipuloma ngaphandle kwebanga leshumi		14	14	14	14	14	14	14	14	14	14	14	14	14	14
	15 edu = Grade 12/Standard 10/Form 5/Matric / Ibanga leshumi		15	15	15	15	15	15	15	15	15	15	15	15	15	15
	16 edu = Certificate with Grade 12/Standard 10; Diploma with Grade 12/Standard 10 / Isitifiketi noma idipuloma ehambisana nebanga leshumi		16	16	16	16	16	16	16	16	16	16	16	16	16	16
	17 edu = Other *(specify)* / Okunye *(cacisa)*		17	17	17	17	17	17	17	17	17	17	17	17	17	17
	18 edu = Don't know / Angazi		18	18	18	18	18	18	18	18	18	18	18	18	18	18

Question Number / Inombolo yombuzo	**Is …… currently enrolled and attending school? / Kungabe uyafunda noma uyaya yini esikoleni u . . . . ?**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.2 (G&M)	0 = No → *go to Q4.5* / Cha → *yiya ku Q4.5*		0	0	0	0	0	0	0	0	0	0	0	0	0	0
	1 = Yes → *go to Q4.3* / Yebo → *yiya ku Q4.3*		1	1	1	1	1	1	1	1	1	1	1	1	1	1

Question Number / Inombolo yombuzo	*Ask only if participant answered "Yes" to Q4.2. / Buza kuphela uma obuzwayo ephendule"Yebo" ku Q4.2.:* **The school.....attends is a..... / Isikole ..... angenakuso i .....**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.3(M)	**1 = a school where I pay fees** → *go to Q4.4* / **isikole lapho ngibhadala khona imali yesikole** → *qhubekela ku Q4.4*		1	1	1	1	1	1	1	1	1	1	1	1	1	1
	2 = a school where they get a fees exemption / isikole lapho bathola ukusulelwa isikweletu bengasakhokhi		2	2	2	2	2	2	2	2	2	2	2	2	2	2
	3 = a no fees school / isikole lapho kungakhokhwa khona		3	3	3	3	3	3	3	3	3	3	3	3	3	3
	4 = a school where I owe fees but I have not been able to pay → *go to Q4.4* / **isikole lapho ngikweleda khona futhi angikakwazi ukubhadala** → *qhubekela ku Q4.4*		4	4	4	4	4	4	4	4	4	4	4	4	4	4

Question Number / Inombolo yombuzo	*Ask only if participant answered "Yes" to Q4.2 / Buza kuphela uma obuzwayo ephendule"Yebo" ku Q4.2.:* **How much are the school fees for.....'s school for one academic year? / Malini ekhokhwa u …esikoleni?**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.4(M)	*(specify by writing sideways or indicate don't know) / (chaza ubhale ulandele ukutsheka komugqa noma usho mawungazi)*															

Question Number / Inombolo yombuzo	*Ask only if participant answered "No" to Q4.2. / Buza kuphela uma obuzwayo ephendule"Cha" ku Q4.2.:* **What is the main reason why … . is currently not attending school? / Yisiphi isizathu esikhulu noma esibalulekile esenza ukuthi u…..angayi esikoleni?**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.5 (K&G)	1 = too old/young / mdala kakhulu/mncane kakhul		1	1	1	1	1	1	1	1	1	1	1	1	1	1
	2 = has completed school/education / usesiqedile isikole		2	2	2	2	2	2	2	2	2	2	2	2	2	2
	3 = school/education institution is too far away / Isikole sikude		3	3	3	3	3	3	3	3	3	3	3	3	3	3
	4 = no money for fees or other school related expenses / Ayikho imali yokukhokhela iskole noma ukukhokhela izinto ezithile zesikole		4	4	4	4	4	4	4	4	4	4	4	4	4	4
	5 = he/she is working (at home or job) / Uyasebenza (ekhaya noma emsebenzini)		5	5	5	5	5	5	5	5	5	5	5	5	5	5
	6 = education is useless or uninteresting / imfundo ayinamsebenzi noma ayinamdlandla		6	6	6	6	6	6	6	6	6	6	6	6	6	6
	7 = illness / Ukugula		7	7	7	7	7	7	7	7	7	7	7	7	7	7
	8 = pregnancy / Ukukhulelwa		8	8	8	8	8	8	8	8	8	8	8	8	8	8
	9 = failed exams or unable to cope with work / Wafeyila noma akakwazi ukumelana nomsebenzi		9	9	9	9	9	9	9	9	9	9	9	9	9	9
	10 = got married / Washada		10	10	10	10	10	10	10	10	10	10	10	10	10	10
	11 = looking after sick family Member / Ubheke ilunga lomndeni eligulayo		11	11	11	11	11	11	11	11	11	11	11	11	11	11
	12 = looking after younger children/domestic work / Ubheke izingane ezincane noma imisebenzi yasekhaya		12	12	12	12	12	12	12	12	12	12	12	12	12	12
	13 = was expelled from school / Waxoshwa esikoleni		13	13	13	13	13	13	13	13	13	13	13	13	13	13
	14 = fear of bullying by other children or teacher / Wesaba ukuhlukunyezwa ezinye izingane noma uthisha		14	14	14	14	14	14	14	14	14	14	14	14	14	14
	15 = denied place in class / Unqatsheliwe indawo Ekilasini		15	15	15	15	15	15	15	15	15	15	15	15	15	15
	16 = social unrest/violence in Community / Izinxushunxushu ezijwayelekile noma udlame em-phakathini		16	16	16	16	16	16	16	16	16	16	16	16	16	16
	17 = other *(specify)* / Okunye *(Bhala eceleni):*		17	17	17	17	17	17	17	17	17	17	17	17	17	17

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 let me know.

/ Manje ngicela ukubuza ngabazali. Baningi abazali abangekho noma asebeshonile emiphakathini yethu lokhu okwenza lemibuzo elandelayo ibe nzima. Ngicela ukuku-khumbuza ukuthi singalihlaba ikhefu uma ufisa kanjalo. Ungakhetha futhi ukuthi ungakhulumi ngalendaba noma siyivale manje ingxoxo le. Ngaloku ngeke ujeziswa. Uma ufisa ukuhlaba ikhefu noma ukumisa ingxoxo ngizocela ungazise.

Question Number / Inombolo yombuzo	**Is .....'s biological father part of this household? / Kungabe uyise ka ..... omuzalayo uhlala kulomuzi yini na?**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.6a(G)	0 = No → *go to Q4.6b* / Cha → *yiya ku Q4.6b*		0	0	0	0	0	0	0	0	0	0	0	0	0	0
	1 = Yes → *go to Q4.7a* / Yebo → *yiya ku Q4.7a*		1	1	1	1	1	1	1	1	1	1	1	1	1	1

Question Number / Inombolo yombuzo	*Ask only if the participant answered "No" to Q4.6a. / Buza kuphela uma obuzwayo ephendule"Cha" ku Q4.6a.:* **Why is the biological father absent from this household? / Kungani uyise ka ..... engekho kulomuzi?**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.6b(M)	1 = works away from home to provide financial support to household / usebenza kude ukuze athu-mele imali		1	1	1	1	1	1	1	1	1	1	1	1	1	1
	2 = uninvolved in household life/ akazi nokuthi kwenzekani lapha kulomuzi		2	2	2	2	2	2	2	2	2	2	2	2	2	2
	3 = lives elsewhere, not working, but involved in household / ngihlala kwenye indawo, angisebenzi, kodwa ngiyahlanganyela ezintweni ezenziwayo ekhaya		3	3	3	3	3	3	3	3	3	3	3	3	3	3
	4 = death → *Go to Q4.6c* / washona → *Yiya ku Q4.6c*		4	4	4	4	4	4	4	4	4	4	4	4	4	4
	5 = other *(specify by writing sideways)* / okunye *(chaza ubhale ulandele ukutsheka komugqa):*		5	5	5	5	5	5	5	5	5	5	5	5	5	5
	6 = don't know / Angazi		6	6	6	6	6	6	6	6	6	6	6	6	6	6

Question Number / Inombolo yombuzo	*Ask only if the participant answered "4" to Q4.6b. / Buza kuphela uma obuzwayo ephendule "4" ku Q4.6b:* **Was the father's death due to a ..... / Kungabe ukushona kukababa Kwabangwa .....**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.6c(M)	**1 = health related reason?** → *will need to use extra sheets titled,"Section 2: Children in Home – Sibling Relationships and Cause of Parental Death" /* **okusondelene nezempilo?** → *Kudingeka usebenzise amakhasi angeziwe abhalwe, "Isigaba 2: Izingane Ekhaya Ukuzalana nobudlelwano nakwiSigaba 2: Izingane ekhaya – Isizathu sokushona kwabazali*		1	1	1	1	1	1	1	1	1	1	1	1	1	1
	2 = non-health related reason / isizathu esingahlobene nezempilo:															
	2a = shot / udutshuliwe		2a	2a	2a	2a	2a	2a	2a	2a	2a	2a	2a	2a	2a	2a
	2b = stabbed / wagwazwa		2b	2b	2b	2b	2b	2b	2b	2b	2b	2b	2b	2b	2b	2b
	2c = motor vehicle accident / ingozi yemoto		2c	2c	2c	2c	2c	2c	2c	2c	2c	2c	2c	2c	2c	2c
	2d = poisoned / ufakelwe ubuthi		2d	2d	2d	2d	2d	2d	2d	2d	2d	2d	2d	2d	2d	2d
	2e = burnt / ushile		2e	2e	2e	2e	2e	2e	2e	2e	2e	2e	2e	2e	2e	2e
	2f = other *(specify) /* **okunye** *(cacisa):*		2f	2f	2f	2f	2f	2f	2f	2f	2f	2f	2f	2f	2f	2f
	3 = don't know / angazi		3	3	3	3	3	3	3	3	3	3	3	3	3	3

Question Number / Inombolo yombuzo	**Is .....'s biological mother part of this household? / Kungabe umama ka ..... omuza-layo ukhona yini kulomuzi?**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.7a(G)	0 = No → *go to Q4.7b /* Cha → *yiya ku Q4.7b*		0	0	0	0	0	0	0	0	0	0	0	0	0	0
	1 = Yes →*go to Q4.8 /* Yebo → *yiya ku 4.8*		1	1	1	1	1	1	1	1	1	1	1	1	1	1

Question Number / Inombolo yombuzo	*Ask only if the participant answered "No" to Q4.7a. / Buza kuphela uma obuzwayo ephendule"Cha" ku Q4.7a.:* **Why is the biological mother absent from this household? / Kungani umama ka ..... engekho kulomuzi?**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.7b(M)	1 = works away from home to provide financial support to household / usebenza kude ukuze athu-mele imali		1	1	1	1	1	1	1	1	1	1	1	1	1	1
	2 = uninvolved in household life/ akazi nokuthi kwenzekani lapha kulomuzi		2	2	2	2	2	2	2	2	2	2	2	2	2	2
	3 = lives elsewhere, not working, but involved in household / ngihlala kwenye indawo, angisebenzi, kodwa ngiyahlanganyela ezintweni ezenziwayo ekhaya		3	3	3	3	3	3	3	3	3	3	3	3	3	3
	4 = death → *Go to Q4.7c* / Washona → *yiya ku Q4.7c*		4	4	4	4	4	4	4	4	4	4	4	4	4	4
	5 = other *(specify by writing sideways)* / okunye *(chaza ubhale ulandele ukutsheka komugqa):*		5	5	5	5	5	5	5	5	5	5	5	5	5	5
	6 = don't know / Angazi		6	6	6	6	6	6	6	6	6	6	6	6	6	6

Question Number / Inombolo yombuzo	*Ask only if the participant answered "4" to question 4.7b. / Buza kuphela uma obuzwayo ephendule "4" ku Q4.7b.* **Was the mother's death due to a ..... / Kungabe ukushona kuka mama kwabangwa .....**	Person number / inombolo eqondene nawe														
		01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
4.7c(M)	**1 = health related reason?** → *will need to use extra sheets titled,"Section 2: Children in Home – Sibling Relationships and Cause of Parental Death" /* **okusondelene nezempilo?** → *Kudingeka usebenzise amakhasi angeziwe abhalwe, "Isigaba 2: Izingane Ekhaya Ukuzalana nobudlelwano nakwiSigaba 2: Izingane ekhaya – Isizathu sokushona kwabazali*		1	1	1	1	1	1	1	1	1	1	1	1	1	1
	2 = non-health related reason / isizathu esingahlobene nezempilo:															
	2a = shot / udutshuliwe		2a	2a	2a	2a	2a	2a	2a	2a	2a	2a	2a	2a	2a	2a
	2b = stabbed / wagwazwa		2b	2b	2b	2b	2b	2b	2b	2b	2b	2b	2b	2b	2b	2b
	2c = motor vehicle accident / ingozi yemoto		2c	2c	2c	2c	2c	2c	2c	2c	2c	2c	2c	2c	2c	2c
	2d = poisoned / ufakelwe ubuthi		2d	2d	2d	2d	2d	2d	2d	2d	2d	2d	2d	2d	2d	2d
	2e = burnt / ushile		2e	2e	2e	2e	2e	2e	2e	2e	2e	2e	2e	2e	2e	2e
	2f = other *(specify)* / **okunye** *(cacisa):*		2f	2f	2f	2f	2f	2f	2f	2f	2f	2f	2f	2f	2f	2f
	3 = don't know / angazi		3	3	3	3	3	3	3	3	3	3	3	3	3	3

4.8: **Are any children sick in this family? Which child(ren) are sick?** *(Write down person number(s))* / **Ingabe bakhona abantwana abagulayo kulomndeni?**

Yibaphi abantwana abagulayo? *(Bhala phansi izinombolo zabo):* .....

Answer the following questions about the child that is being interviewed. If no child in the household has been interviewed yet, randomly choose one child (ages 10-17) to be interviewed. What person number is the child? / Phendula lemibuzo elandelayo ngomtwana obuzwa imibuzo. Uma engekho umtwana osebuziwe kulomuzi, ungazikhethela oyedwa kulabo abaneminyaka ephakathi (10-17) ukuze abuzwe imibuzo. Ithini inombolo yalowomtwana?.....

I want to learn about whether your child has been sick. / Ngifisa ukwazi ukuthi umtwana wakho uke wagula yini.

4.9a: **Has ..... had TB in the past two years? / Uke ..... waba nesifo sofuba kuleminyaka emibili edlulile?**

- ❑ 0 = No → *Go to Q4.9b /* Cha → *Yiya ku Q4.9b*
- ❑ 1 = Yes → *Go to Q4.9a(i) /* Yebo → *Yiya ku Q4.9a(i)*
- ❑ 2 = Don't know → *Go to Q4.9b /* Angazi → *yiya ku Q4.9b*

4.9b: **Does ..... have asthma? / Unaso..... isifo somoya?**

- ❑ 0 = No / Cha
- ❑ 1 = Yes / Yebo
- ❑ 2 = Don't know / Angazi

4.9d: **Does ..... have epilepsy? / Unaso ..... isfo sokuwa?**

- ❑ 0 = No / Cha
- ❑ 1 = Yes / Yebo
- ❑ 2 = Don't know / Angazi

4.9a(i): **Did ..... complete their treatment for this? / Wayi..... qedela Imithi yalesosifo?**

- ❑ 0 = No / Cha
- ❑ 1 = Yes / Yebo
- ❑ 2 = Don't know / Angazi

4.9c: **Does ..... have diabetes? / Unaso ..... isifo sikashukela?**

- ❑ 0 = No / Cha
- ❑ 1 = Yes / Yebo
- ❑ 2 = Don't know / Angazi

4.9e: **Has ..... had vomiting, diarrhoea, or a runny tummy in the past 6 months? / Uke..... wabanokuphalaza, nohudo noma isisu esimhambisayo kulezizinyanga eziyisithupha ezindlule?**

- ❑ 0 = No / Cha
- ❑ 1 = Yes / Yebo
- ❑ 2 = Don't know / Angazi

4.10a: **When the child needs to take medication, I remind or watch them take it.... / Uma umtwana kufanele adle imithi yakhe ngiyamkhumbuza noma ngimgade uma \eyithatha....**

- ❑ **1 = Every day / Zonke izinsuku**
- ❑ **2 = Some days / Ngezinye izinsuku**
- ❑ **3 = Never → Why not? / Angizange → Yini Indaba?**

.....

4.10b: **The last time ..... needed to go to the doctor or clinic, ...** *(circle all that apply) /* **Ugcine ..... ukudinga ukuya kwadokotela noma emtholampilo,** *..... (kekelezela konke ovumelana nakho)*

- ❑ **1 = I went with them. / Ngahamba nabo.**
- ❑ **2 = I couldn't go with them as I was too sick myself. / Angikwazanga ukuhamba nabo ngoba ngangigula kakhulu.**
- ❑ **3 = We couldn't afford to go there. / Asibanga namandla emali okufinyelela lapho.**
- ❑ **4 = I sent someone else to take the child. / Ngahambisa omunye umuntu nomtwana.**
- ❑ 5 = Other → *(specify):* Okunye → *(cacisa)* .....

Now I want to learn about your child's behavior. Please answer Not True, Somewhat True or Certainly True for the following statements. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour over the last month. / Manje ngithanda ukwazi ngokuziphatha komtwana wakho. Ngicela uphendule ukuthi akulona iqiniso, kucishe kube yiqiniso, kuyiqiniso uqobo kulezizitatimende ezilandelayo. Kuyosisiza kakhulu uma ungaphendula konke ngawowonke amandla akho noma ungenaso kahle isiqiniseko. Sicela usinikeze Izimpendulo zokuziphatha komtwana wakho uqondanise nalenyanga edlule.

Question Number / Inombolo yombuzo	..... is ..... / ….uya….	Would you say ..... / Ungathini kulokhu		
		1 = Not true / Akulona iqiniso	2 = Somewhat true / Kucishe kube iqiniso	3 = Certainly true / Iqiniso impela
4.11a	Considerate of other people's feelings. / Unozwelo ngemizwa yabanye abantu.	1	2	3
4.11b	Restless, overactive, cannot stay still for long. / Uyashikashikeka, unomdlandla kakhulu akakwazi ukuhlala athule isikhathi eside.	1	2	3
4.11c	Often complains of headaches, stomach-aches or sickness. / Unokuhlala ekhala ngekhanda elibuhlungu, isisu noma ukugula.	1	2	3
4.11d	Shares readily with other youth, for example CDs, games, food. / Uyabelana ngezinto zakhe nabanye abantu abasha, njengama CD, okokudlala, nokudla.	1	2	3
4.11e	Often loses temper. / Uthanda ukuba nenhliziyo encane.	1	2	3
4.11f	Would rather be alone than with other youth. / Ukhetha ukuba yedwa kunokuba nabanye abasha.	1	2	3
4.11g	Generally well behaved, usually does what adults request. / Uziphatha kahle, esikhathini esiningi wenza okushiwo abadala.	1	2	3
4.11h	Many worries or often seems worried. / Uyakhathazeka kakhulu ngokuningi.	1	2	3
4.11i	Helpful if someone is hurt, upset or feeling ill. / Uyasiza makukhona umuntu olimele, akakuthandi ukuzizwa egula.	1	2	3
4.11j	Constantly fidgeting or squirming. / ulokhu njalo eshudushudula noma ukuyobayoba.	1	2	3
4.11k	Has at least one good friend. / Unomngani oyedwa okungenani.	1	2	3
4.11l	Often fights with other youth or bullies them. / Unokulwa nabanye abasha noma abahlukumeze ngodlame.	1	2	3
4.11m	Often unhappy, depressed or tearful. / Unokungajabuli, ebukeka edangele, enezinyembezi eziseduze	1	2	3
4.11n	Generally liked by other youth. / Uyathandeka kwabanye abantu abasha.	1	2	3
4.11o	Easily distracted, concentration wanders. / Uphazamiseka kalula, imicabango yakhe iyazulazula.	1	2	3
4.11p	Nervous in new situations, easily loses confidence. / Unetwetwe nokwesaba ezimeni ezintsha.	1	2	3
4.11q	Kind to younger children. / Unomusa kubantwana abancane.	1	2	3
4.11r	Often lies or cheats. / Unokuqamba amanga, akhohlise.	1	2	3
4.11s	Picked on or bullied by other youth. / Bayathanda ukumsukela, bamhlukumeze abanye abantu abasha.	1	2	3
4.11t	Often offers to help others (parents, teachers, children). / Unokusiza abanye (abazali, othisha, izingane).	1	2	3

Question Number / Inombolo yombuzo	.....4.11 continued from above / ….4.11 uqhuntswa okusukela phezulu	Would you say ..... / Ungathini kulokhu ..... 1 = Not true / Akulona iqiniso	2 = Somewhat true / Kucishe kube iqiniso	3 = Certainly true / Iqiniso impela
4.11u	**Thinks things out before acting. / Uyazicabangisisa izinto ngaphambi kokuzenza.**	1	2	3
4.11v	**Steals from home, school or elsewhere. / Uyantshontsha ekhaya, esikoleni nakwezinye izindawo.**	1	2	3
4.11w	**Gets along better with adults than with other youth. / Uzwana kangcono nabadala kunentsha enye.**	1	2	3
4.11x	**Many fears, easily scared. / Unokwesaba okuningi, uthuswa ubala.**	1	2	3
4.11y	**Good attention span, sees chores or homework through to the end. / Izinga lakhe lokulalela nokucophelela liphezulu futhi wenza umsebenzi wesikole awuqede.**	1	2	3

Question Number / Inombolo yombuzo	Now I want to learn about how you and your child get on. Would you say.... / Manje ngithanda ukwazi ukuthi wena nomtwana wakho nizwana kanjani. Ungathi…	1 = Never / Ngeke ngikwenze	2 = Almost Never / Ngingahle ngikwenze	3 = Sometimes / Ngezinye izikhathi	4 = Often / Kunokwenzeka kaningana	5 = Always / Njalo nje
4.12a	**You let your child know when he/she is doing a good job with something / Uyamtshela umtwana wakho mayenza umsebenzi omuhle ngokuthile**	1	2	3	4	5
4.12b	**You threaten to punish your child and then do not actually punish him/her / Uyaye umesabise ngokumjezisa bese ungamjezisi**	1	2	3	4	5
4.12c	**Your child goes out without a set time to be home / Umtwana wakho uziyela ngaphandle kwekhaya kuzekweqe isikhathi sasekhaya**	1	2	3	4	5
4.12d	**Your child talks you out of being punished when he/she has done something wrong / Umtwana wakho uyazikhulumela uma kufanele umjezise bese umyekela noma onile**	1	2	3	4	5
4.12e	**Your child stays out in the evening past the time he/she is meant to be home / Umtwana wakho uzihlalela ngaphandle ebusuku noma sekudlule isikhathi sokuba sekhaya**	1	2	3	4	5
4.12f	**You compliment your child when he/she has done something well / Uyamncoma umtwana wakho mayenze okuhle**	1	2	3	4	5
4.12g	**You praise your child when he/she behaves well / Uyamtusa umtwana wakho mayeziphatha kahle**	1	2	3	4	5
4.12h	**Your child goes out with friends you don't know / Umtwana wakho uhamba nabangani ongabazi**	1	2	3	4	5
4.12i	**You let your child out of a punishment early / Usheshe umdedele umtwana wakho esigwebeni omnike sona engakasiqedi**	1	2	3	4	5
4.12j	**You tell your child that you appreciate that they help out around the house / Uyamtshela umtwana wakho ukuthi ukubonga kangakanani ukuba wusizo kwakhe endlini**	1	2	3	4	5

SECTION 5: COPING
/ ISIGABA 5: UKUQINISELA

Question Number / Inom-bolo yombuzo	People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? / Kwezinye izikhathi abantu babheka abanye ukubanika ubungani, usizo noma ezinye izinhlelo zokwesekelwa. Kukangakanani lezizinhlobo zosizo ngazinye uzithola uma uzidinga?	Would you say... / Ungathi				
		1 = None of the time / Lutho sonke isikhathi	2 = A little of the time / Kancan-yana	3 = Some of the time / Kwezinye izikhathi	4 = Most of the time / Ngezikhathi eziningi	5 = All of the time / Ngaso-sonke isikhathi
5.1a	Someone to help you if you were confined to bed. / Umuntu ongakusiza uma ungakwazi ukuphuma embhedeni.	1	2	3	4	5
5.1b	Someone you can count on to listen to you when you need to talk. / Umuntu oyohlala ekhona ukukulalela mawufuna ukukhuluma.	1	2	3	4	5
5.1c	Someone to give you good advice about a crisis. / Umuntu ongakunikeza iseluleko esihle uma usenkingeni.	1	2	3	4	5
5.1d	Someone to take you to the doctor if you needed it. / Umuntu ongakusa kudokotela mawudinga ukuya.	1	2	3	4	5
5.1e	Someone who shows you love and affection. / Umuntu ongakutshengisa uthando nem-fudumalo.	1	2	3	4	5
5.1f	Someone to have a good time with. / Umuntu eningaba nomumnandi naye.	1	2	3	4	5
5.1g	Someone to give you information to help you understand a situation. / Umuntu ongakuni-ka imininingwan engakusiza ukuqonda isimo obhekane naso.	1	2	3	4	5
5.1h	Someone to confide in or talk to about yourself or your problems. / Umuntu ongakhipha imfihlo yakho kuye, ukhulume ngobuwena obujule, nezinkinga zakho.	1	2	3	4	5
5.1i	Someone to hug you. / Umuntu ongakugona, akusingathe.	1	2	3	4	5
5.1j	Someone to get together with for relaxation. / Umuntu ongahlangana naye niphumule.	1	2	3	4	5
5.1k	Someone to prepare your meals if you were unable to do it yourself. / Umuntu ongakwen-zela ukudla mhlazane ungakwazi ukuzenzela.	1	2	3	4	5
5.1l	Someone whose advice you really want. / Umuntu omunye isaluleko sakhe okuyisona osidingayo.	1	2	3	4	5
5.1m	Someone to do things with to help you get your mind off things. / Umuntu ongenza naye izinto eziphumuza umqondo.	1	2	3	4	5
5.1n	Someone to help with daily chores if you were sick. / Umuntu ongakusiza ngemiseben-zana yakho yosuku mawungaphile kahle.	1	2	3	4	5
5.1o	Someone to share your most private worries and fears with. / Umuntu ongaxoxa naye ukwesaba kwakho okusekujuleni kwenhliziyo.	1	2	3	4	5
5.1p	Someone to turn to for suggestions about how to deal with a personal problem. / Umuntu ongaya kuye akuphe imibono yokubhekana nezimo ezisempilweni yakho.	1	2	3	4	5
5.1q	Someone to do something enjoyable with. / Umuntu eningenza naye into ejabulisayo.	1	2	3	4	5
5.1r	Someone who understands your problems. / Umuntu oziqondayo iznkinga zakho.	1	2	3	4	5

Question Number / Inom-bolo yombuzo	....5.2 continued from above / ….5.2 uqhuntswa okusukela phezulu	Would you say... / Ungathi				
		1 = None of the time / Lutho sonke isikhathi	2 = A little of the time / Kancan-yana	3 = Some of the time / Kwezinye izikhathi	4 = Most of the time / Ngezikhathi eziningi	5 = All of the time / Ngaso-sonke isikhathi
5.1s	**Someone to love and make you feel wanted. / Umuntu ongkuathanda futhi akwenze uz-izwe udingekile.**	1	2	3	4	5
5.1t	**Someone to help take care of your children when you can't. / Umuntu onganakelela abantwana bakho uma wena ungakwazi.**	1	2	3	4	5
5.1u	**Someone to lend you money or food if you needed it. / Umuntu ongakuboleka imali noma ukudla uma ukudinga.**	1	2	3	4	5
5.1v	**Someone to tell you that you are doing a good job. / Umuntu okutshela ukuthi wenza umsebenzi omuhle.**	1	2	3	4	5

There are some people we are more likely to be able to rely on for particular types of support. We would like to learn about who provides you with support. / Kunabantu okuyibona esingathembela kubona ukusisekela. Singathanda ukwazi ukuthi obani abakunika usizo nokusekelwa.

Note to Survey Staff: Please mark all boxes that apply. Note that you can list more than one person in the 'others' column. / Abasebenzi bocwaningo ababheke lokhu: Ngicela nibeke uphawu kuwo wonke amabhokisini alokho enivumelana nakho. Nazi ukuthi ningasinikeza abangaphezulu koyedwa kulendawo ebhalwe "okunye".

Question Number / Inombolo yombuzo	**Over the past 12 months has anyone... / Kulezizinyanga eziyishumi nambili ezedlule ngabe ukhona okunike lezizinhlobo ezilan-delayo zokusekelwa...**	Mother / Umama	Father / Ubaba	Sister(s) / Osisi	Brother(s) / Obhuti	Son(s) / Amadodana	Daughter(s) / Amadodakazi	Male friend(s) or neighbour(s) / Abangani besilisa, omakhelwane	Female friend(s) or neighbour(s) / Abangani besifazane, Omakhelwane	Male partner/spouse/boy-friend / Umlingani wesilisa/ umkhwenyana/ohlekisana naye (wesilisa)	Female partner/spouse/girl-friend / Umlingani wesifa-zane/inkosikazi/ ohlekisana naye (wesifazane)	No one / Akekho	Doesn't apply: never needed this help / Akungeni kimi: angikaze ngiludinge lolusizo	Other(s) *(specify relationship to carer and gender of each person by marking 'M' or 'F')* / Abanye *(cacisa ubudlelwane nomnakeleli, ubulili bomunutu nomuntu ubeka uphawu ukuthi "M' noma" F'*
5.2a	**…lent you money or other items (e.g. food, medicines)?** *If 'no', mark the 'no-one' column. If 'yes', ask:* **Who was the person that provided you with the most support with money or other items over the past 12 months?** *(Do not prompt. Circle only one response)* / **Wakubole-ka imali noma ezinye izinto (njengokudla, imithi)?** *Uma 'cha'faka uphawu ku "akekho". Uma 'yebo,' buza:* **Ubani lowomuntu okunike ukusekelwa okukhulu ngemali noma ezinye izinto kulezizinyanga eziyishumi nambili ezedlule?** *(Ungabuzisisi. Kokelezela impendulo eyodwa kuphela)*	1	2	3	4	5	6	7	8	9	10	11	12	13

Question Number / Inombolo yombuzo	*.....5.2 continued from above / ….5.2 uqhuntswa okusukela phezulu:* **Over the past 12 months has anyone... / Kulezizinyanga eziyishumi nambili ezedlule ngabe ukhona okunike lez-izinhlobo ezilandelayo zokusekelwa...**	Mother / Umama	Father / Ubaba	Sister(s) / Osisi	Brother(s) / Obhuti	Son(s) / Amadodana	Daughter(s) / Amadodakazi	Male friend(s) or neighbour(s) / Abangani besilisa, omakhelwane	Female friend(s) or neighbour(s) / Abangani besifazane, Omakhelwane	Male partner/spouse/boy-friend / Umlingani wesilisa/ umkhwenyana/ohlekisana naye (wesilisa)	Female partner/spouse/girl-friend / Umlingani wesifa-zane/inkosikazi/ ohlekisana naye (wesifazane)	No one / Akekho	Doesn't apply: never needed this help / Akungeni kimi: angikaze ngiludinge lolusizo	Other(s) *(specify relationship to carer and gender of each person by marking 'M' or 'F') /* Abanye *(cacisa ubudlelwane nomnakeleli, ubulili bomunutu nomuntu ubeka uphawu ukuthi "M' noma" F'*
5.2b	**… given you good advice or information to help you make a wise decision or solve a problem?** *If 'no', mark the 'no-one' column. If 'yes', ask:* **Who has been the most important person in providing you with advice and/ or information over the past 12 months?** *(Do not prompt. Circle only one response) /* **Wakunika iseluleko esihle noma iminin-ingwane eyakusiza ukuthatha isinqumo esihlakaniphile nokuxazulula inkinga?** *Uma 'cha'faka uphawu ku "akekho". Uma 'yebo,' buza:* **Ubani lowomuntu okunike ukusekelwa okukhulu ngeseluleko esihle noma iminin-ingwane kulezizinyanga eziyishumi nambili ezedlule?** *(Ungabuzisisi. Kokelezela impendulo eyodwa kuphela)*	1	2	3	4	5	6	7	8	9	10	11	12	13
5.2c	**… cheered you up and comforted you when you were feeling sick or sad?** *If 'no', mark the 'no-one' column. If 'yes', ask:* **Who has been the most important person in cheer-ing you up and/or comforting you over the past 12 months?** *(Do not prompt. Circle only one response.) /* **Owazama ukukupha umoya wenjabulo wakududuza ngenkathi ugula unosizi?** *Uma 'cha'faka uphawu ku "akekho". Uma 'yebo,' buza:* **Ubani lowomuntu okunike ukusekelwa okukhulu ngokukupha umoya wenjabulo wakududuza kulezizinyanga eziyishumi nambili ezedlule?** *(Ungabuzisisi. Kokelezela impendulo eyodwa kuphela)*	1	2	3	4	5	6	7	8	9	10	11	12	13

Question Number / Inombolo yombuzo	*.....5.2 continued from above / ….5.2 uqhuntswa okusukela phezulu:* **Over the past 12 months has anyone... / Kulezizinyanga eziyishumi nambili ezedlule ngabe ukhona okunike lezizinhlobo ezilandelayo zokusekelwa...**	Mother / Umama	Father / Ubaba	Sister(s) / Osisi	Brother(s) / Obhuti	Son(s) / Amadodana	Daughter(s) / Amadodakazi	Male friend(s) or neighbour(s) / Abangani besilisa, omakhelwane	Female friend(s) or neighbour(s) / Abangani besifazane, Omakhelwane	Male partner/spouse/boyfriend / Umlingani wesilisa/ umkhwenyana/ohlekisana naye (wesilisa)	Female partner/spouse/girlfriend / Umlingani wesifazane/inkosikazi/ ohlekisana naye (wesifazane)	No one / Akekho	Doesn't apply: never needed this help / Akungeni kimi: angikaze ngiludinge lolusizo	Other(s) *(specify relationship to carer and gender of each person by marking 'M' or 'F')* / Abanye *(cacisa ubudlelwane nomnakeleli, ubulili bomunutu nomuntu ubeka uphawu ukuthi "M" noma" F'*
5.2d	**… told you that you are doing a good job (with work, chores, caring etc) and given you advice on how to do better?** *If 'no', mark the 'no-one' column. If 'yes' , ask:* **Who has been the most important person in providing you with encouragement and advice over the past 12 months?** *(Do not prompt. Circle only one response.)* / **Wakutshela ukuthi wenza umsebenzi omuhle (ngomsebenzi, ekhaya, ekunakekeleni abanye nokunye) wakunika nesaluleko sokuthi ungenza ngcono kanjani?** *Uma 'cha'faka uphawu ku "akekho". Uma 'yebo,' buza:* **Ubani lowomuntu okunike ukusekelwa okukhulu ngokukhuthaza nokukululeka kulezizinyanga eziyishumi nambili ezedlule?** *(Ungabuzisisi. Kokelezela impendulo eyodwa kuphela)*	1	2	3	4	5	6	7	8	9	10	11	12	13
5.2e	**… done enjoyable things with you when you wanted companionship?** *If 'no', mark the 'no-one' column. If 'yes', ask:* **Who has been the most important person in providing you with companionship over the past 12 months?** *(Do not prompt. Circle only one response.)* / **Owenza izinto ezijabulisayo naye ngenkathi udinga ubungani?** *Uma 'cha'faka uphawu ku "akekho". Uma 'yebo,' buza:* **Ubani lowomuntu okunike ukusekelwa okukhulu ngobungani kulezizinyanga eziyishumi nambili ezedlule?** *(Ungabuzisisi. Kokelezela impendulo eyodwa kuphela)*	1	2	3	4	5	6	7	8	9	10	11	12	13

Question Number / Inombolo yombuzo	How important is each of these types of support to you in helping you cope with the challenges you face in your daily life? / Zibaluleke kangakanani ngazinye lezizinhlelo zokwesekelwa ukukusiza ubhekane zezinqinamba zan-sukuzonke.	Would you say... / Ungathi				
		1 = Not at all important / Azibaluleka-nga neze	2 = A little important / Zibaluleke kancane	3 = Neither important nor unimportant / kunokubaluleka noma akubal-ulekanga	4 = Quite important / Kubalulekile kakhulu	5 = Very important / Zibaluleke kakhulu
5.3a	Material support (such as money or food) / Usizo lwezinto ezibambekayo (njenge mali noma ukudla)	1	2	3	4	5
5.3b	Information and advice / Imininingwane ewusizo, nesiyalo	1	2	3	4	5
5.3c	Emotional support (such as care and comforting) / Ukwalulekwa ngokomphe-fumulo (njengo kunakekelwa, nokusingathwa)	1	2	3	4	5
5.3d	Reassurance that you are doing a good job and advice on how to do things better / isiqiniseko ukuthi wenza umsebenzi omuhle nesaluleko sokuthi un-genza ngcono kanjani	1	2	3	4	5
5.3e	Companionship (someone to socialise and do fun things with) / Ubungani (um-untu eningazithokozisa naye)	1	2	3	4	5

Now I want to learn about how people treat you if you are sick or because someone in your family has been sick or died. / Manje ngifisa ukwazi ukuthi abantu bak-uphatha kanjani uma ugula noma uma owomndeni wakho kade egula noma eshonile.

5.4: In the last year, have you or your family experienced the following? / Kulonyaka odlulile, uke noma umndeni wakho uke wabhekana nalezizimo ezilandelayo?	No / Cha	Yes / Yebo
5.4a: Been excluded from a social gathering. / Wakhishwa inyumbazane emcimbini womphakathi.	0	1
5.4b: Been abandoned by your spouse/partner. / Washiywa ngumyeni/nkosikazi noma athandana naye.	0	1
5.4c: Been isolated in your household. / Ukhishwe inyumbazane wabekwa yedwa ekhaya kubo.	0	1
5.4d: Been no longer visited or visited less frequently by family and friends. / Akasavakashelwa abangani nomndeni wakhe.	0	1
5.4e: Been teased, insulted or sworn at. / Uke wachukuluzwa wathukwa noma wafungelwa.	0	1
5.4f: Lost customers from your business or lost a job. / Ulahlekelwe amakhasimede ebhhizinisni lakho noma umsebenzi.	0	1
5.4g: Lost housing or not been able to rent housing. / Ulahlekelwe indlu noma akasakwazi ukukhokhela lapha aqashe khona.	0	1
5.4h: Been denied religious rites/services. / Unqatshelwe amalungelo enkolo.	0	1
5.4i: Had property taken away. / Uthathelwe izakhiwo zakhe.	0	1
5.4j: Been gossiped about. / Bahlebe ngaye.	0	1
5.4k: Lost respect/standing within the family and/or community. / Ulahlekelwe isithunzi kumndeni nasemphakathi.	0	1
5.4l: Been threatened with violence. / Usatshiswe ngodlame.	0	1
5.4m: Been given poorer quality health services. / Unikezwe usizo lwezempilo olungamsizanga olusezingeni eliphansi.	0	1
5.4n: Been physically assaulted. / Uke washaywa.	0	1
5.4o: Been denied promotion/further training. / Bamncishe ukukhushulelwa esikhundleni esiphezulu emsebenzini.	0	1
5.4p: Had an increase of visitors to “check out” how you are doing. / Kwaba nokukhula kwezivashi ezizombona ukuthi uqhuba kanjani.	0	1
5.4q: Been abandoned by your family/sent away to the village. / Ulahlwe umndeni bamthumela emakhaya akude ayohlala khona.	0	1

SECTION 6: LIVING SITUATION / ISIGABA 6: ISIMO SENHLALO

Now, I would like to ask you some questions about your living situation. / Manje ngi cela ukubuza mayelana nesimo senhlalo.

6.1(SADH): **What is the main source of drinking water for members of your household? Is it ..... / Amalungu alomndeni awathola kuphi amanzi okuphuza isikhathi esiningi? Ungathi .....**	
1 = piped water (tap) in dwelling / umpompi ongaphakathi endlini	1
2 = piped water (tap) in site/yard / umpompi osegcekeni	2
3 = bottled water / amanzi asebhodleleni	3
4 = public tap / umpompi osetshenziswa wumphakathi wonke	4
5 = water carrier/tanker / imoto yamanzi	5
6 = borehole/well / umthombo webhakede	6
7 = dam/river/stream/spring / idamu/umfula/umhosha/isiphethu	7
8 = rain-water tank / ithangi lamanzi emvula	8
9 = other *(specify)* / okunye *(cacisa)*:	9

6.2(G&M): **Is the water from the main source of drinking water safe to drink?** *(circle one answer choice)* **/ Ngabe lamanzi eniwatholayo kulomthombo aphephile na?** *(kokelezela impendulo eyodwa)*	
0 = No / Cha	0
1 = Yes / Yebo	1
2 = Don't know / Angazi	2

6.3(SADH): **What kind of toilet facility does your household have? Is it a ....?** *(circle one answer choice)* **/ Kungabe indlu yangasese iluhlobo luni? Kungabe .....?** *(kokelezela impendulo eyodwa)*	
1 = flush toilet (own) / liyashayiwa (elethu)	1
2 = flush toilet (shared) / liyashayiwa (silisebenzisa neminye imizi)	2
3 = bucket latrine / indle ilandwa ngamabhakede	3
4 = pit latrine / umgodi	4
5 = no facility/bush/field / ayikho/sisebenzisa izikhotha/amaqele	5
6 = other *(specify)* / okunye *(cacisa)*:	6

6.4a(LC): **In the last week, have you had a meal with meat? / Kuleliviki elidlule, uke wadla ukudla okunenyama?**	
0 = No / Cha	0
1 = Yes / Yebo	1

6.4b(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?** *(circle one answer choice)* **/ Ake sikhulume ngalomuzi kanye nezinto eninamandla okuba nazo. Ungasho yini ukuthi kuyenzeka noma kungenzeki ukuthi abantu abahlala kulendlu bazithole bengadlile?** *(kokelezela impendulo eyodwa)*	
1 = never / akwenzeki nhlobo	1
2 = seldom / akuvamile	2
3 = sometimes / ngesinye isikhathi	3
4 = often / njalo	4

6.5 (SADH&G): **What is the main source of energy/fuel for this household for ..... / Yini esetshenziswayo kakhulu kulomuzi .....**	*6.5a* **Cooking? / uma kuphekwa?**	*6.5b* **Heating? / uma kuxoshwa amakhaza noma nizifudumeza?**	*6.5c* **Lighting? / uma kukhanyiswa?**
1 = electricity from MAINS / ugesi	1	1	1
2 = electricity from generator / injini yejenereyitha	2	2	2
3 = gas / igesi	3	3	3
4 = paraffin / uphalafini	4	4	4
5 = wood / izinkuni	5	5	5
6 = coal / amalahle	6	6	6
7 = candles / amakhandlela	7	7	7
8 = animal dung / ubulongwe	8	8	8
9 = solar energy / ugesi welanga	9	9	9
10 = other *(specify)* / okunye *(cacisa)*:	10	10	10
11 = none / akukho	11	11	11

SECTION 7: ASSETS AND ECONOMIC INFORMATION / ISIGABA 7: IMININGWANE NGAMAFA NESIMO SOMNOTHO

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.

/ **Manje ngicela ukubuza ngezinto ezahlukahlukene ezikhona kulomuzi.**
Abasizi bocwaningo ababhekelele lokhu: Vezela umnakekeli lemidwebo engezansi uma usufike kulombuzo. .

7.1(SADH): **Does your household have ..... / Kungabe kulomuzi ikhona .....**	No / Cha	Yes / Yebo		No / Cha	Yes / Yebo
7.1a: electricity? / ugesi? 	0	1	7.1g: washing machine? / umshini wokuwasha? 	0	1
7.1b: radio? / umsakazo? 	0	1	7.1h: bicycle? / ibhayisikili? 	0	1
7.1c: television? / umabonakude? 	0	1	7.1i: motorcycle? / isithuthuthu? 	0	1
7.1d: telephone? / ucingo? 	0	1	7.1j: car? /imoto? 	0	1
7.1e: refrigerator? / isibandisi? 	0	1	7.1k: donkey or horse? / imbongolo or ihhashi? 	0	1
7.1f: personal computer or pc? / i-computer? 	0	1	7.1l: sheep or cattle? / isiklabhu or izinkomo? 	0	1

Now I want to ask some questions about this household's source of income. / Manje ngicela ukukubuza ngezindlela lomuzi ongenisa ngazo imali.

7.2a: **Do you have a job (including hawking)? / Unawo yini umsebenzi (kufaka ukuzithengisela okuthile)?**

❑ 0 = No → *Go to Q7.3a* / Cha → *Yiya ku Q7.3a*

❑ 1 = Yes → **What do you do?** *(specify):* / Yebo → **Yini oyenzayo?** *(cacisa)* ..... → *Go to Q7.2b* / → *Yiya ku Q7.2b*

7.2b: **Is your job temporary or permanent? / Kungabe umsebenzi wakho ungowesikhashana kumbe uqashwe ngokugcwele?**

- ❑ 0 = Temporary / Isikhashana
- ❑ 1 = Permanent / Isikhathi eside

7.3a (G,K&M): **What is the main source of income for this household? Is it .....?** *(circle one answer choice)* **/ Iyiphi indlela enkulu engenisa imali kulelikhaya? Kungabe .....?** *(kokelezela impendulo eyodwa)*	
1 = salaries and/or wages / umholo womuntu osebenzayo	1
2 = remittances / imali ethunyelwa ekhaya	2
3 = pensions and grants / imali yezimpesheni nezondlo	3
4 = sales of farm products and services / ukudayisa izinto ezitshaliwe	4
5 = other incomes / ezinye izimali ezingenayo	5
6 = no income / ayikho imali engenayo	6
7.3b: *If participant answers code 6 / :* **How does the household support itself with no income? Is it .....?** *(circle one answer choice) / Uma obuzwayo ephendule ukubhala okufinqiwe/uphawu 6:* **Uzondla kanjani lomndeni uma ingekho imali engenayo? Kungabe ....?** *(kokelezela impendulo eyodwa)*	
1 = Supported by persons not in the household/ Wondliwa abantu abangekho emndenini	1
2 = Supported by charity, church, welfare, etc./ Wondliwa iminikelo, isonto, ezenhlalakahle njalo njalo	2
3 = Savings or money previously earned/ Imali eyabe yayigciniwe kumbe eyayiholiwe	3
4 = other source *(specify)* / Eminye imithombo *(cacisa)*:	4

Now I want to ask you about social grants received by members of this household. / Manje ngifuna ukubuza ngemali kahulumeni etholwa amalunga alomndeni

Note to Survey Staff: Keep using the same person numbers as assigned in Section 1. / Abasizi bocwaningo ababhekelele lokhu: Qhubeka usebenzise izinombolo zabantu ezifana nezesigaba 1.

7.4a: *Ask only if the person(s) in the household are 15 years or younger.* **Does ..... receive a child support grant?** */ Buza kuphela uma umuntu (abantu) ekhaya beneminyaka eyishumi nanhlanu (15) noma ngaphansi.* **Kungabe u.....uyayithola i imali yesondlo yezingane?**	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
0 = No → *Go to Q7.4b* / Cha → *Yiya ku Q7.4b*		0	0	0	0	0	0	0	0	0	0	0	0	0	0
1 = Yes → *Go to Q7.5a* / Yebo → *Yiya ku Q7.5a*		1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Don't know → *Go to Q7.4c* / Angazi → *Yiya ku Q7.4c*		2	2	2	2	2	2	2	2	2	2	2	2	2	2

7.4b: *Ask only if the participant answered "No" to Q7.4a:* **If ..... should be getting a child support grant but isn't, do you know the reason why?** */ Buza kuphela uma obuzwayo ephendule "Cha" kt Q7.4a:* **Uma ..... kufanele athole umxhaso wesondlo somtwana kodwa akayitholi, uyasazi isizathu?** → *Complete and go to Q7.4c / Qedela bese uqhubekela kumuzo Q7.4c.*	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
1 = Didn't have the right documents (ID, birth certificate, etc.) / Ubengenazo izincwadi eziyizimfanelo (ipasi, incwadi yokuzalwa, nokunye)		1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Can't afford transport to grant office / Akanayo imali yokuya emahovisi empesheni		2	2	2	2	2	2	2	2	2	2	2	2	2	2
3 = The grant office sent us away / Ihovisi lempesheni lamjikisa lamxosha		3	3	3	3	3	3	3	3	3	3	3	3	3	3
4 = Another reason *(please specify by writing sideways):* / Esinye isizathu *(sicela ucacise ngokubhala emaceleni):*		4	4	4	4	4	4	4	4	4	4	4	4	4	4
5 = never applied / akaze afake isicelo		5	5	5	5	5	5	5	5	5	5	5	5	5	5

7.4c: *Ask only if the person(s) in the household are 21 years or younger.* **Does ..... receive a foster care grant?** */ Buza kuphela uma umuntu (abantu) ekhaya beneminyaka engamashumi amabili nanye (21) noma ngaphansi.* **Kungabe u .....uyayithola imali yesondolo sekunakekela ingane okungeyona eyakho ngokuzalwa?**	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
0 = No → *Go to Q7.4d* / Cha → *Yiya ku Q7.4d*		0	0	0	0	0	0	0	0	0	0	0	0	0	0
1 = Yes → *Go to Q7.4e* / Yebo → *Yiya ku Q7.4e*		1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Don't know → *Go to Q7.4e* / Angazi → *Yiya ku Q7.4e*		2	2	2	2	2	2	2	2	2	2	2	2	2	2

7.4d: *Ask only if the participant answered "No" to Q7.4c:* **If..... should be getting a foster care grant but isn't, do you know the reason why?** */ Buza kuphela uma obuzwayo ephendule " Cha" ku Q7.4c:* **Uma ..... kufanele athole umxhaso wabantwana abashonelwe abazali (foster care) kodwa akayitholi, uya yini isizathu?** → *Complete and go to Q7.4e / Qedela bese uqhubekela kumuzo Q7.4e.*	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
1 = Didn't have the right documents (ID, birth certificate, etc.) / Ubengenazo izincwadi eziyizimfanelo (ipasi, incwadi yokuzalwa, nokunye)		1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Waiting for a court order / Ulinde umyalelo wasenkantolo		2	2	2	2	2	2	2	2	2	2	2	2	2	2
3 = Can't afford transport to grant office / Akanayo imali yokuya emahovisi empesheni		3	3	3	3	3	3	3	3	3	3	3	3	3	3
4 = The grant office sent us away / Ihovisi lempesheni lamjikisa lamxosha		4	4	4	4	4	4	4	4	4	4	4	4	4	4
5 = Another reason *(please specify by writing sideways):* / Esinye isizathu *(sicela ucacise ngokubhala emaceleni):*		5	5	5	5	5	5	5	5	5	5	5	5	5	5
6 = never applied / akaze afake isicelo		6	6	6	6	6	6	6	6	6	6	6	6	6	6

7.4e: *Ask only if the person(s) in the household are 18 years or younger.* **Does ..... receive a care dependency grant?** */ Buza kuphela uma umuntu (abantu) ekhaya beneminyaka eyishumi nesishagalombili (18) noma ngaphansi.* **Kungabe u.....uyayithola i imali yesondlo yokunakekela ingane egulayo noma ekhubazeke kakhulu?**	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
0 = No → *Go to Q7.4d* / Cha → *Yiya ku Q7.4d*		0	0	0	0	0	0	0	0	0	0	0	0	0	0
1 = Yes → *Go to Q7.5a* / Yebo → *Yiya ku Q7.5a*		1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Don't know → *Go to Q7.5a* / Angazi → *Yiya ku Q7.5a*		2	2	2	2	2	2	2	2	2	2	2	2	2	2

7.4f: *Ask only if the participant answered "No" to Q7.4e:* **If.....should be getting a care dependency grant but isn't, do you know the reason why?** */ Buza kuphela uma obuzwayo ephendule "Cha" ku Q7.4e:* **Uma…..Kufanele ngabe uthola imali yesondlo yomtwana ogulayo kodwa ungayitholi, uyasazi isizathu salokho?** → *Complete and go to Q7.5a / Qedela bese uqhubekela kumuzo Q7.5a.*	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
1 = Didn't have the right documents (ID, birth certificate, etc.) / Ubengenazo izincwadi eziyizimfanelo (ipasi, incwadi yokuzalwa, nokunye)		1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Waiting for a medical assessment or report / Ulinde ukuhlolwa noma umbiko kadokotela.		2	2	2	2	2	2	2	2	2	2	2	2	2	2
3 = Can't afford transport to grant office / Akanayo imali yokuya emahovisi empesheni		3	3	3	3	3	3	3	3	3	3	3	3	3	3
4 = The grant office sent us away / Ihovisi lempesheni lamjikisa lamxosha		4	4	4	4	4	4	4	4	4	4	4	4	4	4
5 = Another reason *(please specify by writing sideways): /* Esinye isizathu *(sicela ucacise ngokubhala emaceleni):*		5	5	5	5	5	5	5	5	5	5	5	5	5	5
6 = never applied / akaze afake isicelo		6	6	6	6	6	6	6	6	6	6	6	6	6	6

7.5a: *Ask only if the person(s) in the household are 60 years or older.* **Does … receive an old age pension?** */ Buza kuphela uma umuntu (abantu) ekhaya beneminyaka engamashumi ayisithupha (60) noma ngaphezulu.* **Kungabe u ..... uyayithola i impesheni yokoguga?**	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
0 = No → *Go to Q7.5b* / Cha → *Yiya ku Q7.5b*	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
1 = Yes → *Go to Q7.5e* / Yebo → *Yiya ku Q7.5e*	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Don't know → *Go to Q7.5c* / Angazi → *Yiya ku Q7.5c*	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2

7.5b: *Ask only if the participant answered "No" to Q7.5a:* **If ..... should be getting an old age pension but isn't, do you know the reason why?** */ Buza kuphela uma obuzwayo ephendule "Cha" ku Q7. 5a:* **Uma.... kufanele athole impesheni yokoguga akatholi, uyasazi isizathu salokho?** → *Complete and go to Q7.5c / Qedela bese uqhubekela kumuzo Q7.5c.*	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
1 = didn't have the right documents (ID, birth certificate, etc.) / Ubengenazo izincwadi eziyizimfanelo (ipasi, incwadi yokuzalwa, nokunye)	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = can't afford transport to the grant office / kanayo imali yokuya emahovisi empesheni	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3 = the grant office sent us away / Ihovisi lempesheni lamjikisa lamxosha	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
4 = don't know / angazi	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
5 = **Another reason** *(please specify by writing sideways): /* **Esinye isizathu** *(sicela ucacise ngokubhala emaceleni):*	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5
6 = never applied / akaze afake isicelo	6	6	6	6	6	6	6	6	6	6	6	6	6	6	6

7.5c: *Ask only if the person(s) in the household are male and between 18 and 64 years OR female and between 18 and 59 years.* **Does … receive a disability grant?** */ Buza kuphela uma umuntu (abantu) ekhaya bengabesilisa futhi bephakathi kweminyaka eyishumi nesishagalombili (18) namashumi ayisithupha nane (64) noma bengabesifazane futhi bephakathi kweminyaka eyishumi nesishagalombili (18) namashumi amahlanu nesishagalolunye (59).* **Kungabe u ..... uyayithola i imali yokukhubazeka?**	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
0 = No → *Go to Q7.5d* / Cha → *Yiya ku Q7.5d*	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
1 = Yes → *Go to Q7.5e* / Yebo → *Yiya ku Q7.5e*	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Don't know → *Go to Q7.5e* / Angazi → *Yiya ku Q7.5e*	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2

7.5d: *Ask only if the participant answered "No" to Q7.5c:* **If ..... should be getting a disability grant but isn't, do you know the reason why?** */ Buza kuphela uma obuzwayo ephendule "Cha" ku Q7. 5c:* **Uma.... kufanele athole imali yokukhubazeka akatholi, uyasazi isizathu salokho?** → *Complete and go to Q7.5f / Qedela bese uqhubekela kumuzo Q7.5f.*	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
1 = didn't have the right documents (ID, birth certificate, etc.) / Ubengenazo izincwadi eziyizimfanelo (ipasi, incwadi yokuzalwa, nokunye)	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Waiting for a medical assessment or report / Ulinde ukuhlolwa noma umbiko kadokotela	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3 = can't afford transport to the grant office / kanayo imali yokuya emahovisi empesheni	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
4 = the grant office sent us away / Ihovisi lempesheni lamjikisa lamxosha	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
5 = don't know / angazi	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5
6 = another reason *(specify by writing sideways): /* **Esinye isizathu** *(sicela ucacise ngokubhala emaceleni):*	6	6	6	6	6	6	6	6	6	6	6	6	6	6	6
7 = never applied / akaze afake isicelo	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7

7.5e: **Does … receive a government housing subsidy, such as RDP housing subsidy? / Kungabe u ..... uyayithola i Umxhaso kahulumeni wezezindlu njengo ndlu yomxhaso?**	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
0 = No → *Go to Q7.5f* / Cha → *Yiya ku Q7.5f*	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
1 = Yes → *Go to end* / Yebo → *Iya ekugcineni.*	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = Don't know → *Go to end* / Angazi → *Iya ekugcineni.*	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2

7.5f: *Ask only if the participant answered "No" to Q7.5e: / Buza kuphela uma obuzwayo ephendule "Cha" ku Q7.5e:* **If ..... should be getting a government housing subsidy, such as RDP housing subsidy, but isn't, do you know the reason why? / Uma…. kufanele athole umxhaso kahulumeni wezezindlu njengo ndlu yomxhaso akatholi, uyasazi isizathu salokho?**	Person number / inombolo eqondene nawe														
	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15
1 = didn't have the right documents (ID, birth certificate, etc.) / Ubengenazo izincwadi eziyizimfanelo (ipasi, incwadi yokuzalwa, nokunye)	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2 = waiting for a housing official to do an assessment / ulindele owomnyango wezezindlu azohlola isimo	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3 = can't afford transport to the housing office / akanayo imali yokuya emahhovisi omnyango wezezindlu	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
4 = the housing office or municipality sent us away / ihhovisi lezezindlu langixosha	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
5 = don't know / angazi	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5
6 = another reason *(specify by writing sideways): /* **Esinye isizathu** *(sicela ucacise ngokubhala emaceleni):*	6	6	6	6	6	6	6	6	6	6	6	6	6	6	6
7 = never applied / akaze afake isicelo	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7

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. / Ngi/Siyabonga kakhulu ngesikhathi esibalulekile osinikeze sona ngokusinikeza lonke lolulwazi. Umsebenzi wakho wokunakekela izingane mukhulu impela. Nakuba singasoze salidalula igama lakho kwabanye abantu, singathembisa kodwa ukuthi sitshele uhulumeni ngalokho esikuzwe ngawe kanye nabanye abanakekeli bezingane.

Please keep on doing the wonderful job you are doing. / Sicela uyibambe iqine uqhubeke nje nomsebenzi wakho omuhle kangaka owenzayo.

Again, we would like to say thank you for your time and for sharing this valuable information with us! / Sicela ukuphinda sisho ukuthi siyabonga kakhulu ngesikhathi sakho nokuthi usinikeze lonke lolulwazi oluningi kangaka osiphe lona!

Note to Survey Staff: Please go to the page 2 and fill in the end time of the interview. / Abasizi locwaningo babheke lokhu: Sicela ubuyele emuva ekhasini lesibili bese uloba phansi isikhathi eniqede ngaso lengxoxo .

TEEN TALK



TEEN TALK SOUTH AFRICA

Whatever you say is confidential. This means we will not report your real name.

Please write your name here:

.....

Now, please think of a different name which we can use when we are writing about this research. You can pick any name you want!

.....

Questionnaire number: ..... Boy/Girl

Place of interview: .....

School/org: ..... Grade: .....

ID number: .....

Interviewer: ..... Date: .....

Enumeration Area Number: .....

GPS lattitude (S): S ° . ‘

GPS longitude (E): E ° . ‘

P #: .....

EMIS #: .....

Privacy code: .....

YoungCarers PROJECT SOUTH AFRICA

Would you mind if we contacted you again? Please write your address and telephone number so we can get back in touch:

Address: .....

.....

.....

Telephone: .....

This is not a test. There are no right or wrong answers! This research aims to help young people in South Africa. Thank you for taking the time to help.

TEEN TALK SOUTH AFRICA

Please take time to read this sheet carefully and decide whether you do or don't want to take part. Ask the research team if there is anything that is not clear or if you have questions. Thank you for reading this.

What is this study about? This study is about young people and their feelings about their lives. The government wants to know more so they can plan how to help young people and families better.



Do I have to take part? Not at all. It is up to you to decide whether or not to take part. If you do not want to, this will not affect any help you may be getting from anyone. You will not get in any trouble if you do not want to take part.

If you decide to take part, you are still free to stop at any time. You don't have to give a reason. Again, this will not affect any help or support you are getting from anyone. In one year's time, we will visit you again to see how you are doing. You can choose then whether you want to talk to us again!

What would I have to do? If you decide to take part, you will first sign a consent form (on the next page), and then spend about an hour talking together and doing activities with a researcher.

What if the questions upset me? You can stop at any point, and you do not have to give a reason. You can also contact the research team at any point after the group, and say that you want your answers about certain questions to be destroyed, which we will do straight away. If you want to talk to someone about anything that has come up from this, you can tell one of the researchers or contact the Young Carers Team at Cape Town Child Welfare (021 638 3127).

Why should I take part in this study? This may help us to know more about what can help young people in South Africa. What you tell us will help inform future government policy.

What if I have a complaint? If there is anything to do with this research which you are unhappy with, you can complain to Dr. Lucie Cluver at Oxford University (lucie.cluver@socres.ox.ac.uk).

Will what I say be kept confidential? Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name and address changed so that you cannot be recognised from it.

But during this study, it may become clear that you are suffering from serious difficulties. If so, the interviewer will explain to you some possibilities for further help. If there is a safety issue, we may contact a welfare organisation for you. All this will be talked over with you first.

What will happen to the results of the research study? The results of this study will be used to help the government and others to make policies for young people and families in situations much like yours.

Who is organising and reviewing the research? The research is being organised by the University of Oxford in England, the University of Witwatersrand, the University of KwaZulu-Natal and is being tested by the University of Cape Town. The research is also organised by The Department of Social Development, the Department of Health and the Department of Education in Pretoria. Ethics groups in both countries have approved the research. If you have any complaints about ethics in the Western Cape, please contact the UCT Health Sciences Research Ethics Committee (E52-23 Old Main Building, Groote Schuur Hospital, Observatory, 7925). If you have any complaints in Kwa-Zulu Natal, please contact the University of Kwa-Zulu Natal Research Ethics Committee - telephone: (031) 260 3587. If you have any complaints in Mpumalanga or in Gauteng, please contact the University of Witwatersrand Research Ethics Committee - telephone: (011) 717 71234.

Contact for further information: Dr Lucie Cluver, Cape Town Child Welfare, Lower Klipfontein Road, Gatesville, Athlone, South Africa 8000
Email: lucie.cluver@socres.ox.ac.uk

Thank you for reading this sheet. If you feel comfortable with everything, you can fill in the box:

Do I want to take part?

	Tick:
1. I have read and understand the information sheet for this study and have had the chance to ask questions	☐
2. I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting	☐
3. I agree that any words I may say during the interview can be used, without giving my name, in the presentation of the research. I agree to take part in the study	☐

Sign:

....
Name of participant Signature

....
Name of researcher Date

Could you give us the names, addresses and telephone numbers of 2 people (who you don't live with) who you think would know how to contact you in a few years time?

1. .....
.....
.....
.....
.....

2. .....
.....
.....
.....
.....

My house

Please circle the one which is most like your home:

1. house made of brick or concrete



2. hut made of traditional materials



3. shack on its own plot

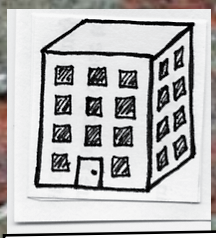


4. living on the street



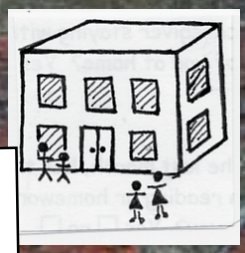
5. shack in a back yard





6. block of flats

7. children's home or shelter for kids



8. other (what kind? .....)

Where do you get your water from?

1: ..... a tap in my house
2: ..... a community tap that lots of people use (how long does it take you to get to it? .....)
3: ..... a river or stream

people looking after other people

Do you have a parent, guardian or caregiver staying with you and taking care of you at home?
..... yes ..... no

If you do, please write their name here: .....
How old is this person? .....

P #: .....

Is this person your:

..... Brother	..... Uncle
..... Stepfather	..... Neighbour/family friend
..... Grandma	..... Biological father
..... Sister	..... Aunt
..... Foster mother	..... Stepmother
..... Grandpa	..... Biological mother
..... No-one	..... Social worker/careworker
..... Foster father	..... Other (who? ....)

Has your caregiver talked to you about who you will live with if they aren't able to look after you anymore?

..... Yes ..... No

If they have, who will that person be?
.....

My day

On a normal weekday, how many hours do you spend:



Sleeping? .....

At school? .....

Playing? .....

Doing homework? .....

Working for money? .....

Helping at home/helping with sick people? .....

Other (what?): .....

.....

.....

People I live with

How many rooms are there in your home, like a bathroom kitchen and other rooms? Draw them below.

1) Who sleeps in each room? 2) Write down their relationship to you, 3) whether they are a boy or girl and 4) how old they are!

5) Please circle anyone in the house who is sick.

6) Now, could you put a tick next to anyone in the home who has a job? Write down next to them whether it is a regular job (every day) a part-time job (some days each week) or a 'sometimes' job (like just over harvest, or on a building project).

Please answer these questions about stuff that happens at home - just tick the best answer:

	Never	Almost never	Sometimes	Often	Always
Your carer says you have done something well					
Your carer threatens to punish you and then does not do it					
You go out without a set time to be home					
You talk your carer out of punishing you after you have done something wrong					
You stay out in the evening past the time you are supposed to be at home					
Your carer compliments you when you have done something well					
Your carer praises you for behaving well					
Your carer does not know who you are friends with					
Your carer lets you out of a punishment early					
Your carer tells you that they like it when you help out around the house					

Please tick the things which you can afford at home:

☐ 3 meals a day





☐ school uniform

☐ toiletries to be able to wash every day



☐ school fees





☐ enough clothes to keep you warm and dry



☐ school equipment





☐ visit to the doctor when you are ill, and all the medicines you need

☐ more than one pair of shoes

Is the household receiving any grants?

..... no grants (XX)
..... foster care grant
..... child support grant
..... pension
..... disability grant
..... care dependency grant

If you should be getting a grant but aren't, do you know the reason why?

..... Didn't have the right documents (ID, birth certificate etc)
..... Waiting for a social worker to do an assessment
..... Can't afford transport to the grant office
..... The grant office sent us away
..... Another reason (tell us?

.....

.....)

..... Not applicable

Stuff at home

Do you have an ID book? ..... Yes ..... No
Do you have a birth certificate? ..... Yes ..... No

Sometimes kids don't have enough food in their home. How many days in the past 7 days did you not have enough food in your home? .....

How many days did you go to bed hungry? .....

Do you get the same amount of food as other kids in your home?
..... More ..... The same ..... Less





What I think and feel...

This part of the questionnaire looks at sadness and other difficulties which many people experience at some point in their lives. For each group of 3 statements, pick out which best describes how you have felt in the last 2 weeks...

1
..... Nothing will ever work out for me
..... I am not sure if things will work out for me
..... Things will work out for me OK

2
..... I am sad once in a while
..... I am sad many times
..... I am sad all the time

3
..... I look OK
..... There are some bad things about my looks
..... I look ugly

4
..... I hate myself
..... I do not like myself
..... I like myself

5
..... I do not feel alone
..... I feel alone many times
..... I feel alone all the time

6
..... I do most things OK
..... I do many things wrong
..... I do everything wrong

7
..... I have plenty of friends
..... I have some friends but wish I had more
..... I don't have any friends

8
..... I feel like crying every day
..... I feel like crying many days
..... I feel like crying once in a while

9
..... Nobody really loves me
..... I am not sure if anybody loves me
..... I am sure that somebody loves me

10
..... Things bother me all the time
..... Things bother me many times
..... Things bother me once in a while

In the past month did you:

Wish you were dead? .....
Want to hurt yourself? .....
Think about killing yourself? .....
Think of a way to kill yourself? .....
Try to kill yourself? .....

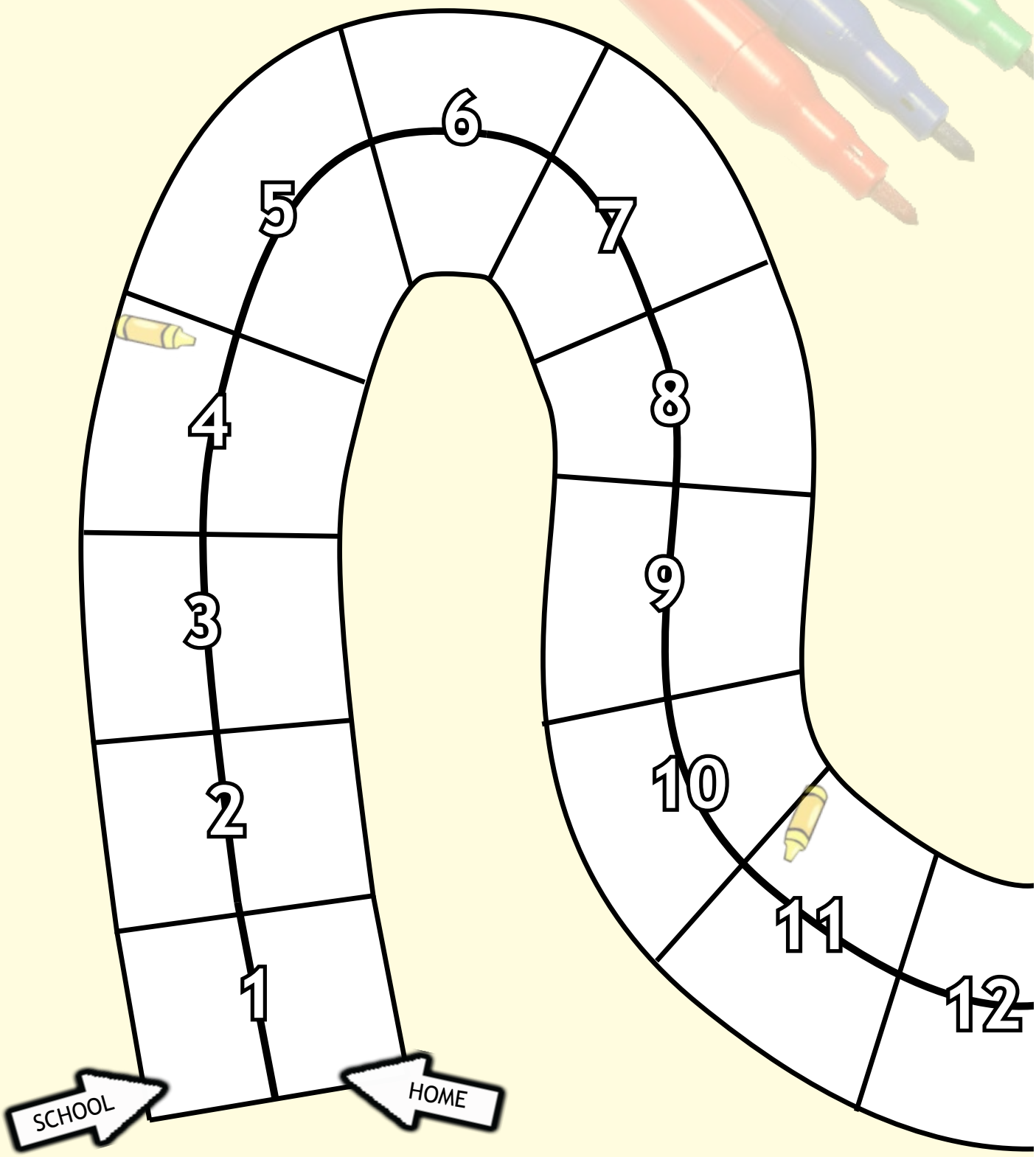
Many kids and teenagers feel nervous or anxious at times. Please say which of these is true for you:

1. I worry a lot of the time	yes	no
2. I worry about what my carers will say to me	yes	no
3. I feel that others do not like the way I do things	yes	no
4. It is hard for me to get to sleep at night	yes	no
5. I worry about what other people think about me	yes	no
6. I feel alone even when there are people with me	yes	no
7. I worry about what is going to happen	yes	no
8. Other children are happier than I am	yes	no
9. I have bad dreams	yes	no
10. I wake up scared some of the time	yes	no
11. I worry when I go to bed at night	yes	no
12. I am nervous	yes	no
13. A lot of people are against me	yes	no
14. I often worry about something bad happening to me	yes	no

my road

1: For **HOME**, write on the road:

- ☐ whose home were you living in?
- ☐ who was the person who looked after you most?
- ☐ why did things change?



START!

I was born on (date) .....

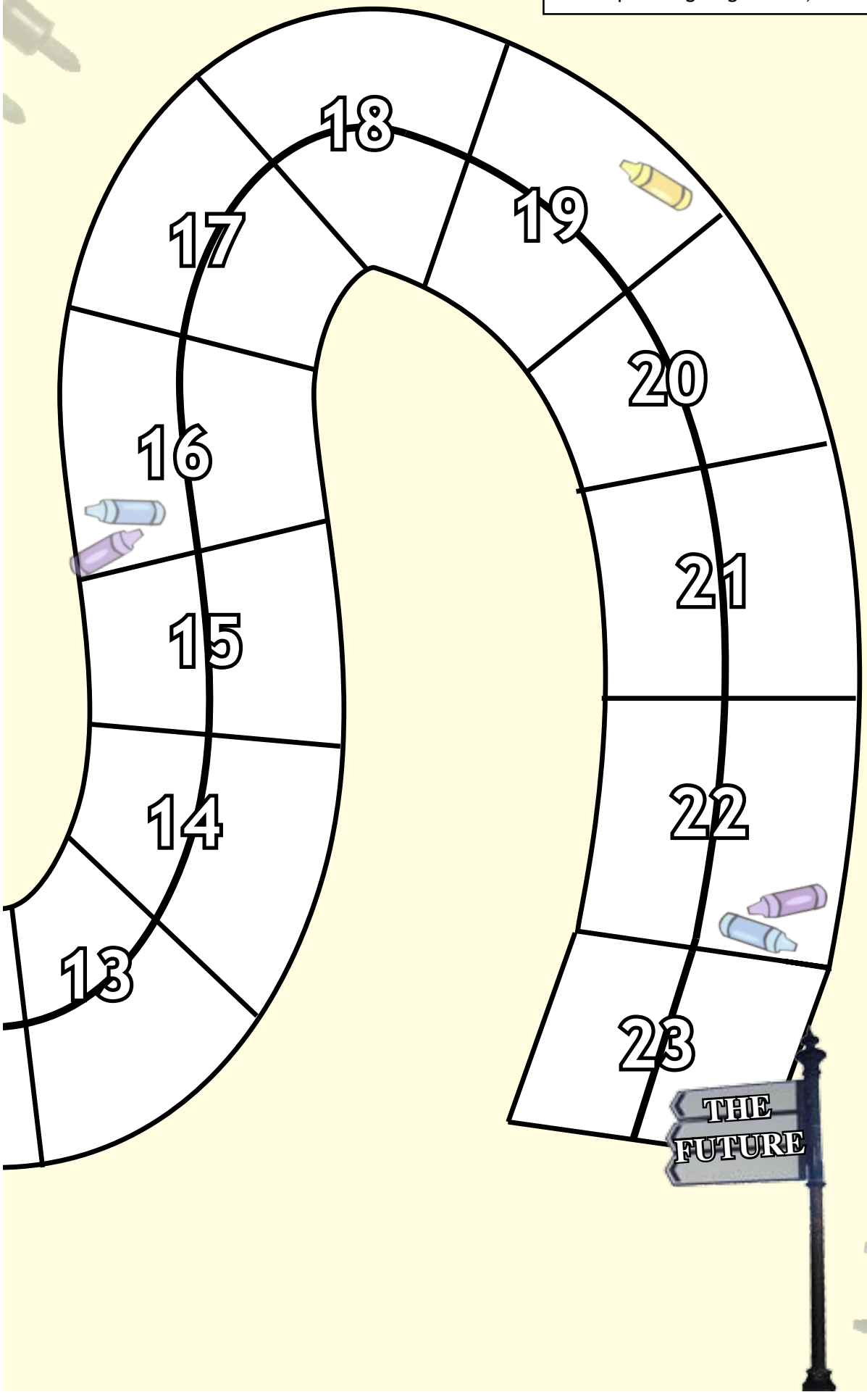
Where? .....

Who looked after you most? .....

# of life

2: For **SCHOOL**, write on the road:

- ☐ what grade you are in now
- ☐ what are the names of your schools
- ☐ any years you repeated and why
- ☐ when you left school and why? (also say if you are planning to go back!)



What kinds of support do you get from people in your life?

	This person is a person in my life		This person is helpful when I have a personal problem			This person is helpful when I need money and other things			I have fun with this person		
	yes	*no*	*not at all*	*sort of*	*very*	*not at all*	*sort of*	*very*	*not at all*	*sort of*	*very*
Your caregiver											
Your sisters or brothers											
A teacher, or the school principal											
A religious leader											
Your best friend											
Your group of close friends											
Other people (tell us who: ....)											

How about these kinds of help? And how reliable are they?

	Regular (at least once a month)	Sometimes	Never
A food parcel			
A meal at a soup kitchen			

Has your family had help from a traditional healer with sickness or death?

..... Yes (what kind of help? ....)

..... No

SUPPORT

Has anyone close to you died? Could you tell us who they were? And when? Do you know what happened? (you can write, or draw them)

Some kids have parents who were ill for some time before they died. Or their parent is unwell at the moment. It's difficult for kids to handle sometimes. Could you say how much these things are true for you?

Because someone in my family is sick or has died...

	Not at all	Sometimes	All the time
I've been teased			
I've been treated badly			
People have gossiped behind my back			
I worry about being rejected			
Parents who know don't want me around their kids			
I avoid making new friends			
I feel different and alone			
If people know, they avoid touching me			
If people know, they are afraid of me			
If people know, they think I am a bad person			

Did this upset you?

..... Not at all

..... Somewhat

..... Very much

CONFIDENTIAL SICKNESS REPORT SHEET

Fill this out only if someone is unwell in the home.

Questionnaire no: .....

Who is the person who you help look after most? .....

How old are they? .....

How long have they been sick for? .....

Thank you for helping us with this. These questions are totally confidential – they will be put in a sealed envelope. Please don't write your name on this sheet.

P #: .....

In the past month, is this person's health

☐ Very good ☐ good ☐ moderate ☐ bad ☐ very bad

Has this person been happy in the past month?

☐ very happy ☐ happy ☐ ok ☐ sad ☐ very sad ☐ angry

How often in the past month has this person been unwell?

☐ never ☐ 1 week ☐ 2 weeks ☐ 3 weeks ☐ all month

When people are unwell, they find it difficult to do everyday things. Could you think about what this person finds hard to do?

	Not at all difficult	A little difficult	Very difficult	Not able to do it
Carrying shopping				
Climbing into a taxi or bus				
Bending or kneeling				
Walking a kilometre				
Walking 100 metres				
Washing or dressing				
Getting out of bed				

(XX)

Could you tell us what this person is sick with?

.....

.....

☐ Have they lost weight and become very thin?
☐ Have they got diabetes?
☐ Have they had any of these things: very pale, or hair changing colour, or legs swelling up, or burning feelings in their feet, or has their skin been very dry?
☐ Do they have emotional problems?
☐ Have their eyes been yellow, and they've had a fever? Or itching?
☐ Have they had shingles or a rash on their skin?
☐ Have they got high blood pressure?
☐ Have they had sores on their body?
☐ Have they had ulcers or white patches in their mouth, or problems swallowing food?
☐ Do they drink alcohol too much?
☐ Do they have cancer? Where is the cancer? .....
☐ Have they had trouble breathing, or a cough for more than 2 days with fever?
☐ Have they had TB in the last five years?
☐ Do they have arthritis?
☐ Have they been bewitched?
☐ Have they had diarrhoea or a runny tummy for more than 2 days?
☐ Do they have HIV?
☐ Have they had anything else we haven't asked about? (What do they have? .....
.....)

CONFIDENTIAL PARENT REPORT SHEET

Fill this out only if a parent has died.

Questionnaire no: .....

Thank you for helping us with this. These questions are totally confidential – they will be put in a sealed envelope. Please don't write your name on this sheet.

How was this person related to you? .....

How old was this person when they died? .....

Do you know what happened?

- ☐ road accident
- ☐ illness – do you know what? .....
- ☐ attacked
- ☐ something else (Could you tell us? .....)

How long were they sick for? .....

Can you get their death certificate when you need it for grants? ☐ Yes ☐ No

XX Could we ask you about some of the symptoms of sickness your parent had before they died?

- ☐ Did they lose weight and become very thin?
- ☐ Did they have diabetes?
- ☐ Did they have any of these things: very pale, or hair changing colour, or legs swelling up, or burning feelings in their feet, or was their skin very dry?
- ☐ Did they have emotional problems?
- ☐ Were their eyes yellow, and they had a fever? Or itching?
- ☐ Did they have shingles or a rash on their skin?
- ☐ Did they have high blood pressure?
- ☐ Did they have sores on their body?
- ☐ Did they have ulcers or white patches in their mouth, or problems swallowing food?
- ☐ Did they drink alcohol too much?
- ☐ Did they have cancer? Where was the cancer? .....
- ☐ Did they have trouble breathing, or a cough for more than 2 days with fever?
- ☐ Did they have TB in the last five years?
- ☐ Did they have arthritis?
- ☐ Were they bewitched?
- ☐ Did they have diarrhoea or a runny tummy for more than 2 days?
- ☐ Did they have HIV?
- ☐ Did they have anything else we haven't asked about? (What did they have? ....)

Would you like to draw or write something for your parent?

Stuff that's been difficult for me



Here are Buntu and Lindiwe, telling us some things which many kids in South Africa have experienced. Could you tell us whether these things have happened to you also?

Buntu's family have lots of arguments. Sometimes adults shout at each other and sometimes there is fighting. This last week, how many days were there arguments with adults shouting in your home? .....

What were these arguments mainly about? .....

.....

How many days were there arguments with adults hitting each other in your home? .....

Buntu has been robbed and had his things stolen. This year, how many times have you had things stolen? ..... times

In the past year, how often did your carers...	weekly	monthly	at least once this year	never
Use a stick, belt or other hard item to hit you?				
Slap, punch or hit you so you were hurt?				
Said that you would be sent away or kicked out of the house?				
Said they would call ghosts or evil spirits, or harmful people?				
Insulted you by calling you dumb, lazy or other names?				

There are inappropriate ways to touch Buntu and Lindiwe. Has anyone ever touched you in a way that made you feel uncomfortable? .....

Has anyone ever made you do anything with your private parts or their private parts that you did not want to do? .....

Buntu was attacked and hit when he was out. Have you ever been hit or attacked outside? .....

Buntu saw someone in his neighbourhood being shot. Lindiwe saw someone being stabbed one evening.

Have you seen someone being shot? .....
Or stabbed? .....

Has anything happened which we have not mentioned which has upset you?

.....

.....

.....

.....

.....

.....

how do you feel about...?

Many kids go through things that are very upsetting or frightening, We would like to know about them and how you felt about it. They might have happened recently or they might have happened a long time ago, but still upset you. They might have been in the list we asked you, or something else.

Can you tell us what was the most upsetting or frightening thing that has happened to you?

.....

.....

.....

.....

Now for each question, could you tick one box to show whether you have felt this way 'not at all', 'some of the time', most of the time' or 'all the time' in this past month:

	Not	Some	Most	All
 Do you get nightmares or bad dreams about what happened?	○	●	●●	●●●
Do you get upset when you think about what happened? 				
When something reminds you of what happened, do you get tense or upset?				
 Do you go over and over what happened in your mind?				
Do you think about (or see pictures in your head of) what happened even when you don't want to? 				
Do you worry that it might happen again?				
Do you try not to think about what happened?				
Do you try to stay away from things that remind you of what happened?				
Do you have trouble remembering important parts of what happened?				
Do you act out things or repeat things like what happened?				
 Do you feel like its happening all over again even when it's not?				

	Not	Some	Most	All
Do you feel it's hard to have any feelings any more, like you feel numb?				
Do you make yourself very busy and do things so you won't think about what happened?				
Do you get physically upset when something reminds you of what happened – like getting sweaty, shaking, your heart pounding, getting short of breath, or stomach aches? 				
 Do you have trouble falling asleep or staying asleep?				
Is it hard for you to pay attention – like listening to your teacher, or doing your work – because you can't concentrate well? 				
Do you feel you need to stay 'on guard', like something could happen and you need to be ready?				
Do you get jumpy or startle easily?				
Do you get annoyed (grouchy) or irritable (kind of angry) real easy?				
 Do you get angry or upset at people for no reason?				
Do you get so angry at people you hit or hurt someone? 				
Do you ever think you won't grow up and be what you want to be?				
 Do you feel it's hard to have fun doing things?				
Do you ever feel it's hard to feel happy?				
Do you feel alone even when other people are around? 				
Do you feel bad or guilty – like what happened was your fault?				
Do you wet your pants or bed by accident?				
Do you feel like you are 'tuned out' or in a 'trance' so you can go away in your mind and not think?				

How do you usually get to your local clinic?

..... Walk ..... Taxi ..... Bus

..... Driven ..... Train

How long does it take to get there? ..... minutes

Health

We all get sick sometimes. Can you tell us whether you've had any of these in the past year?

Do you have any of these?			
Asthma		Yes	No
How many asthma attacks in the last month?			
When you have an attack, do you have a puffer spray you can take?		Yes	No
Epilepsy		Yes	No
How many seizures in the last month?			
Are you taking your treatment every day?		Yes	No
Diabetes		Yes	No
How many times have you been sick in the past month? ..... times			
Are you taking your injections or medicine every day?		Yes	No
If yes to any of these...			
When did you last go to hospital for this?			
Are you able to keep your clinic appointments:	always	sometimes	never

Does your family have a home-based carer who visits you?

..... yes ..... no

How many times did they visit in the last month? ..... times

On the last visit, did they spend time with you? ..... yes ..... no

How did they spend time with you? (XX)

..... time spent with emotional support
..... time showing me how to help the sick person
..... bringing protective gloves or other medical resources
..... time spent talking to me about my health
..... time spent helping me with my schoolwork
..... bringing food parcels or clothes or things to help me

Have you had these in the past month?		
Cold or flu	Yes	No
General body pain (headaches, backaches etc)	Yes	No
Worms	Yes	No
Skin conditions (like a rash, or white itchy skin, or acne)	Yes	No

Have you had these in the past 6 months?		
Pneumonia or bronchitis (really sick with cough, chest pain and yellow spit for at least 1 week)	Yes	No
Vomiting, diarrhoea or a runny tummy	Yes	No
Any injury or burn	Yes	No

Do you have these problems?		
I have problems seeing properly	Yes	No
I have another kind of disability (what kind? .....)	Yes	No

Could you tell us how your health has been recently?

A cough where you spit up green or yellow stuff?		Yes	No
A bad cough lasting 3 weeks or longer		Yes	No
Pains in your chest		Yes	No
Tiredness and weakness		Yes	No
Have you lost weight without meaning to?		Yes	No
Do you have night sweats?		Yes	No
Are you coughing up blood?		Yes	No
Are you having a fever?		Yes	No
Has a nurse or doctor asked you to cough sputum into a little bottle test?	Yes - TB	Yes - not TB	No
Have you had TB in the past 2 years?		Yes	No
Were you given pills to take every day for TB?		Yes	No
If yes, how long did you take pills for? ..... months / none at all			

For anything above (like TB, diabetes, flu...) could you tell us whether you visited these kinds of healthcare in the past two years?

	Yes	No, I didn't need to	I needed to but I couldn't
Chemist/pharmacy			
A public clinic			
A private doctor			
A traditional healer			
A healer at a church or medicines from the church			
A public hospital			
A private hospital			
Other (what kind? .....)			

If you needed to see someone but you couldn't, could you tell us why?

	Tick: (XX)
I saw the person I needed to see	
I didn't have enough money for transport	
I was too busy helping out at home to go	
No one was available to go with me	
The health facility was too far away	
The queue or wait was too long	
The staff were unhelpful or lacked the skills to help me	
I could not decide what to do	
I didn't go for a religious reason	
I was afraid/embarrassed	
Another reason (what reason? .....)	
I don't know	

These are some tasks which kids do to help at home. How often have you done these things in the last month, and how long do they take?

	How many days in the week?	How long does this take you?
1. Wash other people's clothes		
2. Clean your home, yard, or other parts of the house		
3. Work in a food garden or tend animals		
4. Fetch water		
5. Collect fireword and/or make fires		
6. Do the grocery shopping		
7. Cook for other people		
8. Wash the dishes		
9. Do jobs for money (what kind? .....)		
10. Walk your siblings or other children to school/crèche		
11. Wash your siblings or other children		
12. Feed your siblings/other children		
13. Collect medicine from the clinic for a sick person		
14. Remind a sick person to take their medicine		
15. Give a sick person their medicine/treatment (what kind? .....)		
16. Take a sick person to the clinic		
17. Help a sick person to get dressed		
18. Massage a sick person/rub their body		
19. Stay with a sick person (to keep company or to watch them)		
20. Wash or bathe a sick person (feet, face, or other parts)		
21. Help sick person get around the house		
22. Help sick person to use the toilet		
23. Clean up after person has been sick (vomit, diarrhoea or other bodily fluids)		

Doing these things makes me feel: (XX)

☐ proud to help ☐ frustrated or irritated ☐ closer to the sick person ☐ sad

Helping out

Some kinds of caring mean we should be washing our hands or wearing protective gloves (made of a plasticky material).

Have you ever washed a sick person, cleaned or put bandages on a cut of a sick person, or washed the bedclothes or clothes of a sick person when they have vomited or had diarrhoea?		**Yes**	**No**
If yes, did you wear protective gloves?	**Always**	**Sometimes**	**Never**
If yes, did you wash your hands before and after?	**Always**	**Sometimes**	**Never**

My school is:

..... we pay a school fee
..... other kids pay school fees but I have an exemption
..... a no-fees school
..... I can't pay my school fees so I owe them to the school
..... I don't go to school (***If you don't go to school, skip the rest of this page and go on to the next one!)***



Sometimes we miss school a bit, sometimes a lot! And for all sorts of reasons. Remember that this is confidential. This year, how many times have you missed school for more than a week? .....

Why was that? .....
.....
.....
.....
.....

Could you draw in this timetable for the past week what days you missed school and why?

Monday	
Tuesday	
Wednesday	
Thursday	
Friday	

Have you ever seen a counsellor at school?
..... yes ..... no

Does you teacher understand your home situation?
..... no
..... a little bit
..... yes, a lot

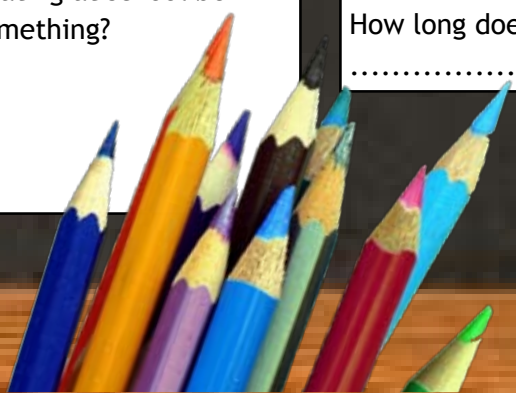
Are you ever hungry at school?
..... never
..... sometimes
..... often
..... all the time

Do you have problems concentrating at school because you're worrying about something?
..... never
..... sometimes
..... often
..... all the time

Tick if you have any of these free at school:
..... Free meal at school every day
(how many days in the past 7 days? .....)
..... Free transport (like a school bus)
..... Free school uniform
..... Free school textbooks

How do you usually get to school?
..... walk ..... taxi
..... bus ..... driven
..... train ..... bicycle

How long does it take you to get there?
..... minutes



Other kids and teenagers can be great. They can also be really mean to each other. Think about how things have been for you in the last 6 months. It would help if you answered all the questions even if you are not certain or if it seems silly!

	Not true for me	Somewhat true for me	Certainly true for me
I am usually on my own. I generally play alone or keep to myself			
I have one good friend or more			
Other people my age generally like me			
Other children or young people pick on me			
I get on better with adults than with people my age			
I try to be nice to other people			
I usually share with others			
I am helpful if someone is hurt, upset or feeling ill			
I am kind to younger children			
I often volunteer to help others			

OTHER TEENS AND ME





Now we want to know about the past year. During this year have other kids...

	Not at all	Once	2-3 times	4 or more times
Called me names or swore at me				
Tried to get me into trouble with my friends				
Took something without permission or stole things from me				
Made fun of me for some reason				
Made me uncomfortable by standing too close or touching me				
Punched, kicked or beat me up				
Hurt me physically in some way				
Tried to break or damaged something of mine				
Refused to talk to me or made other people not talk to me				

TEEN TALK CONFIDENTIAL PAGE

Questionnaire no: .....

Thank you for helping us with this. These questions are totally confidential – they will be put in a sealed envelope. Please don't write your name on this sheet.

Sometimes we get upset, or just plain angry. Can you tell us how true these are for you in the past 6 months...?

	Not true	Somewhat true	Definitely true
I cut classes or skip school.			
I run away from home.			
I use alcohol or drugs for non-medical purposes.			
I don't feel guilty after doing something I shouldn't.			
I hang around with kids who get in trouble.			
I would rather be with older kids than with kids my own age.			
I graffiti or break windows.			
I steal at home.			
I steal things from places other than home.			
I swear or use dirty language.			
I lie or cheat.			
I get very angry and often lose my temper.			
I fight a lot. I can make other people do what I want.			
I usually do as I am told.			
I carry a knife on me for protection.			
I carry a gun on me for protection.			

During the past month, how often did you drink alcohol?

Never .....
Every day .....
Several times per week .....
Once a week .....
Once a month .....

In the past year, have you used any drug to make yourself feel high? Tick any you have: (XX)

..... not at all
..... dagga
..... mandrax
..... glue
..... petrol
..... tik
..... heroin
..... benzene
..... other (what? .....)

Have you been drunk in the past month?

Yes .....
No .....

TEEN TALK CONFIDENTIAL PAGE

Questionnaire no: .....

Thank you for helping us with this. These questions are totally confidential – they will be put in a sealed envelope. Please don't write your name on this sheet.

We all know that 'having sex' can mean a lot of things. Girls can sleep with boys, girls with girls, or boys with boys. Some of them have had anal sex. When we say 'had sex', we mean any one of these!

Have you ever had sex? ..... Yes ..... No

If your answer is 'No', do not fill in the rest of this page. Go on to the next page!

1 How old were you the first time you had sex? Write down the age: .....

2 How many people have you had sex with in the past year? Write down the number: .....

3 Of these people in the past year, write down how many of them were:
..... your main boyfriend/girlfriend, or a husband/wife?
..... someone who wasn't your main partner, but you had sex with quite regularly?
..... a casual partner like a one-night stand?
..... someone you paid to have sex with?

4 If you have had sex in the past year, how often did you use condoms?
..... always
..... more than half the time
..... half the time
..... less than half the time
..... never



5 Has anyone that you've had sex with been more than 5 years older than you?
..... Yes ..... No

6 Have you ever had sex when you were drunk?
..... Yes ..... No

7 Have you ever had sex when you were high on a drug like tik, dagga or anything else?
..... Yes ..... No

8 Have you ever had sex with someone when you didn't want to because they hurt you, or you were afraid that they were going to hurt you if you didn't?
..... Yes ..... No

9 Have you ever heard of HIV/AIDS?
..... Yes ..... No

Quickly write down any things you think a person can do to avoid getting HIV, the virus that causes AIDS.

.....

.....

.....

.....

.....

.....

10 People have sex for lots of different reasons and for different benefits. Sometimes, people give presents to the person they are having sex with. Have you had any of the following presents given to you because you had sex with someone? Circle which ones:

XX

Money Buying you drinks

Clothes Cellphone airtime

A place to stay Lifts in a car/taxi

Better marks at school School fees

Food Anything else

11 HIV can be spread when people have sex. What do you think your chances of getting HIV/AIDS are?
..... no chance at all
..... a little chance
..... pretty much 50/50
..... a very big chance
..... I have been tested in the past 3 months and know my status
..... I don't know what HIV/AIDS is

12 Have you ever been pregnant or made someone pregnant?
..... Yes ..... No

13 Do you have any children? Please write their ages:
.....

Plants and animals

Some kids grow food to eat or have animals to take care of. Can you answer these quick questions about your home?

Do you or your family grow food to eat in any of these?

..... a school garden,

..... a community garden

..... at home

List any vegetables or fruit that you grow in a garden, and any animals that your family owns!

.....

.....

.....

.....

.....

NOW

MY PLANS

MY FUTURE!

What job do you want when you are grown up? What are your plans to get there?

MY JOB!



"The greatest glory in living lies not in never falling, but in rising every time we fall."

- Nelson Mandela

Caregiver consent form

Dear Parents/Guardians

We would like to invite your child to take part in research that is being run by a number of universities and by the South African government. The research will be asking about the well-being of children in South Africa. We will be talking to 6000 children in four different provinces and the research will take what children and their carers say to the South African Government and to other organisations working with children. The government will use this research to help their planning for children.

This research will be asking young people about their everyday lives, their feelings and their relationships. If you give permission, your child will fill in a questionnaire, with the help of an interviewer. This will take about an hour. Young people can choose whether they want to take part or not, and they can stop the interview at any time. Everything we are told will be treated as entirely confidential, unless children are at risk of serious harm, in which case we will try to help.

If you have any questions or worries about the research, please tell a member of our research team and they will be very happy to discuss or explain further to you.

Please fill in the slip below and let us know whether you give permission.

Thank you,

Lucie Cluver

Dr Lucie Cluver (Researcher), Cape Town Child Welfare

YoungCarers PROJECT SOUTH AFRICA

If you have any questions or complaints about this study, please contact Dr Lucie Cluver at Cape Town Child Welfare: 021 638 3127
Email: lucie.cluver@socres.ox.ac.uk

Privacy code: .....

Name of Participant	Child's grade	
Can the child I care for take part in this study?	YES	NO
Name of parent/guardian.....	Date	

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TEEN TALK

CERTIFICATE

TEEN TALK SOUTH AFRICA

.....

Has participated as an

ASSISTANT RESEARCHER

in a study for young people
in South Africa.

Thank you, and congratulations!

.....

social development
Department:
Social Development
REPUBLIC OF SOUTH AFRICA

education
Department:
Education

health
Department:
Health
REPUBLIC OF SOUTH AFRICA

UNIVERSITY OF KWAZULU-NATAL

Cape Town Child Welfare

HEARD

BROWN

UNIVERSITY OF OXFORD



Important details for you to keep

If you want to talk about anything that has come up from the study, or have a complaint about the study, you can contact:

The Young Carers Team at Cape Town Child Welfare
Lower Klipfontein Road, Gatesville,
Athlone, South Africa 8000
Email: lucie.cluver@socres.ox.ac.uk
TELEPHONE: (021) 638 3127

If you have a complaint about the ethics of the study, you can contact:

The University of Kwa-Zulu Natal Research Ethics Committee
TELEPHONE: (031) 260 3587

If you are being hurt or frightened by other people or adults, and need help, you can contact:

Childline
TELEPHONE: 0800 055 555 (toll free)

Children in Distress (CINDI)
TELEPHONE: (033) 345 7994

Police Station (local)
TELEPHONE: 10111

Sexually abused children helpline
TELEPHONE: 0800 035 553 (toll free)

If you would like some advice or information about HIV/AIDS, you can contact:

Durban HIV/AIDS Programme
TELEPHONE: (031) 311 3604

Lovelife (for advice on sexual matters)
TELEPHONE: 0800 121 900 (toll free)

YoungCarers PROJECT SOUTH AFRICA