

DEPARTMENT OF PSYCHOLOGY, UNIVERSITY OF CAPE TOWN

**The protective role of social support
for the health of caregivers of
children in HIV-endemic South Africa**

Marisa Casale

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ABSTRACT

The protective role of social support for the health of caregivers of children in HIV-endemic South Africa

Marisa Casale, June 2013

In HIV-endemic areas of Southern Africa, the increasing number of orphans and vulnerable children in need of care have been taken in mainly by the extended family. Primary caregivers of children in poor HIV-endemic communities represent a high risk population for mental and physical health conditions, as a result of health risks associated with caregiving in difficult social and financial conditions. Evidence also suggests that caregivers living with HIV, and its related stressors, may be particularly at risk for poor health.

In contexts of limited institutional support and formal health services, 'informal' support from family, friends and the broader community may constitute a valuable resource for coping and health. Research with diverse adult populations - including HIV-affected individuals and caregivers of children - has shown more social support to be directly associated with better health outcomes (main effects) and/or to buffer against negative effects of stress or specific stressors on health (stress-buffering effects). However, the protective effects of social support on health have remained vastly under-explored in the Southern Africa region. Moreover, in Southern Africa and beyond, key gaps remain in our understanding of the mediating mechanisms and pathways explaining the support-health relationship.

The objective of this mixed methods study was to investigate the relationship between social support and the (mental and physical) health of primary adult caregivers of children

aged 10-17, living in two HIV-endemic South African communities. A particular focus was afforded to the role of social support for the health of HIV-positive caregivers, compared to healthy caregivers and caregivers living with other chronic illness. A model illustrating effects and processes explaining the relationship between social support and health, published by House et al in 1988, was used as the conceptual framework to guide the design, analysis and discussion of this study.

The quantitative component of this study consisted of household survey research with 2477 primary caregivers of children in two sites in KwaZulu-Natal. Multiple linear and hierarchical logistic regression analyses were conducted, in order to test for main and stress-buffering effects of social support on symptomatic depression and anxiety, and for main effects on self-reported general health and functioning. The qualitative component of this study consisted of in-depth semi-structured interviews with 24 (12 HIV-positive and 12 HIV-negative) caregivers who had participated in the quantitative survey, in order to explore the pathways and mechanisms through which they perceived social support to be affecting their mental and physical health.

Overall, findings provide evidence of the important protective role of social support for health among this sample of caregivers, particularly for mental health. However, they also suggest that the relationship between social support and health may differ depending on caregiver characteristics, such as illness status, and the specific health outcome investigated.

Findings of the quantitative analysis show main effects of social support on symptomatic anxiety, and a stress-buffering effect of social support on symptomatic depression specifically for caregivers living with non-HIV-related chronic illness. More social support was also found to be positively associated with better self-reported mental health for all caregivers, as measured by the mental health component of the SF-12 general

health and functioning indicator. However, a significant relationship between more social support and a higher score for the physical health component of the SF-12 was found only for 'healthy' caregivers, who were not living with (HIV-related or other) chronic illness. The qualitative data indicate that multiple – direct and indirect - pathways and mediating processes may be explaining observed quantitative associations between more social support and better health outcomes. Perceived mediating mechanisms included psychological resilience factors, coping processes and more positive health behaviours.

Findings suggest that greater attention should be paid to the social environment when designing and implementing caregiver health interventions and that social support could be a valuable component of these interventions. Pathways and mediators highlighted by the qualitative work should best be further investigated by future quantitative research with representative caregiver populations.

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This thesis focuses on the importance of social support for health and wellbeing. And without a doubt its completion would not have been possible without the emotional and instrumental support of many people, including friends, family, colleagues, study participants, mentors and members of the broader academic community.

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I would also like to thank members of the two communities we worked in, for allowing me and the research teams access to their communities, and for supporting us. This includes the Ward Councillors and members of the Community Policing Forum (CPF) in Lamontville, and the tribal leaders and our NGO partner (Tholulwazi Uzivikele) in Manguzi. And of course the important contribution of all members of the field research and data teams, who worked on both the survey and qualitative study, deserves acknowledgement.

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PUBLICATIONS AND PRESENTATIONS THIS DOCTORAL WORK HAS CONTRIBUTED TO

The work included in this thesis has contributed to a number of papers and presentations, including recent publications in international peer-reviewed journals. These are listed below. As first author of these publications, I took the lead in developing the conceptual arguments and analytic design, conducting the analysis and writing up the papers. I believe that the peer-review publication processes for these articles have provided valuable feedback on certain aspects or sections of this doctoral work, which has been useful in helping refine and strengthen the research presented in this thesis.

Peer-reviewed journal articles

Casale, M., Wild, L., Cluver, L., & Kuo, C. (In press). The relationship between social support and anxiety among caregivers of children in HIV-endemic South Africa. *Psychology, Health and Medicine*.

Casale, M., & Wild, L. (2013). Effects and processes linking social support to caregiver health among HIV/AIDS-affected carer-child dyads: a critical review of the empirical evidence. *AIDS and Behavior*, 17(5), 1591-1611.

Casale, M., Wild, L., & Kuo, C. (2013). "They give us hope": HIV-positive caregivers' perspectives on the role of social support for health. *AIDS Care*. doi:10.1080/09540121.2013.763893.

Casale, M., Lane, Y., Sello, L., Kuo, C., & Cluver, L. (2013). Conducting health survey research in a deep rural South African community: challenges and adaptive strategies. *Health Research Policy and Systems*. doi:10.1186/1478-4505-11-14.

Casale, M., & Wild, L. (2012). The relationship between social support and the health of HIV-positive caregivers of children: a review of the empirical literature. *Vulnerable Children and Youth Studies*, 7(3), 260-282.

Invited book chapter

Casale, M., & Wild, L. (2013). Family and community support matters for the health of people living with HIV: A discussion of the existing literature and key areas for future research. In A. Pallotti, & M. Zamponi, (Eds), *HIV/AIDS in Southern Africa: challenges, policies, actors*. Villa Verucchio, Italy: La Pieve Poligrafica Editore.

Regional and international conference presentations

Casale, M. (2013). *Social support as a protective resource for depression among female caregivers of children in HIV-endemic South Africa*. Paper presented at the World Mental Health Congress, Buenos Aires, Argentina.

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Casale, M., Wild, L., Kuo, C., & Cluver, L. (2013). *The protective role of social support for mental health among caregivers of children in HIV-endemic South Africa*. Paper presented at the 6th SA AIDS Conference, Durban, South Africa.

Casale, M., Wild, L., Kuo, C., & Cluver, L. (2012). *The relationship between social support and self-reported health among HIV-positive and HIV-negative caregivers of children in two HIV-endemic South African communities*. Paper presented at the XIX International AIDS Conference. Washington, DC, USA.

Casale, M., Sello, L., Lane, T., Cluver, L., & Kuo, C. (2011). *Snakes, sand and Satanists: Fieldwork challenges of HIV/AIDS research in rural South Africa*. Paper presented at the 5th SA AIDS Conference, Durban, South Africa.

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List of abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ANOVA	Analysis of variance
ART	Antiretroviral therapy
ARV	Antiretrovirals
BAI	Beck Anxiety Inventory
CBO	Community-based organisations
CES-D	Centre for Epidemiologic Studies Depression Scale
CHBC	Community home-based carer
CPF	Community policing forum
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
EAI	Economic asset index
GIS	Geographic information system(s)
HBC	Home-based carer
HEARD	Health Economics and HIV and AIDS Research Division
HIV	Human Immunodeficiency Virus
KZN	KwaZulu-Natal
MOS-SSS	Medical Outcomes Study – Social Support Survey
NGO	Non-governmental organisation
PI	Principal Investigator
PLWHIV	People living with HIV
PTSD	Post-traumatic stress disorder
RCT	Randomized control trial
SF-12	Short Form-12
TB	Tuberculosis
UCT	University of Cape Town
UKZN	University of KwaZulu-Natal
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDP	United Nations Development Program
UNICEF	United Nations Children’s Fund
USA	United States of America
USAID	United States Agency for International Development
VA	Verbal Autopsy
WHO	World Health Organization

“One of the reasons social support is such an important feature of life is that, while how it is expressed might change, feelings of acceptance, belongingness and being valued by others stay with us all our lives” (Sarason & Sarason, 2009, p. 120).



“Things have never been easy in life, but the main thing is to feel free emotionally or to be free emotionally, so when I get advice or support, that helps me.” (Male caregiver with non-HIV-related health condition).

“If you give them [HIV-positive individuals] hope, you have done everything, hope for them means ‘I will survive’. It is very important because I can give you money, you can do whatever but if you tell yourself that ‘I will survive’, you will survive ... because when you are taking that pill, you are taking it because ‘I want to get well.’ ” (HIV-positive female caregiver).

CHAPTER 1: INTRODUCTION

1.1 Background

1.1.1 Health risks associated with HIV and caregiving

In Southern Africa and other parts of the developing world, HIV constitutes a key risk factor for poor physical and mental health. This is both a result of the direct effects of illness on HIV-positive individuals (Folkman, Chesney, Pollack, & Coates, 1993; Linn, Poku, Cain, Holzapfel, & Crawford, 1995) and the broader social consequences of the disease (Barnett & Whiteside, 2006). Sub-Saharan Africa is by far the world's most affected region: nearly 1 in every 20 adults (4.9%) in sub-Saharan Africa is reported to be living with HIV, accounting for 69% of the global HIV-positive population (UNAIDS, 2012).

Individuals living with an HIV-positive diagnosis and/or HIV-related illness may face multiple stressors, including experiences of physical illness, financial stress, concerns around disclosure, social isolation, stigma and fear of death (Clucas et al., 2011; Sherr et al., 2012; World Health Organisation, 2008). The physical health effects of HIV are well known and documented (World Health Organisation, 2005). However, there is also ample evidence showing that individuals who are HIV-positive and/or experiencing more HIV-related symptoms are likely to have worse mental health (Breuer, Myer, Struthers, & Joska, 2011; Leserman, 2003; Sherr, Clucas, Harding, Sibley, & Catalan, 2011; World Health Organisation, 2008). This is not surprising, given that the presence of many other serious

medical illnesses has been associated with poorer mental health (Ciesla & Roberts, 2001; Rodin & Voshart, 1986). However, research also suggests that the mental health effects of living with HIV may derive from the social, as well as health, consequences of the disease (Ciesla & Roberts, 2001).

At the same time, the increasing number of orphans and vulnerable children in need of care is arguably the greatest social impact of this “long wave event” epidemic (Barnett & Whiteside, 2006). In HIV-endemic areas, the epidemic has significantly contributed to the demand for child care, and this phenomenon is likely to increase further as the social consequences of the epidemic continue to unfold. Once again Southern Africa is the world’s most affected region, as almost 90% of the approximately 17 million children orphaned as a result of AIDS world-wide are estimated to live in sub-Saharan Africa (UNAIDS, 2010). Moreover, this figure does not include other orphans and vulnerable children in need of care. The majority of these children have to date been cared for by the extended family. Though considered a better option for children than institutional care, this places significant strain on ‘informal’ caregivers, most of whom are women (Kuo & Operario, 2009; Steinberg, Johnson, Schierhout, & Ndegwa, 2002; Yamano, Shimarura, & SSerunkuuma, 2006).

Caregivers of children in HIV-endemic Southern Africa likely represent a high risk population for mental and physical health conditions. Research from Southern Africa and beyond shows that stress derived from caregiving responsibilities may also lead to increased mental and physical health risks, especially in conditions of poverty and other livelihood stressors (Belue, Schreiner, Taylor-Richardson, Murray-Kolb, & Beard, 2008; Casale, 2011; Howard et al., 2006; Leder, Grinstead, & Torres, 2007; Pinquart & Sorensen, 2007; Ssengonzi, 2009). Caregivers of children who are also living with HIV or other illness may be a particularly high risk population for (mental and physical) health conditions, as they would be facing both stressors related to caregiving and stressors related to illness.

These risks are particularly salient in Southern African countries dealing with high rates of HIV and other physical and mental health challenges (Herman et al., 2009; Norman, Bradshaw, Schneider, & Groenewald, 2006; Patel, 2007; UNAIDS, 2010). For example, South Africa's first national burden of disease estimates showed that physical illnesses accounted for 17 of the 20 top leading causes of deaths in the country¹ (Norman, et al., 2006). The first nationally-representative South African study of common mental disorders estimated that approximately 30% of the population experienced a lifetime mental disorder (Herman, et al., 2009). Though exact rates are not directly comparable due to different measurement tools used, recent survey research conducted with caregivers of children in a poor HIV-endemic community in South Africa's KwaZulu-Natal province points to a particularly high prevalence of mental health conditions among this population: over 60% of caregivers were found to be experiencing moderate or high anxiety and 30% met the threshold for clinically significant depression (Kuo & Operario, 2011). These findings are concerning, not only with regard to the wellbeing of caregivers, but also for the children in their care, as worse caregiver health has been shown to pose challenges for both parenting and child health (Smith Fawzi et al., 2010; Stein, Ramchandani, & Murray, 2008).

¹ These 17 physical ailments included: HIV/AIDS, ischaemic heart disease, stroke, tuberculosis, lower respiratory infections, diarrhoeal diseases, hypertensive heart disease, diabetes, chronic obstructive pulmonary disease, low birth weight, nephritis/nephrosis, trachea/bronch/lung cancer, asthma, septicemia, oesophageal cancer, cirrhosis of liver, and protein-energy malnutrition. Physical illnesses accounted for a large percentage of years of life lost with HIV ranking as the highest cause of all years of life lost (35%) followed by tuberculosis (5.5%), diarrhoeal disease (5.0%), and lower respiratory infections (5.0%) (Norman et al. 2006).

1.1.2 The potential protective role of social support for health

It has been argued that: “One of the reasons social support is such an important feature of life is that, while how it is expressed might change, feelings of acceptance, belongingness and being valued by others stay with us all our lives” (Sarason & Sarason, 2009, p. 120).

Besides being an important feature of life, social support has also been shown to be an important resource for health. The positive role of social support in relation to health has been described simply as “... supportive relationships that directly provide something that people need to stay healthy or adapt to stress.” (House, Umberson, & Landis, 1988, p. 302). This ‘something’ refers to various types of support, which may include emotional support, such as love or care, or instrumental support, such as tangible items or practical assistance (House & Khan, 1985).

Social support has been shown to be a protective factor for both mental and physical health among various adult populations. Over the past four decades numerous empirical studies have shown a positive relationship between more social support and better mental and physical outcomes among ill and healthy adults (Barrera, 1986; S. Cohen & Wills, 1985; House, Umberson, et al., 1988; Lakey & Cronin, 2008; Thoits, 2011; Uchino, Bowen, Carlisle, & Birmingham, 2012). Social support has been found to have both a direct relationship with better mental health (that is, to have main or general health sustaining effects) and to buffer effects of stress or specific stressors on mental health (S. Cohen & Hoberman, 1983; House, Umberson, et al., 1988). The important protective role of social support for health has also been highlighted by its relationship with lower mortality risk. There is perhaps no better example than a recent (2010) meta-analytic review, covering data

from 308,849 individuals over an average of 7.5 years, which found participants with stronger relationships (including dimensions of social support) to have a 50% increased likelihood of survival, after controlling for initial health status (Holt-Lanstad, Smith, & Layton, 2010). The influence of social relations on mortality risk was thus shown to be “comparable with well-established risk factors for mortality” (Holt-Lanstad, et al., 2010, p. 12) such as obesity and physical inactivity.

More specifically, social support has been shown to be positively associated with better health outcomes among caregivers of children (Gerard, Landry-Meyer, & Guzell Roe, 2006; Musil, Warner, Zauszniewski, Wykle, & Standing, 2009) and HIV-positive individuals (Linn, Lewis, Cain, & Kimbrough, 1993; Martinez, Israelski, Walker, & Koopman, 2003; Serovich, Kimberly, Mosack, & Lewis, 2001). Similarly to findings of studies with broader adult populations, social support has been found to have a direct relationship with better health outcomes among these populations, as well as to buffer against effects of HIV- and caregiving- related stressors on mental health (Musil, et al., 2009; Ray & Ritchie, 1993; Robbins et al., 2003; Tsai & Wang, 2009).

1.2 Research gaps and rationale for this doctoral work

In many Southern African contexts of overstretched formal health systems and low uptake of available services (Howard, et al., 2006; Seedat et al., 2009; World Health Organisation, 2011), the potential protective role of informal community or social resources for caregiver and HIV-affected populations beckons greater attention. Informal social support, from friends, family and the broader community, may constitute a particularly

important resource for coping and health, and may be the key to more effective caregiver health interventions. Qualitative research conducted in HIV-affected Southern African communities suggests, in fact, that family and community support and reciprocity are a key resource for caregivers who are coping with financial and emotional hardship (Campbell, Nair, Maimane, & Sibiyi, 2008; Casale, 2011; Kiggundu & Oldewage-Theron, 2009).

Exploring the potential protective effects of informal social support on health with similar under-researched and vulnerable populations is especially important in light of evidence that these effects are not uniform across groups in society, but may depend on the interaction of factors such as the types of stressors, types of support and the individual context (Kawachi & Berkman, 2001; Li, Seltzer, & Greenberg, 1997; Wallen & Lachman, 2000). However research on social support and health has remained vastly under-explored in Southern Africa. Most of the literature documenting the protective effects of social support on health among caregivers and/or HIV-positive individuals is based on studies conducted in the developed world, and predominantly in the United States. The few quantitative studies on social support and health conducted in Southern Africa have, however, shown more social support to be associated with better health outcomes among various adult populations (although not with caregivers of children or HIV-positive adults specifically). For example, social support has been associated with better physical functioning and general health among the elderly (Ice, Zidron, & Juma, 2008), better physical and psychological health among low-income individuals (Moroka, 2005) and better reported physical and mental health among carers of AIDS-affected individuals (Bakasa, 2007)².

Moreover, in Southern Africa and beyond, key gaps remain in our understanding of the mediating mechanisms and pathways explaining the observed protective effects of social support for health (Sarason & Sarason, 2009; Uchino, et al., 2012). Social support is, in fact,

² These studies worked with respective samples of 287 and 133 participants.

hypothesised to positively impact health outcomes through various, potentially co-existing, pathways and processes. It may have a direct independent effect on health (main effects), or may buffer against the effects of stressors on health (stress-buffering effects) (House, Umberson, et al., 1988). These effects may, in turn, be direct or mediated through – potentially multiple – biological, psychological and behavioural processes, that include promoting self-esteem, encouraging positive health behaviours, and increasing access to resources that help cope with stress (Heaney & Israel, 1997; House, Landis, & Umberson, 1988; Lakey & Cohen, 2000; Thoits, 1982).

Various key authors in the field of social relations and health have highlighted the importance of moving beyond ‘first order’ questions of *whether* social relations influence health, to also provide answers to ‘second order’ questions, of *how* and *why* they do so. Better understanding the mechanisms explaining the support-health relationship is deemed essential in order to refine theory and design more effective interventions (Sarason & Sarason, 2009; Thoits, 2011). To this end, it has been argued that greater attention should be paid – among other things - to the conceptualisation of support and the support context (Uchino, et al., 2012). This would include more openness to refining hypothesised links and models and to identifying potential new mediating mechanisms to inform this process (Uchino, et al., 2012).

In sum, the literature suggests that, in order to achieve a good understanding of the relationship between social support and health among specific adult populations (such as HIV-affected caregivers in Southern Africa) it would be important to investigate both the existence and direction of possible associations between social support and health outcomes, as well as the pathways and mediating processes that may be explaining these associations.

1.3 Purpose, research questions and overall methodological approach of this study

This study aims to contribute to the research gaps described above by conducting mixed methods research. The overall purpose of the study is to investigate the relationship between social support and the (mental and physical) health of caregivers of children, from two HIV-endemic South African communities. The study aims to (quantitatively) determine whether social support is a protective factor for caregiver health, and (qualitatively) explore the perceived pathways and mechanisms explaining the support – health relationship. Moreover, this research has a particular focus on the protective role of social support for the health of HIV-positive caregivers, compared to caregivers living with other chronic illness and to ‘healthy’ caregivers.

More specifically, this study aims to address the following general research questions, which will be discussed in further detail and broken down in the respective chapters describing the quantitative and qualitative component methods (Chapters 5 and 7) :

1. Is living with HIV/AIDS a risk factor for depression and anxiety among caregivers of children, and how does this compare to living with other chronic illness?
2. Does social support have a main effect on caregiver depression and anxiety and/or buffer against the effects of HIV/AIDS- and other illness- related stressors on depression and anxiety?
3. Is more social support associated with better self-reported general health and functioning among caregivers living with HIV/AIDS, caregivers living with other illness and healthy caregivers respectively?

4. What are the perceived pathways and mediating processes explaining the relationship between social support and caregiver health?

An explanatory sequential mixed methods research design was employed to address these general and specific research questions, in that quantitative and qualitative data were collected and analysed in two consecutive phases within this study and the second phase (qualitative component) was informed by and intended to provide further insight on findings of the first phase (quantitative component) (Ivankova, Creswell, & Stick, 2006).

Mixed methods research has been defined as “a procedure for collecting, analysing and ‘mixing’ or integrating both quantitative and qualitative data at some stage of the research process within a single study for the purpose of gaining a better understanding of the research problem” (Ivankova, Creswell, & Stick, 2006, p. 3). This choice is motivated by the fact that neither quantitative nor qualitative methods are in themselves sufficient to capture the details of a particular situation. Instead, together, they allow for a more robust analysis which includes the strengths of each type of method, and allows for the use of a wider range of research tools (Green, Caracelli & Graham, 1989). While quantitative research is less subject to personal interpretations and its findings are more easily generalisable, qualitative research is more effective at providing an understanding of the research context, and participants’ voices. The rationale for a mixed methods sequential explanatory design of this nature is that the quantitative data and analysis provide a general understanding of the research problem, while the qualitative analysis is able to refine and further explain the quantitative results, by exploring participants’ views (Ivankova, Creswell, & Stick, 2006; Creswell, Piano Clark, Gutmann & Hanson, 2003).

Specifically, in this study main and stress-buffering effects of social support on health were investigated through (primary) quantitative analysis of survey data, whereas perceived

pathways and mediating variables explaining these observed effects were explored qualitatively. Each of the two components was given more or less equal weight in this study.

The quantitative component consisted of a cross-sectional survey with 2,477 primary adult caregivers (18+) of children between 10 and 17 years, in a respective urban and rural site in KwaZulu-Natal, South Africa. The survey data was collected in 2009 and 2010. It was part of a larger health survey, with both caregivers and children, for which the doctoral candidate was Co-Investigator and Project Manager. The qualitative component was designed and conducted by the doctoral candidate, following preliminary quantitative analysis of the survey data. It consisted of in-depth semi-structured interviews with 24 purposively-chosen caregivers who had participated in the quantitative survey. These two respective components will be described in greater detail in Chapters 5 and 7 of this thesis. The four general research questions guiding this thesis, outlined above, were each addressed through either analysis of the quantitative data or analysis of the qualitative data. These general research questions, and a summary of the methods used to address each of these, are illustrated below in Table 1.1. Moreover, a critical reflection on both the quantitative and qualitative findings served to highlight further insight on the conceptualisation and measurement of social support among this population of caregivers that may have emerged from this work, of relevance for future studies. This will be addressed in the concluding chapter of this thesis (Chapter 9).

Table 1.1. General research questions and methods used to address these

1) Is living with HIV/AIDS a risk factor for depression and anxiety among caregivers of children, and how does this compare to living with other chronic illness?

- Methods: hierarchical logistic regression analysis of quantitative data

2) Does social support have a main effect on caregiver depression and anxiety and/or buffer against the effects of HIV/AIDS- and other illness- related stressors on depression and anxiety?

- Methods: hierarchical logistic regression analysis of quantitative data, with interaction terms

3) Is more social support associated with better self-reported general health and functioning among HIV-positive, other ill and healthy caregivers respectively?

- Methods: linear regression analysis of quantitative data

4) What are the perceived pathways and mediating processes explaining the relationship between social support and caregiver health?

- Methods: thematic analysis of qualitative data

This particular mixed methods study design was chosen, as it was deemed best suited to the study purpose and research questions, informed by the methodological and conceptual gaps identified through the theoretical and empirical literature reviews conducted (to be described further in Chapters 2, 3 and 4). As indicated above, this work aimed to both test for the existence of (main and stress-buffering) effects of social support on caregiver health outcomes, as well as explore the potential processes or pathways through which these may be

occurring. The main advantage of working with a larger health survey dataset was that it allowed for analysis of quantitative associations between social support and health outcomes with a large caregiver sample (n=2477), which is resource-intensive and would not otherwise have been possible to achieve through this doctoral work. However, a key limitation was that constructs included in the quantitative analysis were necessarily limited to variables included in the broader survey, of which social support was only one component. Since the quantitative dataset did not contain the potential biopsychosocial mediating variables of interest for this analysis, the qualitative component of this study was designed to address this gap. Perceived mediating pathways and processes between social support and health were therefore explored qualitatively. It should, however, be noted that, while the qualitative work had the disadvantage of limited generalizability, it also had the strength of providing a more exploratory approach, to potentially allow less-examined mediators and pathways to emerge from the data (Uchino, et al., 2012). Also, the duration of the study and available funding allowed for the qualitative data to be collected in a second follow-up phase (sequential design), once the quantitative data had been analysed.

Both the quantitative and qualitative samples may be divided into comparison groups of caregivers living with HIV/AIDS, caregivers living with other illness, and caregivers without a health condition. The value of the two reference groups (healthy and other ill) is that they allow for an investigation of: a) whether the presence of HIV/AIDS specifically, as opposed to chronic illness more generally, poses a particular risk for mental health (Ciesla & Roberts, 2001; Kuo & Operario, 2011); b) whether social support plays a different or greater role in buffering HIV/AIDS-related stressors versus stressors related to other illness; c) associations between social support and self-reported general health and functioning for HIV-positive, other ill and healthy caregivers respectively and; d) whether there are differences in

the perceived pathways and mechanisms explaining the support-health relationship between sub-groups of HIV-positive, other ill and healthy caregivers.

1.4 Conceptual framework

A model developed by House et al (House, Umberson, et al., 1988) was used as a conceptual framework to guide the design of this research, the diagrammatic representation of findings, and their discussion in relation to the broader theory and empirical literature on social support and health. The House et al framework illustrates the positioning of social support within the broader structure of social relationships, as well as the potential effects and biopsychosocial mediating processes through which social support may affect mental and physical health outcomes. This particular framework was chosen because it recognises the complexity of the relationship between social support and health, and is comprehensive in its illustration of and distinction between the potential (stress-buffering and main) effects of social support and the processes explaining these. The model was developed drawing from the authors' reviews of previous empirical and theoretical literature on social relations and health, most of which derived from Northern Europe and the United States (House, Umberson, et al., 1988).

The House et al framework is illustrated below in Figure 1.1, and will be discussed in greater detail in Chapter 2. Figure 1.1 includes the entire House et al model, with the associations of interest for this study highlighted in bold text and colour. The *e* pathway represents direct main effects of social support on health (in the absence of mediation), while the *b/d* pathway illustrates main effects mediated by biopsychosocial mechanisms. The *a*

pathway represents direct buffering effects against psychosocial stress/stressors (in the absence of mediation), while the *b/c* pathway illustrates buffering effects mediated by biopsychosocial mechanisms.

Figure 1.1. Framework to illustrate structures and processes of social relationships in relation to health (House, Umberson, et al., 1988, p. 303).

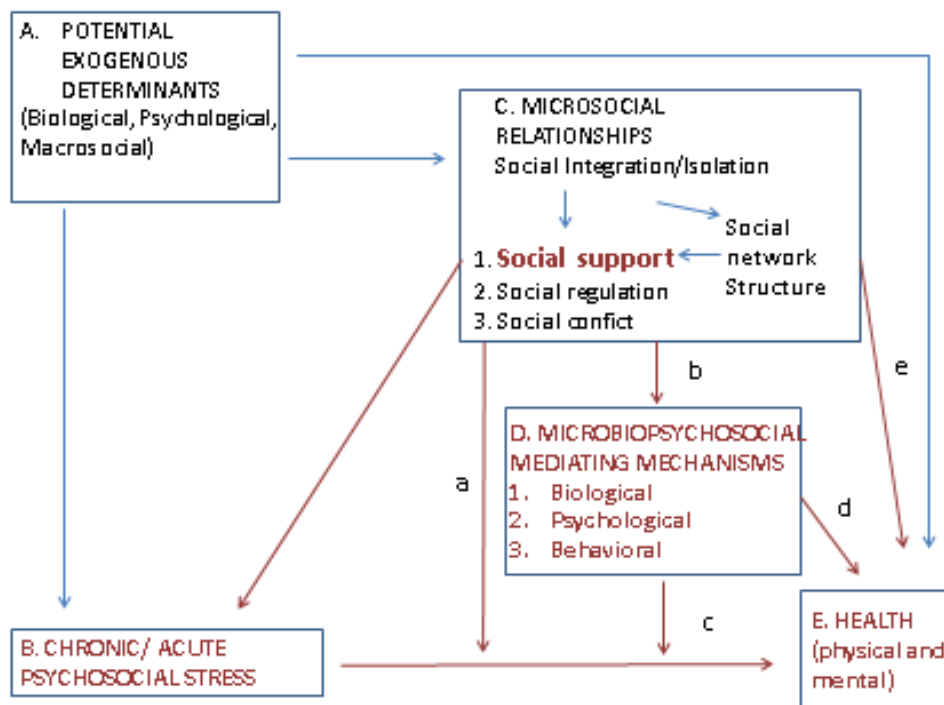
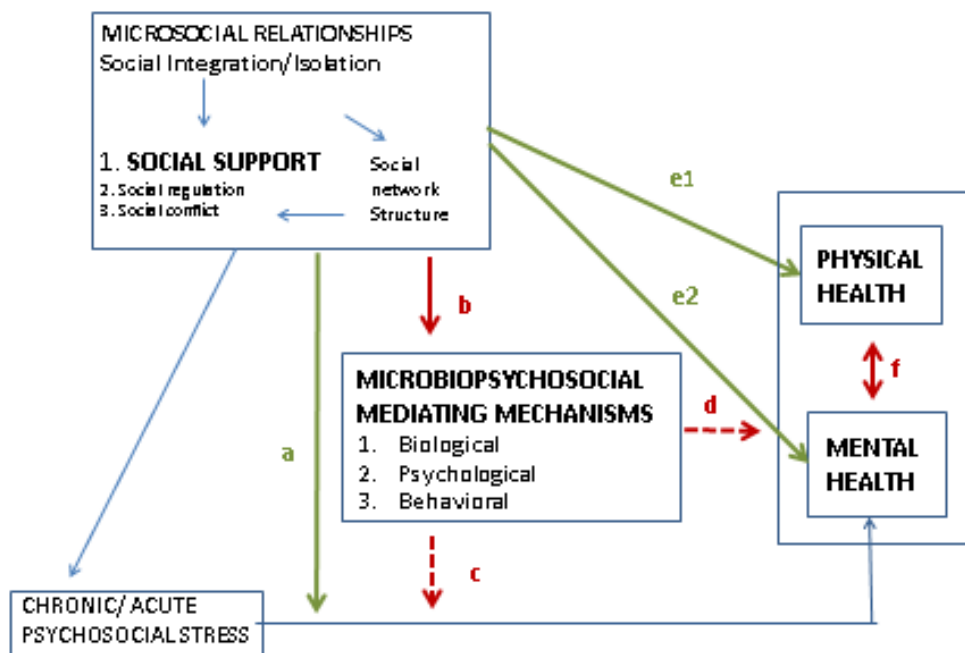


Figure 1.2 below, taken from a section of the House et al theoretical framework, shows the effects and processes that this study aims to investigate. The green arrows in the diagram illustrate the associations to be explored quantitatively, namely direct main effects (*e1* and *e2*) and stress-buffering effects (*a*) of social support on health. The red arrows represent the relationships to be explored qualitatively, namely the biopsychosocial mediating

mechanisms linking social support to mental and physical health outcomes. For the purpose of this research, the stressors of interest (represented by the ‘chronic/acute psychosocial stress’ box in the diagram) will refer to stressors related to living with HIV or other illness. The red arrows with interrupted lines (*c* and *d*) indicate that biopsychosocial mediating processes identified through the qualitative work may be explaining main effects, stress-buffering effects or both.

Figure 1.2. Diagrammatic representation of the associations and pathways to be investigated quantitatively and qualitatively by this study



The above House et al model is referred to multiple times throughout this thesis, as a framework to illustrate and discuss findings of the systematic literature review, the

quantitative analysis and the qualitative analysis. The model is also used, in the final discussion, to highlight potential linkages between quantitative and qualitative results.

1.5 Importance of this research and unique contribution to the literature

This study has the potential to make a unique contribution to the existing literature on social relations and health, for various reasons. First, it works with an important and under-researched population: caregivers of children living in HIV-endemic Southern Africa. This research was conducted in KwaZulu-Natal, one of the highest HIV-affected areas of South Africa and the world. The quantitative component alone makes this the first study of this dimension to investigate associations between social support and health among caregivers of children in HIV-endemic Southern Africa. Moreover, no known previous studies in the region have investigated these relationships with comparison groups of HIV-positive, other ill and healthy caregivers.

Second, this is the first known study conducted in Southern Africa to investigate both effects and processes explaining the support-health relationship, through mixed methods research. As a result, it is uniquely placed to contribute to the broader empirical evidence and theory in this area. The opportunity to conduct the qualitative component subsequent to preliminary quantitative analysis allowed the qualitative work to be informed by and to further qualify the quantitative findings. As is evident from the literature on social support and health, this type of mixed methods research has the potential to add particular value to the existing literature, given the well-documented need to achieve a better understanding of pathways and processes explaining observed links between social support and health.

Lastly, the positioning of the quantitative component of this research within a broader health survey, conducted with both children and caregivers, means that it is well-placed to inform future cross sectional analyses linking caregiver and child outcomes; for example to explore whether parental social support may be directly or indirectly associated with child health or developmental outcomes. It is also well-positioned to inform policy and practice. The larger study is a collaboration between various South African and international universities, South African national government departments and the National Action Committee for Children affected by AIDS (NACCA), and is currently being undertaken in three South African provinces. Key findings of this research can, therefore, be disseminated as part of the larger study's utilisation activities. Given the existing partnerships with government departments and NGOs, the channels for using findings from this research to inform policy and practice are already in place.

1.6 Structure of this thesis

This thesis consists of nine chapters which are organised as follows:

Chapter 2 synthesises the key international theoretical and empirical literature on social relations and health. It describes, in more detail, the House et al theoretical framework (House, Umberson, et al., 1988) chosen to guide the design, analysis and discussion of this research. Lastly, it provides a brief discussion of key findings and research gaps of the international empirical work on social support and health conducted to date, in relation to the House et al theoretical framework.

Chapter 3 describes the methodology and findings of the systematic literature review, carried out in order to consolidate the existing literature quantitatively assessing the relationship between social support and health among caregivers of children living with HIV. Methodological characteristics and findings of relevant studies identified are presented. Research gaps and key potential foci for future research are also discussed, taking into consideration the methodological limitations of studies reviewed and the House et al theoretical framework.

Chapter 4 presents a review of the broader literature, conducted to synthesise findings of empirical research with populations of HIV-positive adults and caregivers of children respectively. It presents and discusses literature documenting the respective health risks of caregiving and of living with HIV, as well as literature showing protective effects of social support on health among populations of caregivers of children and/or HIV-positive individuals. This review takes into account the global literature, but specifically highlights studies pertaining to Southern Africa, the region of interest for this study. A brief discussion on research gaps in relation to this empirical literature is also included.

Chapter 5 describes, in greater detail, the objectives and methodology of the quantitative (survey) component of this research. This includes the quantitative research design, a description of the study sites, methodological tools and instruments used, the data management, the quantitative analysis approach and ethics considerations.

Chapter 6 presents the quantitative (survey) findings of this study. Specifically, it provides descriptive data for the entire caregiver sample and sub-samples of interest (HIV-positive, other ill and healthy caregivers), and presents results of the bivariate and multivariate analyses conducted to quantitatively assess the relationship between social support and (mental and physical) health outcomes among caregivers.

Chapter 7 describes the qualitative methodology. Similarly to the description of the quantitative methodology, this chapter documents the qualitative component research design, the sampling strategy and frame, the data collection tools and process, the qualitative analysis approach and ethical issues.

Chapter 8 then presents and discusses the findings of the qualitative data, with the objective of providing further insight on, and possible explanations for, the quantitative findings presented in Chapter 6. More specifically, the analysis of this data aims to further explore the perceived pathways and processes explaining the relationship between social support and health for this sample of caregivers of children. These factors and pathways are illustrated in the form of a diagrammatically illustrated exploratory model, developed by drawing from the House et al theoretical framework.

Finally, Chapter 9 contains the overall discussion and conclusion of this mixed methods study. Both quantitative and qualitative results are considered in relation to the House et al (1988) theoretical framework. This final chapter discusses findings on both the observed effects of social support on caregiver health outcomes, and the processes or pathways through which social support was perceived to be affecting health. Implications for social support and health theory are considered, as are implications for future research and practice.

CHAPTER 2. KEY THEORETICAL AND EMPIRICAL LITERATURE ON SOCIAL SUPPORT AND HEALTH

The purpose of this chapter is to introduce the construct of social support, synthesise the key international theoretical and empirical literature on the social support – health relationship, and describe the theoretical framework used as a reference to guide this research. The first part of this chapter will introduce the construct of social support, as well as its various sub-constructs and dimensions, indicating the dimensions of interest for this study. The second part will present, in greater detail, the House et al theoretical framework chosen to guide the design and analysis of this research (introduced briefly in Chapter 1). The last two sections of this chapter will synthesise the seminal theoretical literature in the area of social support and health, as well as overall trends and gaps emerging from the global empirical literature on effects and processes linking social support to health.

2.1 Definitions, constructs and dimensions of social support

Social support has been defined in simple terms as “a measure of how much help you can count on, or believe you can count on, from your friends and family, especially in crises and hard times” (Lara, Leader, Klein, & Kendler, 1998; p. 6). House et al (1988) describe the importance of social support in relation to health as “... supportive relationships that directly provide something that people need to stay healthy or adapt to stress.” (House, Umberson, et

al., 1988, p. 302). Social support is a meta-construct, embracing multiple sub-constructs or dimensions of social relationships. In fact, some of the complexities of conducting research on social support derive from its multi-dimensional nature and the diversity of definitions and measurement tools used. Dimensions of social support may include (i) the existence, quantity and type of interpersonal relationships (network structure or social interaction), (ii) the functional content of social relationships (e.g. types of support provided, including emotional and tangible support), and (iii) the perceived quality or adequacy of this support (Green, 1993; Haber, Cohen, Lucas, & Batles, 2007; House & Khan, 1985; Vaux et al., 1986). With regard to the functional content of social relationships (point ii above), the construct of 'social support' therefore invariably encompasses the functions performed for an individual by support providers (Thoits, 2011). These functions, or 'types' of support, are most frequently categorised as emotional, informational and instrumental assistance (House & Khan, 1985). Emotional support includes demonstrations of love, care, esteem and sympathy, while informational support involves the provision of advice or facts that could, for example, help deal with a difficult situation or solve a problem (Thoits, 2011). Appraisal support is sometimes considered an element of informational assistance, and sometimes as a separate function of support; this refers to feedback, constructive encouragement and guidance, for example on an individual's performance in an area or possible courses of action to take. Lastly, instrumental support refers to more tangible behavioural or material assistance (e.g. help in carrying out practical tasks or providing money or other items). These functional aspects of social support are distinct from, but also linked to, the structural aspects of support, in that the amount and types of support accessible and/or received will ultimately depend on an individual's structural ties, including social network size and the type of relationships (Thoits, 2011). It should, however, be noted that measures of functional aspects of support have been found to be more important for health outcomes than structural properties of

support, in that functional dimensions of support have been found to be more strongly and frequently associated with better mental health outcomes, than structural aspects of support. This is especially the case with regard to stress-buffering effects (S. Cohen & Wills, 1985; Ryan & Willits, 2007).

Moreover, measures of perceived social support - based on the perception of how available and adequate this support is - appear to be more strongly and consistently linked to mental health outcomes than retrospective measures of actual support received (House, Umberson, et al., 1988; McDowell & Serovich, 2007; Peterson & Govender, 2010). It is hypothesised that enacted support (actual support received) influences perceptions of support availability but that it is only one determinant of perceived support. The independence of these two constructs is, in fact, supported by empirical findings. For example, a 2007 meta-analysis of studies measuring received support (using the Barrera et al 1981 Inventory of Socially Supportive Behaviours) and perceived support (using any measure) showed that received support accounted for a part of the variance of perceived support (about 10-15%), but that there were other determinants explaining the larger part of the variance (Haber, et al., 2007). There are various possible explanations for differences in perceived and enacted support. First, support received may be confounded with the severity of stress and support needs, as individuals would more likely seek or receive support in the presence of challenging situations. Second, support received may refer to a shorter timeframe or particular stressful situation, while perceptions of available support may derive from generalisations based on multiple past or regular daily experiences of support (Thoits, 2011). Third, perceived support may also be influenced by individual differences in perceptions, memory and value judgments of relationships and broader social contexts (Haber, et al., 2007; Sarason & Sarason, 2009). Given the observed importance of perceived support for

health, it has even been argued that received support may improve health outcomes only to the extent that it modifies perceived support (Haber, et al., 2007).

As is clear from the above, outcomes of empirical work investigating the relationship between social support and health will in part depend on the social support construct and measurement tool used, as well the specific health outcomes researched. It has been argued that the lack of consensus on how social support should be conceptualized is reflected in its measurement (Green, 1993), in that there is a multiplicity of methodologies and instruments that may be measuring slightly different constructs; thus, strengthening links between constructs about the nature of support and how it is assessed is deemed to be essential (Sarason & Sarason, 2009). This also implies that attention needs to be paid to the constructs and tools used for specific analyses, and that these should be taken into account when considering findings.

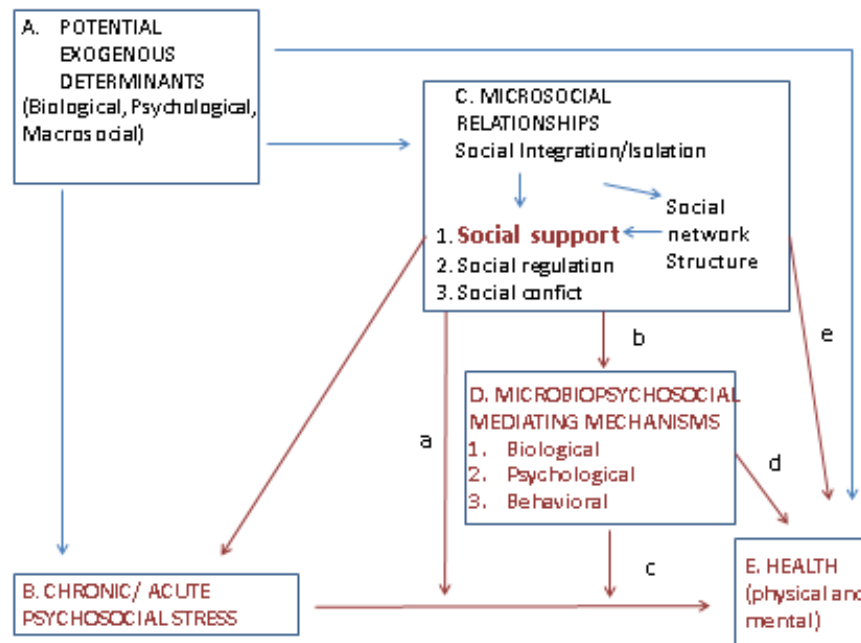
The social support construct chosen for this study is perceived availability of support, given the evidence of a closer relationship between perceived (versus enacted) support and health outcomes, and the lower risk of this construct being confounded with recent support needs, as described above. Moreover, this work will focus on the functional (versus structural) aspects of social relations, that is: the type, nature and perceived amount of support received, as opposed to the size and nature of an individual's social network. These dimensions of social support are incorporated in the measurement tool used for the quantitative analysis of this study (the Medical Outcomes Study Social Support Survey or MOS-SSS; see Sherbourne & Stewart, 1991), which measures perceived availability of functional support (including emotional support, informational support, tangible support, positive social interaction and affection). They were also used to guide the design of the

qualitative instrument and analysis. These tools will be described in more detail in the methods chapters (Chapters 5 and 7) of this thesis.

2.2 Theoretical framework illustrating structures and processes linking social relations to health

In order to better position and discuss the findings of existing empirical work and of this doctoral research in relation to the broader theory on social support and health, the conceptual framework developed by House et al (House, Umberson, et al., 1988), briefly introduced in Chapter 1, will be used to guide this research. This model illustrates the positioning of social support within the broader structure of social relationships, as well as the potential effects and biopsychosocial processes through which social support may affect mental and physical health outcomes. This framework, highlighting associations of interest for this study, is illustrated once again in figure 2.1 below, for ease of reference. It is explained in greater detail below.

Figure 2.1. Framework to illustrate structures and processes of social relationships in relation to health (House, Umberson, et al., 1988, p. 303).



2.2.1 Positioning of social support within social relationships for health

House et al (1988) define the concept of social support as a key dimension of microsocial relationships for health³, distinct from social integration and social network structure. While the latter two variables refer respectively to the existence or quantity of social relationships and the structure characterising these relationships, social support is an

³ The authors also illustrate and discuss the potential exogenous biological, psychological or social variables influencing the existence and nature of social relationships (as illustrated in block A of the diagram), and highlight these as an area for further investigation. These relationships are, however, beyond the scope of this thesis, and therefore have not been discussed.

element of the relational content, that is the “functional nature or quality” of social relationships (House, Umberson, et al., 1988, p. 302), through which the effects of social integration and social networks can be mediated. As explained by the authors: “Support refers to the positive, potentially health promoting or stress-buffering, aspects of relationships such as instrumental aid, emotional caring or concern, and information.” (House, Umberson, et al., 1988, p. 302). It is worth noting that the other two forms of relational content included in the model are: 1) relational demands and conflicts and 2) social regulation or control. The former refers to the negative or conflictive aspects of relationships that may have an adverse effect on health. The latter is defined as the controlling or regulating quality of social relationships, which may either have a positive or negative effect on health. While the existence and possible effects of these aspects of relational content are important to note, they are, however, beyond the scope of this thesis, which focuses specifically on the functional social support dimension.

2.2.2 Effects of social support

House et al's (1988) framework above illustrates how social support is postulated to influence health through two distinct types of effects, namely ‘stress-buffering’ and ‘main effects’. The stress-buffering hypothesis suggests that social support is protective of health primarily or only in the presence of stressful circumstances (House, Umberson, et al., 1988; Kaplan, Cassel, & Gore, 1977). Stress-buffering therefore changes or moderates the relationship between the stressor/stress and health outcomes, and is observed when the association between stress and worse health is stronger for individuals with low social support than for individuals with high social support. Main effects, instead, occur when

people with more social support have better health outcomes than people with less social support, regardless of the presence or level of stress. Direct stress-buffering effects are illustrated in the House et al (1988) model through the 'a' pathway, while direct main effects are represented by the 'e' pathway.

2.2.3 Mediating processes linking social support to health

The House et al (1988) model also illustrates the potential processes or mechanisms linking social support and other dimensions of social relationships to health. These processes may be biological, psychological or behavioural (House, Umberson, et al., 1988). These are distinct from the issue of whether social support produces main or buffering effects, which, as described above, indicates instead whether these processes operate at all times or mainly/only when an individual is confronted by stress or health hazards (House, Umberson, et al., 1988). In fact, it is hypothesised that both main and stress-buffering effects can occur through any of these three types of (potentially co-existing) processes. The authors highlight that ultimately the impact of social variables on physical – and to some extent mental – health must occur through biological mechanisms; this is supported by human and animal studies showing, for example, how the presence of, and more so affectionate contact with, another similar organism can reduce cardiovascular and other forms of physiological reactivity (House, 1981 as cited in House et al, 1988, p. 307; Lynch, 1979). Psychological mechanisms, representing the second type of process, may in part be related to biological mechanisms but are also distinct: relationships or attachments may lead people to feel better psychologically, and this could have physiological effects (House, Umberson, et al., 1988). Social relationships may also change individuals' perceptions of the world and of stressful situations; this can be

linked to the much-cited work of Lazarus et al (Lazarus, Averill, & Opton, 1974) on the role of social relationships in moderating the appraisal of stressors (explained in greater detail below). Finally, social relationships can lead to behavioural change, the third type of process, including health-promoting behaviours and behaviours that are protective of health in stressful or threatening situations (e.g. more sleep, better diet, exercise, better treatment adherence).

In sum, the above theoretical framework illustrates how both main and stress-buffering effects can occur directly and/or indirectly through - potentially multiple - mediating processes. As indicated above, buffering effects and main effects not mediated by these microbiopsychosocial processes are represented by pathways 'a' and 'e' respectively. Instead, buffering effects mediated through biosychosocial processes, such as psychological and behaviour mechanisms related to coping, would be illustrated by pathways 'b' and 'c'. Main effects mediated by biosychosocial processes, such as changes in thought and action, would be represented by pathways 'b' and 'd'.

2.3 Theories explaining mediating mechanisms for main and stress-buffering effects

Various key authors in the field of social relations and health have pointed out that, while research has clearly demonstrated the existence of a relationship between the quantity and quality of social relationships and health outcomes, we still do not fully understand what it is about these relationships that affects health and how these effects occur (see for example: House, Landis, et al., 1988; House, Umberson, et al., 1988; Sarason & Sarason, 2009; Uchino, et al., 2012). The relative empirical lacuna on mediating processes accounting for

both stress-buffering and main effects of social support on health may explain the existence of a considerable amount of theoretical work in this area.

2.3.1 Theories explaining mediating mechanisms for stress-buffering effects

Earlier social support research focused primarily on stress-buffering and the processes explaining this effect (Cassel, 1976; Cobb, 1976). In the literature, stress-buffering is most often associated with the protective effects of social support on mental health mediated by adaptive coping behaviour (Berkman & Breslow, 1983; House, Umberson, et al., 1988).

The stress-buffering hypothesis may, in fact, be considered an extension of stress and coping theory, developed by Lazarus and colleagues over a number of years (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Lakey & Orehek, 2011; Lazarus, 1966; Lazarus & Folkman, 1984). According to this stress process framework, the relationship between stressful events encountered and emotional outcomes for an individual is mediated by the processes of cognitive appraisal and coping. Cognitive appraisal is the process through which a person evaluates the importance of the stressor for their wellbeing, and the options for coping (Folkman, et al., 1986). Coping responses are defined as constantly changing cognitive and behavioural efforts (thoughts and acts) employed by individuals to manage stressful events (Folkman, et al., 1986; Lazarus & Folkman, 1984). It is therefore not stress/stressors alone but also the way that an individual appraises and copes with stress that determines the effect of stress on individual health. Social support may be considered an example of an external (relational) coping resource that can be drawn on for help and that can influence the choice of coping strategies (for example by providing information or advice, or

influencing the decision to seek the support of others) (Dunkel-Schetter, Folkman, & Lazarus, 1987; Thoits, 1986).

‘Maladaptive’ and ‘adaptive’ coping strategies refer to the effectiveness of coping in promoting emotional wellbeing and addressing problems causing distress (Folkman & Moskowitz, 2004). The term ‘adaptive coping’ is used to refer to situations in which there is a fit between the controllability of the stressor situation and the choice of coping, which leads to fewer psychological symptoms; conversely ‘maladaptive coping’ refers to coping that fails to regulate distress or manage the underlying problem (Chesney, et al., 2006). Types of coping include active problem-focused coping strategies (e.g. facing and defining the problem, problem-solving, choosing and acting on a solution, seeking support from others in addressing the problem) and emotion-focused coping strategies (e.g. attempting to ignore the problem by distancing, keeping feelings to oneself, cognitive escape-avoidance, seeking emotional support) (Burns, Feaster, Mitrani, Ow, & Szapocznik, 2008; Folkman & Moskowitz, 2004). While active coping strategies are often associated with more social support and positive mental health outcomes, and passive coping with less social support and worse health outcomes (Folkman & Moskowitz, 2004; Patterson et al., 1993; Wolf et al., 1991), this is not always the case. Coping processes are not ‘good’ or ‘bad’ – adaptive or maladaptive - in themselves; rather their effects depend on the specific context in which they occur (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984), and there are situations in which distancing or other forms of emotion-focused coping may be associated with better mental health outcomes (for example, in the case of less controllable stressors) (Folkman & Lazarus, 1985; Folkman & Moskowitz, 2004). Thus, according to stress process frameworks, social support is posited to buffer the effects of stress on mental health at least in part by positively influencing the choice of coping responses associated with better mental health outcomes, whether these responses are problem-focused or emotion-focused. Social support

would therefore be expected to buffer stress through both psychological and behavioural mediating processes related to coping; these are represented by the pathways 'b' and 'c' in the House et al (1988) model.

2.3.2 Theories explaining mediating mechanisms for main effects

In recent years, however, greater attention has been paid to potential mediating processes explaining more frequently-observed main effects of social support on mental and physical health outcomes (Lakey & Cronin, 2008; Lakey & Orehek, 2011; Uchino, 2009). Attempts to explain main effects hypothesise that these effects are a result of ordinary social interaction rather than stress and coping specifically (Lakey & Orehek, 2011; Thoits, 1985). For example, drawing from previous sociological writings (Durkheim, 1951; Mead, 1934), some authors refer to social interaction and support providing people with regular positive experiences, stability and a sense of self-worth (S. Cohen & Wills, 1985) and social roles resulting in a sense of identity, belonging and self-esteem (Thoits, 1985). More recently, Lakey and Orehek (2011) have argued for a greater focus on 'relational regulation theory', which hypothesises that main effects of support occur when people regulate their affect, thought and action through regular ordinary conversations and shared activities with specific support providers in both stressful and non-stressful situations, rather than conversations specifically about how to cope with stress (Lakey & Orehek, 2011). This suggests that supportiveness primarily reflects relational influences and that its effects on health are mediated through various psychological and behavioural processes. These theories, suggesting that main effects are mediated by changes in thought and action, would be represented by pathways 'b' and 'd' in the House et al (1988) model above.

Focusing more specifically on the identified associations between social support and physical health outcomes, Uchino (2009) proposes an alternative explanation for main effects, defined as a 'life-span perspective,' which focuses more on the individual than on relationships. It suggests that individuals with positive early family environments develop 'positive psychosocial profiles,' including perceived support, certain personality traits and/or individual differences, social skills, self-esteem and feelings of personal control (Uchino, 2009, p. 237). These positive profiles are hypothesised to be related to health through various behavioural mechanisms, mainly more proactive coping but also healthy behavioural choices (e.g. improved treatment adherence) (Uchino, 2009). A key difference between Uchino et al's (2009) theory and explanations based on psychosocial mediating variables (Thoits, 1985) is that self-esteem is hypothesised to be developed as part of a positive profile, simultaneously with perceived support, rather than a mediating factor explaining links between support and health at a particular time during adult life. This theory would therefore be more coherent with direct main effects of social support (versus main effects mediated through biopsychosocial processes), as represented by pathway 'e' in the House et al (1988) model.

2.3.3 Theories bridging stress-buffering and main effects processes

As highlighted by House et al (1988), buffering and main effects either occur through different mechanisms, or by the same mechanisms that "operate more intensively in the presence of stress or other health hazards" (House, Umberson, et al., 1988, p. 307). The theories described thus far suggest slightly different mechanisms at play. In a recent article, Thoits (2011) instead bridges buffering and main effects processes, by suggesting that both main and stress-buffering effects may be explained by the same social psychological

mechanisms that operate differently in the presence of stressful situations (Thoits, 2011). The author identifies the following as potential variables mediating effects of social support, and social relations more broadly, on health: social influence/social comparison, social control, role-based purpose and meaning (mattering), self-esteem, sense of control, belonging and companionship. Social influence/comparison is described as the process through which individuals “obtain normative and behavioural guidance through comparisons with similar others in their reference groups” (Thoits, 2011, p. 147), including norms about health behaviours, such as drug use, dieting or exercise, seeking care and adhering to treatment. Social control is described as a more direct and active form of social influence that may have similar effects, except that it refers to “explicit attempts of social network members to monitor, encourage, persuade, remind or pressure a person to adopt or adhere to positive health practices” (Thoits, 2011, p. 148). A third mechanism, and less explicit form of social control, is identified as “behavioural guidance, purpose and meaning (mattering),” which derives from role relationships or positions in social structure, encompassing reciprocal norms and obligations. These role identities are also posited to provide meaning and purpose in life (or a sense of mattering to others), which in turn could have positive effects on behaviour and psychological wellbeing. A further two psychological mechanisms highlighted are self-esteem and a sense of mastery or control over life. Connections to others and acceptance/inclusion in social networks are also hypothesised to foster a sense of belonging and provide companionship (e.g. others with whom to share social activities), which in turn may have favourable effects on wellbeing.

Thoits (2011) argues that, while the mediating mechanisms (described above) are the same for buffering and main effects, social support “changes in character” in the presence of major stressors, and supportive actions change from “everyday” to “major stress-related” activities (Thoits, 2011, p. 150). Everyday support would include demonstrations of love,

caring, information exchanges and informal discussions about potential problems and/or how to avoid these. These exchanges may influence the psychological mechanisms listed above and may thus improve psychological and, through positive affect, physical wellbeing. The author argues that when major stressors or adverse events occur, this support moves from being “invisible” to deliberate, albeit through the same mechanisms. Expected reciprocity is put on hold and network members’ assistance is focused on changing the individual’s situation and feelings. This coping assistance includes advising or carrying out coping strategies that network members would themselves adopt in a similar situation, which may directly reduce the consequences of the stressor or change the person’s emotional reactions and ability to cope. Emotional support may also continue to improve the person’s wellbeing by indirectly acting through these psychological mechanisms (Thoits, 2011). Thoits’s explanations for main effects and stress-buffering would be mediated by psychosocial and behavioural processes represented by both the ‘*b/c*’ and ‘*b/d*’ pathways in the House et al (1988) model.

2.4 Empirical evidence for effects of social support on health and mediating processes

2.4.1 Empirical evidence for stress-buffering and main effects

While theory on the relationship between social support and health has its roots in seminal sociological literature on social integration (see for example: Durkheim, 1951), research on these themes rapidly gained momentum in the 1970s and 1980s through work

conducted mainly by health scientists with a psychology orientation (House, Umberson, et al., 1988). Since the 1970s, numerous empirical studies, meta-analyses and literature reviews have revealed positive relationships between both structural and functional dimensions of social support and various mental and physical health outcomes, both among ill and healthy individuals (see for example: Berkman, 1995; Broadhead, Berton, James, Wagner, & Schoenbach, 1983; S. Cohen & Janicki-Deverts, 2009; S. Cohen & Wills, 1985; House, Landis, et al., 1988; Kessler & McLeod, 1985; Seeman, 1996; Thoits, 2011; Turner, 1981; Uchino, 2006; D Umberson & Montez, 2010; Wang, Wu, & Liu, 2003). These studies have shown either a significant main effect or stress-buffering effect of social relationships, or both. While neither type of effect has been found uniformly across studies (S. Cohen & Wills, 1985; House & Khan, 1985), overall, main effects of social support have been most frequently observed, showing positive associations with mental health, physical health and longevity (House, Landis, et al., 1988; Thoits, 2011). Some empirical longitudinal studies also suggest causal directionality, as less social support has been found to precede negative mental health outcomes and mortality (see for example: Berkman & Syme, 1979; Broadhead, et al., 1983; House, Robbins, & Metzner, 1982; Leserman et al., 1999; Turner, 1981).

Overall, the body of literature on social support and mental health is greater than that on social support and physical health, and stress-buffering effects in particular have been assessed and found primarily for mental health dimensions. Better mental health outcomes found to be associated with more social support include depression, anxiety, mood disorders, psychological adjustment to life events or stressors, and other psychological or psychiatric symptoms (see studies and reviews cited above). Better physical health dimensions associated with more social support include the presence of physical or somatic symptoms, the presence of chronic and infectious disease, recovery from illness and self-reported health status (House, Umberson, et al., 1988; Uchino, 2006). Moreover, as could be expected given

observed links to physical health, some studies have shown positive associations between more social support and lower risk of mortality. Among the earlier seminal studies is the work of Berkman and Syme (1979), House et al (1982) and Blazer (1982) with adults in the USA. More recently, Holt-Lunstad et al (2010) conducted a meta-analytic review of existing literature in this area, to determine the extent to which social relationships influenced mortality risk (Holt-Lanstad, et al., 2010). The 148 identified studies reviewed, covering data with 308,849 individuals over an average of 7.5 years, showed that participants with stronger relationships, including dimensions of social support, had a 50% increased likelihood of survival, after controlling for age, sex, cause of death and initial health status. Measures of social relationships used by these studies included functional measures (received support, perceptions of social support, perceptions of loneliness), structural measures (marital status, social networks, social integration, living alone, social isolation) and multifaceted measures, combining more than one of these constructs, for which the associations were strongest (Holt-Lanstad, et al., 2010). The authors conclude that the influence of social relations (including social support) on mortality risk is “comparable with well-established risk factors for mortality” (Holt-Lanstad, et al., 2010, p. 12), and in fact exceeds many key risk factors for mortality, such as obesity and physical inactivity. This analysis also supports the causal assumption of social relationships influencing health and mortality, as most participants of these studies were not suffering from chronic health conditions at the point of baseline evaluations, and initial health status was not found to moderate the effect of social relationships on mortality.

2.4.2 Empirical evidence of mediating mechanisms

As indicated above, there is a much greater and more conclusive body of evidence supporting both main and stress-buffering effects of social support on (mental and physical) health than evidence supporting the hypothesised biological, psychological and behavioural mediating mechanisms explaining these. There is some evidence of social support being linked to mental health, such as depression or mood changes, through psychological mediators such as self-esteem, optimism and perceived situational control (see for example: Atienza, Collins, & King, 2001; Krause, 1987; Shaw, Krause, & Chatters, 2004; Symister & Friend, 2003; Uchino, et al., 2012). There are also numerous examples of studies providing evidence of effects mediated by coping processes. For example, various empirical studies with individuals living with HIV or other chronic illness have shown active coping strategies to be associated with more social support and positive health outcomes, and passive or avoidance coping styles to be associated with less social support, higher health risk behaviours and increased psychological distress (Burns, et al., 2008; Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984; Moneyham et al., 1998; Namir, Wolcott, & Fawzy, 1989; Nyamathi, Stein, & Brecht, 1995; Pakenham, Dadds, & Terry, 1994; Patterson, et al., 1993; R. Thompson, 1992; White, Richter, & Fry, 1992; Wolf, et al., 1991).

The evidence of mechanisms linking social support to physical health, however, is thinner and more equivocal. Perhaps the most conclusive evidence of mediating mechanisms for physical health involves physiological processes, as highlighted in literature reviews conducted by Uchino and colleagues over the past two decades (Uchino, 2004, 2006; Uchino, Cacioppo, & Kiecolt-Glaser, 1996). The three main biological mechanisms investigated relate to cardiovascular function, neuroendocrine function and immune function (Berkman,

Glass, Brisette, & Seeman, 2000; Uchino, 2006; Uchino, et al., 1996). The strongest evidence of these processes links social support to the cardiovascular system and the immune system. Findings of various studies appear to be coherent with the hypothesised effects of social support's stress-buffering function on indicators such as cardiovascular reactivity (usually measured by blood pressure or heart rate) (Berkman, Leo-Summers, & Horwitz, 1992; Uchino, 2006; Uchino, et al., 1996). Similarly, various studies have documented links between social support and immune function processes, for example natural killer cell activity in cancer patients and T-cell counts in HIV-positive individuals (Persson, Gullberg, Hanson, Moestrup, & Ostergren, 1994; Theorell, Blomkvist, Jonsson, Schulman, & Berntorp, 1995; Uchino, 2006; Uchino, et al., 1996). Evidence linking social support to neuroendocrine processes includes associations found between support and levels of hormones such as cortisol, which is known to have immunosuppressive effects (Turner-Cobb, Sephton, Koopman, Blake-Mortimer, & Spiegel, 2000; Uchino, 2006). Uchino et al.'s 2006 review of these physiological processes also identifies preliminary data linking social support to more integrative physiological mechanisms, such as immune-mediated inflammatory processes (Hawkey, Bosch, Engeland, Marucha, & Cacioppo, 2007; Uchino, 2006); despite the complexity of this type of research, the authors consider this an important development given that research points to the beneficial effects of social support across a number of diseases (Uchino, 2006). Moreover, there is also some evidence of positive health behaviours partly explaining the relationship between social support, physical health outcomes and mortality (Uchino, 2006). Types of positive health behaviours shown to be linked to more social support include: healthier eating, exercising, smoking cessation and treatment adherence (Chouinard & Robichaud-Ekstrand, 2007; DiMatteo, 2004; Emmons, Barbeau, Gutheil, Stryker, & Stoddard, 2007; Hawkey, Thisted, & Cacioppo, 2009; Reblin & Uchino, 2008; D.

Umberson, 1987)⁴. The influence of social support on health-related behaviours can be direct, for example through encouragement and health-related information, or indirect, for example through life meaning or self-efficacy (Uchino, 2006). There is also evidence that lack of social support, or social isolation, can be an obstacle to positive health behaviours, such as adherence, among people living with HIV and other chronic illnesses (Alfonso, Geller, Bermbach, Drummond, & Montaner, 2006; Reblin & Uchino, 2008; H. Thompson, Littles, Jakob, & Coker, 2006). Moreover, there is evidence of psychological and behavioural mediating processes being associated with each other. For instance, studies have shown stress to negatively influence good health behaviours, while good health behaviours can positively affect stress and anxiety-related thoughts (Ng & Jeffery, 2003; Rejeski, Thompson, Brubaker, & Miller, 1992; Uchino, 2006). This points once again to the potential co-existence of multiple mediating factors and/or multiple mediating pathways between social support and health outcomes.

2.4.3 Gaps in empirical evidence on mediating processes

The global literature on mediating mechanisms explaining the social support-health relationship highlights that there are still significant gaps in the evidence showing the existence of posited psychological pathways linking social support to physiological processes and physical health outcomes (these include psychosocial factors discussed by Thoits in the

⁴ It is important to note that the influence of supportive behaviours on health is distinct from the influence of control behaviours, or 'social control' on health, which can potentially have either a positive or negative effect on health (see for example: Franks, Stephens, Rook, & al, 2006; House, Umberson, et al., 1988; Reblin & Uchino, 2008)

2011 article cited above). This prompts Uchino et al, in a recent (2012) critical review article, entitled “A visit with the ghosts of research past, present and future,” to compare the search for psychological mechanisms linking social support to biological indicators of disease to the ghosts who visit the main protagonist of a famous Charles Dickens novel “A Christmas Carol” (Uchino, et al., 2012). The authors argue that the existing evidence regarding the psychological pathways explaining links between social support and physical health is inconclusive, despite social support being one of the most documented psychosocial factors affecting physical health and mortality, and despite an on-going attempt over the past few decades, to uncover these pathways. While most models postulate the importance of psychological mechanisms such as depression, perceived stress and resilience variables such as self-esteem or self-efficacy, the authors argue that research conducted to date is not strong enough to support this hypothesis in the physical health domain (Uchino, et al., 2012).

Uchino et al (2012) add their voice to that of Sarason and Sarason (2009) and other key authors, such as House et al (1988) more than two decades earlier, in arguing that it is important to focus not only on “first generation” questions around the existence of relationships between social support and morbidity/mortality, but also “second generation” questions, that are concerned with the mechanisms explaining these (Uchino, et al., 2012, p. 954). Uchino et al (2012), for example, highlight the need to dedicate greater systematic attention to this area of social support and health research (Uchino, et al., 2012, p. 955). Suggestions by the authors for future research include paying more attention to possible design and statistical errors (e.g. mediation models), carrying out more longitudinal research and possibly examining multiple psychological mechanisms simultaneously (a suggestion that also recalls House et al.’s earlier recommendations). Conceptual issues are also highlighted, including the need to pay more attention to the conceptualisation of support in its multiple dimensions (e.g. perceived versus received support; different types of support) and

to different support contexts. The authors also suggest expanding consideration of potential psychological mediators to further previously-unexamined factors. In this regard they advocate for more openness to reconceptualising or refining hypothesised links and models and to identifying potential new mediators to inform this process (Uchino, et al., 2012).

One may question why it matters to go beyond determining the existence of relationships between social support and health to understanding *how* these outcomes come about. Thoits (2011) explains that “in order to design effective interventions it is crucial to understand intervening mechanisms as well as the relative impact of each of those mechanisms on health outcomes” (Thoits, 2011, p. 156). More generally, it has been argued that a better understanding of these processes would be important for multiple reasons, including the ability to test and refine existing conceptual models, and to design appropriate health interventions that take into account the complexity of the links between social support and health (Uchino, 2006, p. 378).

CHAPTER 3. SYSTEMATIC REVIEW OF THE LITERATURE ON SOCIAL SUPPORT AND HEALTH AMONG HIV-POSITIVE CAREGIVERS OF CHILDREN

The previous chapter (Chapter 2) described the House et al theoretical framework used to guide this research, which illustrates the effects and processes explaining associations between social support and health. It then presented the key global theoretical and empirical literature on the protective role of social support for health. This highlighted a considerable body of evidence exposing a positive relationship between more social support and better mental and physical health outcomes among various (ill and healthy) adult populations. It also showed how multiple psychological, behavioural and biological processes have been found to be mediating this relationship, and that there is still considerable scope for future research aimed at better understanding these processes.

This chapter will describe the methodology and findings of a systematic review of the literature quantitatively assessing the association between social support and (mental or physical) health outcomes, among HIV-positive adult caregivers of children (the key focus population of this study). Methodological limitations and findings of relevant papers retrieved will be discussed. The discussion of findings of the identified studies will be guided by the House et al theoretical framework and the research questions of interest, that is: a) whether these studies provide evidence of main effects or stress-buffering effects of social support on the measured mental or physical health outcomes and; b) whether these studies further our knowledge on the biopsychosocial mediating processes explaining these effects. Associations found by the studies retrieved will also be illustrated diagrammatically, based on an adapted

version of the House et al model. Lastly, taking into consideration methodological limitations and findings of studies reviewed, gaps for future research on social support and health among HIV-positive caregivers will be discussed.

3.1 Systematic review methodology

From April to September 2011 a systematic literature review was conducted to identify all existing published and unpublished international studies that quantitatively assessed the association between one or more measurable dimension of social support and one or more measurable physical or mental health outcome, among HIV-positive adult caregivers of children. Table 3.1, below, summarises the search strategy and final sources of relevant papers retrieved. First, a keyword search strategy and composite search term were developed by defining: a) the population of interest as ‘HIV-positive caregivers of children’; b) the intervention or phenomenon of interest as ‘social support’ and; c) the key outcomes of interest as measured ‘mental or physical health outcomes’ (O’Connor, Green, & Higgins, 2011). This search term was, however, not limited to specific health outcomes, in anticipation of the small number of existing studies and wide possible range of outcomes measured, and was not restricted by the presence of terms for ‘child’; rather, abstracts were hand searched to determine relevance. The search was limited to English-language studies, given the absence of resources for translation; however no date or geographical limitations were imposed.

Table 3.1. Systematic review search strategy and sources of final relevant papers

<p>Search criteria (as per the PICO inclusion criteria; Cochrane Collaboration)</p>	<p>Population: HIV-positive and/or AIDS-ill adult caregivers of children</p> <p>Intervention: social support</p> <p>Comparison: HIV-negative caregivers of children; HIV-positive adults not caregivers of children</p> <p>Outcome: measured mental health outcomes; measured physical health outcomes</p>
<p>Composite search strings</p>	<p>Construction of composite search strings</p> <p>Composite search strings were constructed for each database using the following terms and all variations:</p> <p>To describe the population: carer, caring for, caregiver, guardian, parent, custodian, mother, father, caretaker AND hiv, human immunodeficiency virus, human immunodeficiency virus, human immuno-deficiency virus, human immune-deficiency virus, acquired immunodeficiency syndrome, acquired immunodeficiency syndrome, acquired immuno-deficiency syndrome, acquired immune-deficiency syndrome</p> <p>To describe the intervention: social support, social network, support system, psychosocial support, psycho-social support</p> <p>To describe the outcomes of interest (mental and physical health): no limiters included in the search term for mental or physical health outcomes; these were determined through hand-searching abstracts</p> <p>Example of composite search string</p> <p>("social support" OR "social network*" OR "support system*" OR "psychosocial support" OR "psycho-social support") AND (carer* OR "caring for" OR caregiv* OR "care giver*" OR guardian* OR parent* OR custodian* OR mother* OR father* OR caretaker*) AND (HIV OR HIV-* OR HIV/AIDS* OR AIDS* OR hiv OR hiv-1* OR hiv-2* OR hiv1 OR hiv2 OR "human immunodeficiency virus" OR "human immunodeficiency virus" OR "human immuno-deficiency virus" OR "human immune-deficiency virus" OR ("human immun*" AND "deficiency virus") OR "acquired immunodeficiency syndrome" OR "acquired immunodeficiency syndrome" OR "acquired immuno-deficiency syndrome" OR "acquired immune-deficiency syndrome" OR ("acquired immun*" AND "deficiency syndrome"))</p> <p>Other search restrictions imposed (geographical, dates etc): none</p>
<p>Databases searched</p>	<p>Ebscohost linked databases (Academic search complete, Africa wide information, ATLA religion, CINAHL, Econ List, ERIC, Health Consumer, Health Source nursing, Master file, Medline, MLA directory, MLA international, PsychArticles, PsycINFO, Religion and philosophy collection); Pubmed; Cochrane Library; JSTOR; Sabinet; SCat-2001; SA thesis; Proquest; Oxford Journals; AJOL; Sociological Abstracts; CABI direct; Proquest dissertations and theses; African Journal Archive; Anthropological Index; Combined Health Information; Cambridge Online Journals; Directory of Open access; Social Science Citation Index; Social Science Databases, WHOLIS, African Index Medicus</p>

Other sources searched	<ul style="list-style-type: none"> - International AIDS Conferences and International AIDS Society conference abstracts searched for conferences held from 2005 – 2011; available at: http://www.iasociety.org/AbstractSearch.aspx - Google search using key words such as ‘social support’, ‘caregivers’ and ‘health’ - Searched websites of key development, HIV/AIDS and public health organisations: UNAIDS, UNICEF, WHO, International AIDS Society - Searched reference lists of all full text articles identified as relevant - Contacted first authors of all articles identified as relevant, for further recent publications
Date or geographical limitations	- NONE
Sources of final relevant articles (16)	<ul style="list-style-type: none"> - Database search: 11 - Reference lists of relevant articles: 3 - Papers/references sent by authors: 2

Twenty database groups were searched (see Table 3.1 for a detailed list). Additional strategies to identify further relevant published or ‘grey’ literature included: a) searching key HIV/AIDS and public health websites; b) searching online through the Google search-engine, using keywords such as ‘HIV’, ‘AIDS’ and ‘social support’; c) searching International AIDS Conference and International AIDS Society conference abstracts for the period 2005 – 2011, to identify potential full papers not yet publicly available; d) searching the bibliographies of all studies identified as relevant; and e) contacting the first author of each relevant manuscript to enquire about recent work on these themes not publicly available. Sources of final relevant papers included in this review are also indicated in table 3.1. The majority of relevant articles (11) were retrieved through database searches, a further three from the reference lists of relevant articles and two from direct contact with authors. The web searches did not yield any further results. Two potentially relevant abstracts were identified from the lists of international AIDS conference abstracts and first authors were contacted; however, full papers were not available.

Excel spread sheets were used to record the details of each source searched (date, search string etc.), the number of abstracts retrieved and the number of duplicates. All

abstracts were read and hand-searched to determine relevance, and full text was retrieved for all potentially relevant abstracts. These full text papers were then read thoroughly to determine inclusion and exclusion. Papers that did not fit with the PICO criteria were excluded, and reasons for exclusion recorded in a separate excel spread sheet. Reasons for exclusion included: wrong population or intervention, absence of health outcomes or social support measures, associations of interest not quantitatively assessed.

3.2 Characteristics of relevant studies found

Of the over 5000 database and conference abstracts reviewed, only 34 were identified as potentially relevant and full text articles for these were retrieved. After reading full articles, a final number of 16 papers and 15 studies were identified as relevant and included in this review (two papers report findings from the same broader study and sample, and will therefore be considered as one study (Burns, et al., 2008; Prado et al., 2004)). Table A1, included in Appendix 1, summarises the key characteristics of the 15 relevant studies, including location, sampling and analytical methodologies. Four were documented through doctoral theses and the remaining 11 through published academic journal articles. Almost all of the studies included in this review (14) were conducted in the U.S., with the exception of Rotherum-Borus et al's research (2010) conducted in Thailand. Publication years ranged from 1995 to 2010, although most papers were published before 2005. Sample sizes ranged from 25 to 409 and study samples consisted predominantly of African American biological mothers. All studies collected data through some form of administered survey instrument; in addition three studies examined medical records to obtain specific health indicators (D. Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002; Robbins, et al., 2003; Stock,

2001) and one study recorded observations of maternal engagement with children (Gay, 1995). All studies employed statistical analysis, with the majority of studies using multivariate regression analysis (8) or structural equation modelling (4) (Burns, et al., 2008; Hough, Brumitt, Templin, Saltz, & Mood, 2003; Leslie, Stein, & Rotheram-Borus, 2002; Prado, et al., 2004; Rotheram-Borus et al., 2010).

As expected, relationships explored, as well as constructs and measurement tools used, differed across studies, excluding the possibility of a statistical meta-analysis (the constructs and measurement tools used for social support and key health outcomes measured are listed below in Table 3.2). Each paper in the final sample was read multiple times by the doctoral candidate and analysed with regard to: a) methodological characteristics and; b) findings in relation to associations between social support and mental or physical health outcomes of caregivers. This information was extracted, synthesized and organized using excel spread sheets. Content analysis was conducted and findings organized based on the type of associations and pathways identified between social support and measured health outcomes, as per House et al.'s conceptual framework presented in previous chapters (Figures 1.1 and 1.2 in Chapter 1). Based on this model, the following key questions guided the organisation and discussion of systematic review findings:

- Is there evidence of main effects of social support on mental or physical health among caregivers of children?
- Is there evidence that social support buffers the effects of HIV-related stressors on caregiver health outcomes (stress-buffering effects)?
- Do these studies further our knowledge on the processes explaining these effects (i.e. the biopsychosocial processes highlighted by the House et al theoretical framework described in Chapters 1 and 2)?

3.3 Results of the systematic review: findings of studies reviewed

Measurement tools used, effects and pathways tested, as well as key findings of relevant studies relating to social support and health, are summarized below in Table 3.2. Significant associations found are also illustrated graphically in Figure 3.1, based on the House et al (1988) framework.

While most studies in this review assessed the association between social support and mental health outcomes (11), one study focused on physical health outcomes (Stock, 2001) and two studies explored both types of health outcomes (D. Murphy, et al., 2002; Rotheram-Borus, et al., 2010). Thirteen studies tested for main effects, through either regression analysis or structural equation models. Six studies tested main effects as mediated by coping processes (Lazarus & Folkman, 1984), through either bivariate tests, regressions or structural equation models, thus testing coping-related appraisal and behaviour as biopsychosocial mediators, as described above (House, Umberson, et al., 1988). Four studies tested for stress-buffering effects, through interaction terms in regression analysis, to explore whether social support changed the relationship between a specific stressor/stressors and the health outcome(s) of interest.

Of the four studies that explored stress-buffering effects of social support on health outcomes, two found evidence of these effects and two did not find significant associations. Of the thirteen studies that tested for direct main effects, eight found evidence of these effects and five did not. Of the six studies that tested for main effects through coping, three found evidence of these effects and three did not. The paragraphs below summarise these findings, based on the type of effects and processes explored. Associations found by relevant studies are also illustrated diagrammatically in Figure 3.2 below; the arrows in bold represent

associations found and the numbers to the left of each arrow indicate the numbers of studies (as numbered in Table 3.2) that found significant associations represented by the arrow.

Figure 3.2. Associations between social support and health outcomes found by papers reviewed

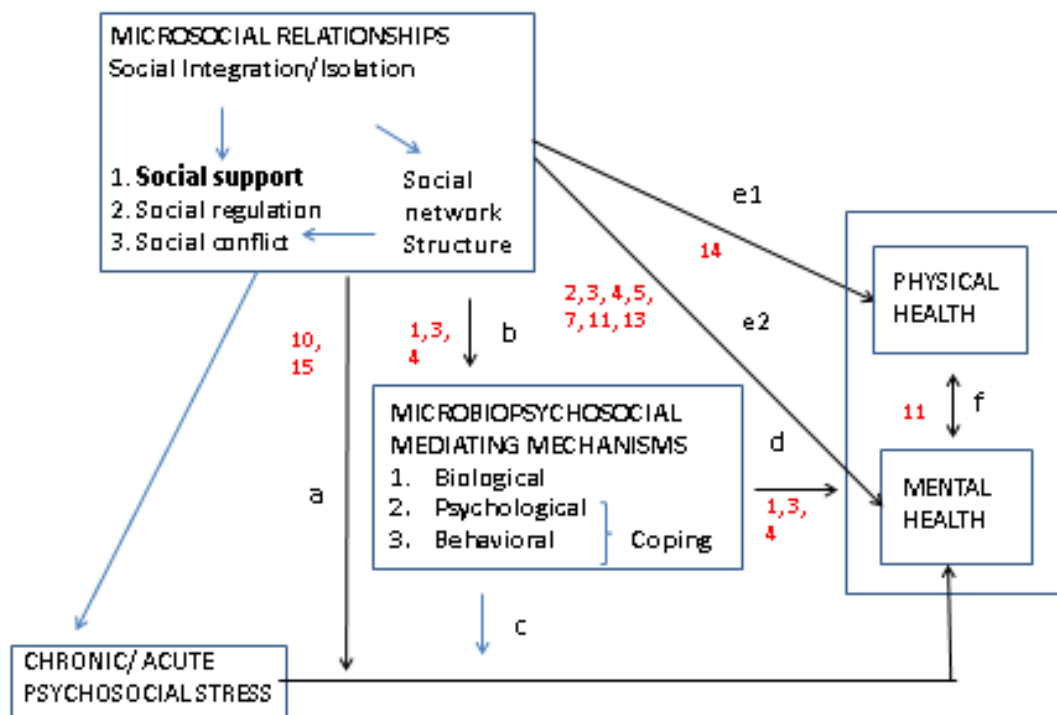


Table 3.2. Summary of measurement tools, effects and mediators explored, and key social support and health findings

Study	Citations of relevant articles found	Social support dimensions and scales used	Stressors, coping and health outcomes measured	Effects and mediators explored	Findings in relation to associations between social support and health outcomes
1	<p>Burns, M., et al. (2008). Stress processes in HIV-positive African American mothers: Moderating effects of drug abuse history. <i>Anxiety, Stress, & Coping</i>, 21(1), 95-116.</p> <p>Prado, G., et al. (2004). Religious Involvement, Coping, Social Support, and Psychological Distress in HIV-Seropositive African American Mothers. <i>AIDS and Behavior</i>, 8(3), 221-235.</p>	<p>Social support network: Social Support Questionnaire - Short Form SSQ6 (Radloff, 1977; Sarason, Sarason, Shearin, & Pierce, 1987).</p>	<p>Stress: composite score created from three measures: (1) Hassles Scale (DeLongis, Folkman, & Lazarus, 1988); (2) Difficult Life Circumstances Questionnaire (Barnard, 1989); and (3) Life Events Scale shortened version (Sarason, Johnson, & Siegal, 1978)</p> <p>Coping: Brief Cope (Carver, 1997) Psychological distress: Brief Symptom Inventory (Derogatis, 1993)</p>	<ul style="list-style-type: none"> - Direct main effects on psychological distress - Main effects, as mediated by coping strategies 	<p>Evidence of main effects mediated through coping but no direct main effects:</p> <ul style="list-style-type: none"> - More stressors positively associated with greater distress both directly and indirectly through more avoidant coping - Larger social support network indirectly associated with less psychological distress through its negative relationship with avoidance coping and positive relationship with active coping - No direct relationship between social support and psychological distress after controlling for coping

2	Cook, K. (1997). <i>Psychological distress and mediating variables in HIV-positive mothers of young children</i> . Doctoral thesis, California School of Professional Psychology, United States, California	Functional aspects of support including reliance alliance, attachment, guidance, nurturance, social integration and reassurance of worth: Social Provisions Scale (Cutrona & Russell, 1987)	<p>Chronic life stressors: Urban Life Stress Scale (Harrell, 1994)</p> <p>Coping: Strategic Approach to Coping Scale (Hobfoll, Dunahoo, Ben-Porath, & Monnier, 1994)</p> <p>Depression: CES Depression Scale (Radloff, 1977)</p> <p>Anxiety: Spielberger State Anxiety Inventory (Spielberger, Gorsuch, Lushene, & Jacobs, 1983)</p>	<ul style="list-style-type: none"> - Direct main effects - Main effects, as mediated by coping strategies 	<p>Evidence of direct main effects but not main effects mediated by coping:</p> <ul style="list-style-type: none"> - Social support directly associated with pro-social coping subscales, but these were not associated with anxiety or depression - Attachment social support subscale directly associated with lower anxiety - No significant relationship between social support and depression
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3	Gay, C. (1995). <i>Psychological distress among mothers infected with HIV: A risk and resistance model</i> . Doctoral degree, University of Miami, Miami, U.S.A.	Social support network size/availability and satisfaction with support: Social Support Questionnaire six-item version (Sarason, et al., 1987).	<p>Stressors: <i>Stress measures not included in analysis</i></p> <p>Depression: Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961)</p> <p>Maternal Effect and engagement: direct observation</p> <p>Coping: Coping strategies inventory (Tobin, Holroyd, & Reynolds, 1984)</p>	<ul style="list-style-type: none"> - Direct main effects - Main effects, as mediated by coping strategies 	<p>Evidence of both direct main effects and main effects mediated by coping:</p> <ul style="list-style-type: none"> - No direct association between social support availability and psychological distress - Higher social support satisfaction directly related to less psychological distress - Indirect relationship between more social support satisfaction and availability and less distress through less disengaged coping
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4	<p>Hough, E., et al. (2003). A model of mother–child coping and adjustment to HIV. <i>Social Science & Medicine</i>, 56(2003), 643-655.</p>	<p>Composite social support score computed from two tools, measuring:</p> <p>a) Functional aspects of social support (including adequacy and satisfaction): Brief Questionnaire (Zich & Temoshok, 1990)</p> <p>b) Structural aspects of social support: Convoy model of social networks (Antonucci, 1985)</p>	<p>HIV-associated maternal stressors: General Symptom Subscale of the HIV Assessment Tool—Revised (Nokes, Wheeler, & Kendres, 1994)</p> <p>Coping: Dealing with Illness Inventory (Namir, Woolcott, Fawzy, & Alambaugh, 1987; S. Namir, D Woolcott, F Fawzy, & M Alambaugh, 1990)</p> <p>Emotional distress: Profile of Mood States (McNair & Lorr, 1964)</p>	<ul style="list-style-type: none"> - Direct main effects - Main effects, as mediated by coping strategies 	<p>Evidence of both direct main effects and main effects mediated by coping:</p> <ul style="list-style-type: none"> - Higher level of maternal HIV-associated stressors associated with greater maternal distress through more passive coping (but not active coping) - Social support directly associated with less emotional distress - Social support indirectly associated with less emotional distress through more active coping
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5	<p>Klein, K., et al. (2000). Socio-emotional Support in African American Families Coping With Maternal HIV: An Examination of Mothers' and Children's Psychosocial Adjustment. <i>Behavior Therapy</i>, 31, 1-26.</p>	<p>Mother's Emotional Support from Child: Mother's Emotional Support Provided by Child Questionnaire (MESQ), designed by authors to assess how often a mother relies on her child as a source of emotional support</p> <ul style="list-style-type: none"> - Mother's Perceived Parenting Support: Modified form of the Parenting Convergence Scale (Ahrons, 1979) Mother's Perceived Support from Neighbours and Friends: Social Support Scale (derived from Belle, 1982) 	<p>Stress: no measure of stress used, though maternal HIV infection (HIV status) represents key stressor</p> <p>Psychological Distress: measured with Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1982) and rated using the Hamilton Rating Scale for Depression (Hamilton, 1960).</p>	<ul style="list-style-type: none"> - Stress-buffering (explored through interaction terms in regression analysis) - Main effects 	<p>Evidence of main effects but not stress-buffering:</p> <ul style="list-style-type: none"> - Higher levels of support from neighbours and friends and parenting support associated with less psychological distress - Higher levels of emotional support from children associated with greater psychological distress - No evidence of stress-buffering effects of social support (i.e. social support moderating the relationship between stress and distress)
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6	<p>Leslie, M., et al. (2002). The impact of coping strategies, personal relationships, and emotional distress on health-related outcomes of parents living with HIV or AIDS. <i>Journal of Social and Personal Relationships</i>, 19(1), 45-66.</p>	<p>Respondents asked to list the most important people in their lives. Social support variable computed from answers to the following questions, for each person listed: 1) how supportive they are regarding the illness, 2) how often they see that person and 3) how often they discuss their illness with this person.</p>	<p>Stress: no measure of stress or stressors included in analysis, though outcome variable suggests HIV/AIDS symptoms are a key stressor</p> <p>Coping: 76-item Coping with Illness Questionnaire derived from the Dealing with Illness scale (Namir, et al., 1987)</p> <p>Distress over HIV or AIDS symptoms: 5 indicators created from 23 item questionnaire (Hein, Dell, Futterman, & Shaffer, 1995; Rotheram-Borus & Stein, 1999)</p>	<p>- Direct main effects</p> <p>- Main effects as mediated by coping strategies</p>	<p>No evidence of direct main effects or main effects mediated by coping:</p> <p>- No direct or indirect relationship between social support and distress over HIV and AIDS symptoms</p>
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7	Mellins, C., et al. (2000). Psychosocial Factors Associated with Adaptation in HIV-Infected Mothers. <i>AIDS and Behavior</i> , 4(4 Health Module), 317-328.	Functional dimension of social support (includes availability and adequacy of various types of social support): Multidimensional Social Support Inventory (Bauman, 1997).	<p>Stressful events: Psychiatric Epidemiology Research Interview (B. S. Dohrenwend, Krasnoff, Ashehasy, & Dohrenwend, 1978)</p> <p>Psychiatric disorder: Structured Clinical interview for DSM (Spitzer, Williams, Gibbon, & First, 1990)</p> <p>Psychological distress: short form of the Demoralization Scale of the Psychiatric Epidemiology Research Interview (B. Dohrenwend, Shrout, Egri, & Mendelsohn, 1980).</p>	<ul style="list-style-type: none"> - Stress-buffering (explored through interaction terms in regression analysis) - Main effects 	<p>Evidence of main effects but not stress-buffering:</p> <ul style="list-style-type: none"> - More social support directly associated with less psychological distress and less psychiatric symptoms - No evidence of the stress-buffering (moderating) effect of social support on distress
8	Miles, M., et al. (1997). Personal, Family, and Health-Related Correlates of Depressive Symptoms in Mothers With HIV. <i>Journal of Family Psychology</i> , 11(1), 23-24.	Satisfaction with support from family and friends in relation to child-rearing: Satisfaction with Support subscale of the Stress Support Scale (Miles, 1995).	Depression: Centre for Epidemiological Studies Depression scale (Radloff, 1977)	- Main effects	<p>No evidence of main effects:</p> <ul style="list-style-type: none"> - No significant relationship between satisfaction with support for child-rearing and depression

9	Murphy, D., et al. (2002). Mothers living with HIV/AIDS: mental, physical, and family functioning. <i>AIDS Care</i> , 14(5), 633-644.	Social support network in relation to emotional support, physical assistance and negative interactions: Arizona Social Support Scale (Barrera, 1981; Payne & Jones, 1987).	<ul style="list-style-type: none"> - Disease severity (measured by CD4 cell count) - Depression: Hamilton Depression Inventory (Reynolds & Kobak, 1995) - Anxiety: four items assessing health-related anxiety within the past week: troubles with sleeping, eating, socializing and school/work activities in reaction to thinking about HIV/AIDS and health (D Murphy, Steers, & Dello Stritto, 2001) - Reported physical health: Physical functioning, bodily pain and vitality sub-scales from the Medical Outcome Short Form 36 (Ware & Sherbourne, 1992) 	- Main effects	<p>No evidence of main effects:</p> <ul style="list-style-type: none"> - No significant association found between social support and any of the health outcomes
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10	Robbins, M., et al. (2003). The Protective Role of the Family and Social Support Network in a Sample of HIV-Positive African American Women: Results of a Pilot Study. <i>Journal of Black Psychology, 29</i> (1), 17-37.	Social network size/availability and satisfaction with support: Social Support Questionnaire six-item version SSQ6 (Sarason, et al., 1987).	<p>Stressor: disease progression, indicated by average monthly reduction in CD4 count</p> <p>Anxiety and Depression: SIGH-AD (Williams, Ware, Donald, & Donald, 1981).</p>	- Stress-buffering (tested through separate regression analysis for participants with low and high levels of support)	<p>Evidence of stress buffering:</p> <ul style="list-style-type: none"> - Social support satisfaction moderated the relationship between negative changes in health status (CD4 count changes) and psychological distress: average monthly decrease in CD4 cell count predicted psychological distress only among women with low social support satisfaction - No evidence of a moderating effect of social support network size
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11	Rotheram-Borus, M., et al. (2010). Benefits of Family and Social Relationships for Thai Parents living with HIV. <i>Prevention Science</i> 11 (3), 298 - 307	Functional aspects of social support (perceived availability of types of support): Medical Outcomes Study Social Support Scale (Sherbourne & Stewart, 1991)	<p>Depression: 15-item screening test developed and used previously in Thailand (Thai Department of Mental Health, 2006).</p> <p>Perceived physical health: three items from the MOS-HIV Health Survey Manual (Wu, 1999)</p> <p>Quality of life: Thai version of the Short Form (26 items) of the WHO Quality of Life Questionnaire (Thai Department of Mental Health. Ministry of Public Health, 1998; World Health Organization, 2004)</p>	- Main effects	<p>Evidence of main effects:</p> <ul style="list-style-type: none"> - Higher levels of social support directly associated with less depression - Higher levels of social support indirectly associated with better perceived physical health through less depression and better quality of life
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12	Sharts-Hopko, N., et al. (1996). Problem-Focused Coping in HIV-Infected Mothers in Relation to Self-Efficacy, Uncertainty, Social Support, and Psychological Distress. <i>Journal of Nursing Scholarship</i> , 28(2), 107-111.	Perceived social support availability and conflict/perceived cost of support: short form of the Interpersonal Relationship Inventory (IPRI) (Tilden, 1991).	<p>Stressors: no specific measure of stress used, though potential stressor variables included unemployment and length of child's illness</p> <p>Coping: Problem-focused coping subscale from the Ways of Coping Revised Checklist (S Folkman & Lazarus, 1980, 1985)</p> <p>Psychological Distress: The Brief Symptom Inventory (Derogatis & Spencer, 1982)</p>	<ul style="list-style-type: none"> - Direct main effects - Main effects, as mediated by problem-focused coping 	<p>No evidence of stress-buffering and main effects only of the cost of support subscale:</p> <ul style="list-style-type: none"> - No significant relationship between the social support subscale and distress - Perceived <i>cost</i> of support subscale associated with less psychological distress
13	Silver, E., et al. (2003). Factors Associated with Psychological Distress in Urban Mothers with Late-Stage HIV/AIDS. <i>AIDS and Behavior</i> , 7(4), 421-431.	Structural and functional dimensions of support systems: Multidimensional Social Support Inventory (Bauman & Weiss, 1995)	<p>Psychological distress: Psychiatric Symptom Index (Ilfeld, 1976) .</p>	<ul style="list-style-type: none"> - Main effects 	<p>Evidence of main effects:</p> <ul style="list-style-type: none"> - More social support associated with higher depressive symptoms - Higher perceived adequacy of support associated with less distress (though relationship is weak)

14	<p>Stock, M. (2001). <i>The effects of received and perceived social support on the health status of HIV-positive African-American women</i>. Doctoral thesis, Tulane University, U.S.A., Louisiana.</p>	<p>Perceived support availability: questions from the Social Support Scale (Belle, 1982) Received social support: 2-item subset of questions from a semi-structured interview instrument, the Descriptive Interview (Morse et al., 1993).</p>	<p>Physical health status: medical chart review to abstract data on CD4 count and CDC staging (Center for Disease Control's classification system to categorize progression of HIV disease, based on both CD4 count and opportunistic illnesses; (Centers for Disease Control and Prevention, 1992))</p> <p>Perceived health: participants asked how they would describe their physical health.</p>	<p>- Main effects</p>	<p>Evidence of main effects:</p> <ul style="list-style-type: none"> - Direct positive relationship between perceived emotional support and better health (as measured by CD4 count and CDC staging) - Negative relationship between perceived economic dependence on others and CD4 count - Daily dependence on others was positively associated to subjective health - No relationship between received support and health outcomes - Perceived economic dependence inversely related to health measured by CD4 count.
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15	Wyatt, A. (1997). <i>Prediction of hopelessness among HIV positive mothers: Evidence for the social support buffering and diathesis-stress models</i> . Doctoral thesis, Chicago Medical School, Illinois, U.S.A.	Social network size and satisfaction with support: Abbreviated version of the Social Support Questionnaire SSQ6 (Sarason, et al., 1987).	Hopelessness: Hopelessness scale (Beck, Weissman, Lester, & Trexler, 1974) Depression: CES Depression scale (Radloff, 1977).	- Stress-buffering (explored through interaction terms in regression analysis)	Evidence of stress buffering: - Social support, especially satisfaction with support, is associated with less hopelessness among mothers under high, but not low, stress, and for mothers with low internal locus of control.
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University of Cape Town

3.3.1 Stress-buffering effects of social support on (mental) health

Two studies provided evidence of stress-buffering of specific (general life or HIV-related) stressors through interaction terms in regression analysis (pathway *a* in Figure 3.2). Robbins et al (Robbins, et al., 2003) found that social support satisfaction moderated the relationship between change in health status (as measured by change in CD4 cell counts) and psychological distress. Specifically, among HIV-positive mothers with low social support satisfaction, the average monthly decrease in CD4 cell count predicted increased psychological distress; instead, for participants who reported high support satisfaction, there was no evidence of a similar relationship between this indicator of physical health status and distress. Moreover, the authors' analysis did not show significant relationships between social network size and distress, suggesting that it was the quality, rather than quantity, of social support that moderated these mothers' psychological distress reactions (Robbins, et al., 2003). Wyatt (Wyatt, 1997), instead, focused on the construct of hopelessness and found social support, especially satisfaction with support, to be a predictor of less hopelessness for HIV-positive mothers under high stress, but not for mothers with low stress.

3.3.2 Main effects of social support on health outcomes

Eight studies found evidence of at least one significant direct association between at least one dimension of social support and at least one mental or physical health outcome explored. Most of these studies found positive associations between more social support and better health, however three studies also document negative relationships, for which authors

provide possible explanations included below. Findings related respectively to main effects on mental health (represented by pathway *e2* in Figure 3.2) and physical health (represented by pathway *e1* in Figure 3.2) are described below. Moreover, three studies found evidence of indirect main effects of social support on mental health, mediated by coping processes (represented by the *b/d* pathway in Figure 3.2).

Direct positive associations between social support and health. Seven studies provided evidence of a positive association between social support and mental health outcomes, one study found social support to be positively associated with physical health outcomes, and one study's findings suggest an indirect effect of social support on physical health through its association with mental health.

Five studies found a positive relationship between a functional measure of social support (perceived availability or adequacy) and a measure of psychological distress among HIV-positive caregivers. Mellins et al (Mellins, Ehrhardt, Rapkin, & Havens, 2000) found that increased social support was associated with fewer symptoms of mental health conditions among HIV infected mothers of young children. Various dimensions of social support were found to directly impact psychological distress and psychiatric disorder. While some of these associations held across stress levels (i.e. availability of support on psychiatric symptoms and adequacy of support on demoralization), others were significant only for mothers experiencing low levels of stress (e.g. more negative support with more demoralization and more support adequacy with less psychiatric symptoms), suggesting that at high levels of stress the impact of this stress on mental health might be too large to witness the support impact (Mellins, et al., 2000). Hough et al (Hough, et al., 2003) found social support to have a direct effect on distress among HIV-positive mothers even after accounting for its indirect

effect on coping behaviour. Gay (1995) found that social support satisfaction was directly associated with less self-reported psychological distress. Klein et al (Klein et al., 2000) showed that higher levels of parenting support and support from neighbours and friends, were associated with less psychological distress. Rotheram-Borus et al (Rotheram-Borus, et al., 2010) found functional dimensions of social support to be significantly correlated with better quality of life and less depression among Thai parents living with HIV. Silver et al (Silver, Bauman, Camacho, & Hudis, 2003) found that higher rated adequacy of support was negatively associated with psychological distress among mothers with late stage HIV/AIDS, although its relationship to distress was quite modest. Only one study (Cook, 1997) focused on anxiety as an outcome and found that greater emotional closeness or attachment in relationships was associated with less anxiety among HIV-positive mothers of young children.

In addition, one study reviewed found a direct positive relationship between social support and physical health indicators (Stock, 2001). Stock (Stock, 2001) found that perceived emotional support from others and support from friends and neighbours were the most important factors positively influencing the health status of HIV-positive mothers (as measured by CD4 count and CDC staging); this was not the case, however, for received support. More specifically, emotional support and support from friends and neighbours were positively associated with better health status. Moreover, a measure of daily dependence (aimed at determining whether the participant had people who could help and how much he/she depended on them for emotional, economic help and daily coping (Morse, et al., 1993)) was associated with better subjective physical health.

Rotheram-Borus et al.'s (Rotheram-Borus, et al., 2010) study also suggests a possible indirect positive effect of social support on physical health through mental health, by including respective pathways between social support and mental health and mental health

and physical health in the same model. As indicated above, the authors found social support to be significantly correlated with better quality of life and less depression; in turn, less depression was associated with better ARV adherence and better perceived physical health. This pathway is represented by the bidirectional *f* arrow included in diagram 3.2, intended to illustrate potential associations between mental and physical health outcomes. However, it may also be considered to represent an example of a psychological process through which social support has a main effect on physical health (pathway *b/d*) (House, Umberson, et al., 1988).

Direct negative associations between social support and health. Two studies found a negative relationship between a dimension of social support and a mental health outcome and one study found a negative relationship between social support and a physical health outcome⁵.

Silver et al.'s (2003) analysis showed that receiving more social support was significantly related to higher depressive symptoms among low income mothers with late stage HIV/AIDS. Authors concluded that this probably reflected greater mobilization of the support system among the women experiencing the most distress (2003). Instead, Klein et al. (2000) found that, while support from neighbours and friends was associated with less psychological distress, higher levels of emotional support from children cared for were associated with greater psychological distress. An explanation for this finding offered by the

⁵ It is also worth mentioning that Sharts-Hopko et al. (1996) found that the perceived cost of social support was inversely associated with psychological distress among HIV-positive mothers; however this has not been included among reported negative associations between social support and health, since the cost of support is a distinct concept from that of availability of social support.

authors was that support from children could reflect the absence of adult sources of support, which are generally preferred (Barbee, Derlega, Sherburne, & Grimshaw, 1998), as well as the inability of the child to meet the adult's emotional needs (Klein, et al., 2000).

Stock's (2001) analysis also found a negative relationship between one component of a perceived social support scale and physical health. Specifically, perceived economic dependence was found to be inversely related to CD4 count among HIV-positive mothers in her study, thus associated with worse health status (Stock, 2001). However, as the author suggested, it is likely that the inverse direction of causality held in this case; that is that HIV-positive women with more advanced HIV illness were more likely to be unable to work and hence economically dependent (Stock, 2001). Hence this construct may not have been the most appropriate to measure perceived support in relation to health in this situation, as it likely indicated support needs rather than availability.

Evidence of indirect effects of social support on mental health through coping processes. While five studies found evidence of a direct association between social support and coping styles or processes (Burns, et al., 2008; Cook, 1997; Gay, 1995; Hough, et al., 2003; Leslie, et al., 2002; Prado, et al., 2004), only three of these studies also found a significant relationship between these coping processes and carer mental health outcomes, thus suggesting a main effect of social support as mediated by coping styles (pathway *b/d* in Figure 3.2).

Prado et al (Prado, et al., 2004) and Burns et al (Burns, et al., 2008) found that, among low-income HIV-positive mothers, a larger social support network was a significant predictor of more support coping and active coping and less avoidant coping, indicating that more available supportive persons were associated with more utilization of support (support

coping), the use of positive reframing, planning and taking action as coping responses (active coping) and with less use of avoidant coping such as disengagement, distraction and suppression of thoughts (Carver, 1997). In turn active coping was associated with less psychological distress and avoidant coping with greater psychological distress. Thus, social support network size was posited to have an indirect (positive) effect on distress through these two coping strategies. Once controlling for coping, no significant direct relationship between social support and psychological distress was found, suggesting that the effect of social support on distress occurred entirely through its effect on coping, in line with stress-process models.

Similarly, Hough et al.'s (2003) findings suggested a positive effect of both functional and structural aspects of social support on the use of active meaning-making coping, which in turn was associated with decreased emotional distress in mothers (Hough, et al., 2003). Active meaning-making coping referred to forms of active and support coping employed specifically to cope with illness; this includes active cognitive efforts to deal with the appraisal of the stressfulness of the illness, active-behavioural efforts that deal with problems related to illness and reliance on others for support (Namir, et al., 1987; Namir, D Woolcott, F Fawzy, & M Alambaugh, 1990).

In her work with HIV-infected mothers of HIV-infected children, Gay (Gay, 1995) also found evidence of a relationship between social support and these mothers' psychological distress, mediated through coping processes. Specifically, more social support availability and satisfaction were associated with a less disengaged coping style; less disengaged coping was in turn associated with less self-reported psychological distress. The disengaged coping construct used in this study was similar to passive or avoidance coping variables in the studies cited above; it included behaviours such as problem avoidance, self-criticism and self-withdrawal. Unlike the Prado et al (Prado, et al., 2004) and Burns et al

(Burns, et al., 2008) study, however, both Hough et al (Hough, et al., 2003) and Gay (Gay, 1995) found significant residual main effects of social support on distress levels once controlling for coping; this suggested that the effect of social support on these carers' mental health occurred in part through other channels.

3.4 Discussion of findings, strengths and weaknesses of studies reviewed

3.4.1 Synthesis and discussion of findings

Findings of relevant studies retrieved in this systematic review will be discussed with reference to the House et al theoretical framework and the key questions guiding the review, defined above in Section 3.2. In terms of the existence and direction of relationships, the majority of studies reviewed found evidence of a significant positive association between at least one dimension of social support and at least one health outcome among HIV-positive caregivers of children. In particular, findings confirm the importance of social support for the mental health of these caregivers, as most studies focused on mental health outcomes.

Findings were not, however, consistent across studies, as a minority of studies did not find significant associations or even found negative associations (i.e. social support associated with worse health outcomes). This is in line with previous research on social support which suggests that protective effects of this support on mental health are not uniform across groups in society (Kawachi & Berkman, 2001); outcomes may differ depending on the interaction between the type of stressor, the type of social support and the individual context (Li, et al., 1997), and in some cases social support responses can even be

‘negative’ (B. Andrews, Brewin, & Rose, 2003; Kawachi & Berkman, 2001). Outcomes are also closely linked to constructs and measurement tools utilised; as indicated above, the choice of these variables may explain some of the negative relationships observed in these studies. Overall, findings of studies reviewed also appear to confirm the importance of perceived availability and adequacy of support for health outcomes, though it is difficult to draw strong conclusions from this review as fewer studies explored structural dimensions of support.

Consistent with the broader existing research on social support and health among adult populations, most studies found evidence of either stress-buffering or main effects of social support or both. Though evidence for main effects was stronger, it should be noted that a much larger number of studies explored main versus stress buffering effects. Nevertheless, this beckons attention to Lakey and Orehek’s (Lakey & Orehek, 2011) argument that more attention should shift towards a better understanding of the more frequently-observed main effects and the processes that may explain these. It should also, however, be noted that in the case of stress-buffering of specific stressors explored through moderation analysis, associations between outcomes will invariably depend on the stressors and indicators chosen. The lack of an expected outcome may also indicate that the stressors explored may not be the most important for the population in question and/or those for which social support plays a key role in attenuating mental health effects. A similar argument can be made for structural equation models (SEM) that fail to find significance for (all) expected associations between stressors explored, specific coping responses and distress.

In terms of a greater understanding of the biopsychosocial processes explaining the effects of social support on health outcomes (House, Umberson, et al., 1988), the studies reviewed offer little insight beyond exploring coping processes as a mediating factor for main effects. Findings suggest that social support can positively affect mental health among HIV-

positive carers by increasing the likelihood of active strategies (including seeking support and dealing constructively with stressors) and decreasing the likelihood of passive strategies (e.g. avoidance, emotion-based coping) in coping with stress. With reference to the theoretical framework, this suggests that social support is influencing health among HIV-affected caregivers through both psychological (appraisal) and behavioural processes related to coping. Interestingly, these studies assessing coping as a mediator only test for and find *main* effects of social support mediated by coping, despite the fact that coping processes are more typically associated with stress-buffering. This does not, however, exclude the existence of stress-buffering effects mediated through similar coping processes. Also, it should be noted that not all studies in this review showing associations between social support and coping styles provide evidence of these effects translating into better health outcomes. Furthermore, two of the three studies showing indirect effects on health through coping also show a residual direct relationship between social support and health, suggesting that there may be co-existing alternative mediating processes through which social support is influencing health in this population. One study reviewed (Rotheram-Borus & Stein, 1999) also provides evidence that social support may be positively influencing physical health through mental health, which could be considered an example of a psychological mediating process (House, Umberson, et al., 1988).

3.4.2 Methodological strengths and weaknesses of studies reviewed

The articles retrieved had a number of methodological strengths. For example, most were peer-reviewed articles published in academic journals, suggesting a high standard and level of scientific rigour. Also, most were guided by a theoretical framework (e.g. stress-

coping models) or clear arguments based on existing empirical literature. The majority of studies employed multivariate analytical methods or structural equation modelling, which allowed for the assessment of the relative importance of key variables and mediation analysis.

In contrast, a key weakness of these studies was their limited geographical and population focus. As indicated above, most studies (all but one) were conducted in the USA. The large majority (13 of the 15) worked with samples of only mothers or female caregivers of children, and the sample of the remaining two studies consisted predominantly of women (Leslie, et al., 2002; Rotheram-Borus & Stein, 1999). Sample sizes were relatively small and most samples were recruited from clinics (versus household surveys) so they were not representative of the general population of caregivers. Most of the studies did not work with control or comparison groups of HIV-negative caregivers, thus limiting the ability to compare outcomes between HIV-positive and other carers⁶. Moreover, most of the studies were cross-sectional; while SEM models construe causality based on theory, longitudinal data would be better suited to explore causality (Turner, 1981). Most of the studies were also dated (1990s and early 2000s).

⁶ Only 1 study (Klein et al, 2000) conducted comparative analysis with a control group of HIV-negative caregivers with similar demographic characteristics, and worked with longitudinal data from two assessments conducted over 12 – 14 months. Differences in results regarding the association between types of socio-emotional support and psychosocial functioning among HIV-positive versus HIV-negative caregivers were tested in the regression models using interaction terms (HIV status x type of support). No significant differences were found. However, the study showed that HIV-infected women reported lower levels of emotional support from children and from neighbours and friends, as well as higher levels of psychological distress. Longitudinal analysis highlighted the importance of socio-emotional support from friends and neighbours as a resource factor; that is: an increase in the level of this support was associated with a decrease in levels of psychological distress.

It should also be highlighted that where studies only test for one type of effect (stress-buffering or main), it is not possible to conclude that the other is not present. Similarly, where mediating pathways are not explored, it is not possible to know the biopsychosocial processes through which effects occur (House, Umberson, et al., 1988). For example, if stress-buffering is observed but coping processes are not explored as mediating variables, it is not possible to determine whether buffering effects observed occur through coping or other pathways.

3.5 Research gaps emerging from the systematic review

Based on both the methodological limitations of studies and the theoretical framework presented in Figure 1.1, a number of gaps and opportunities emerge for future research. First, given the location, dates and methodological limitations of studies reviewed, there is clearly a need for research exploring associations between social support and health outcomes of HIV-positive caregivers in Southern Africa and other parts of the developing world. In these areas most affected by the HIV/AIDS epidemic, experiences of caregiving and health challenges are no doubt significantly different from those faced by populations in the USA and developed world. There is also a need for larger studies with samples that are more representative of general caregiver populations. In particular, further attention should be paid to research with caregivers of non-biological children living with HIV, such as grandparents or older carers, who are taking on increasing caregiving responsibilities in the context of high young adult mortality in Southern Africa (Kimuna & Makiwane, 2007). Moreover, studies with HIV-negative control or comparison groups of caregivers with similar socio-demographic characteristics would allow one to identify similar and differing outcomes between HIV-positive and HIV-negative caregivers.

With reference to the theoretical framework guiding this review and broader doctoral research (House, Umberson, et al., 1988), a number of gaps are evident. For example, there is a need to focus further on the effects and processes through which social support may be influencing *physical* health among HIV-affected caregivers. While the studies conducted to date provide some evidence of positive associations between physical health outcomes and social support, most of the studies focused on mental health outcomes. Also, as is the case for the broader literature on social support and health, most studies in this review looking at mental health outcomes focused on depression or psychological distress. It would be useful for future research to explore other mental health outcomes such as anxiety, which, for example, has been found to be the most common mental health disorder among the general population in South Africa, and, more specifically, among caregivers of children in HIV-endemic communities (Herman et al., 2009; Kuo & Operario, 2011). Further attention should also be dedicated to investigating the extent to which effects on physical health outcomes may be mediated by or associated with these mental health outcomes.

Moreover, as the large majority of studies included in this review investigated main effects, further focus among this population should be afforded to testing stress-buffering effects as well as these main effects, specifically with regard to HIV/AIDS-related stressors. Also, while study findings point to both stress-buffering and main effects on health, further research would be needed to obtain a better understanding of the mechanisms or processes through which these effects occur. For example, none of the studies reviewed explored the potential physiological processes through which social support may have been influencing physical or mental health, nor the potential behavioural or psychological mediating processes beyond coping.

CHAPTER 4. BROADER LITERATURE REVIEW ON THE HEALTH RISKS OF HIV AND CAREGIVING, AND THE PROTECTIVE ROLE OF SOCIAL SUPPORT

The systematic review presented in the previous chapter exposed a relatively small number of existing studies (15) quantitatively investigating the relationship between social support and health outcomes among the population of particular interest for this study – that is, HIV-positive caregivers of children. Therefore, in order to better contextualize systematic review findings and this doctoral work within the broader literature on HIV, caregiving and social support, a further, broader literature review was conducted. The aim of this review was to identify and synthesize the global literature focusing on: a) the respective health risks associated with living with HIV, and providing care for children, and; b) the protective role of social support for health among populations of HIV-positive adults and adult caregivers of children.

First, this chapter will present and discuss key findings of the literature reviewed, highlighting work conducted in Southern Africa and other parts of the developing world. Second, this chapter will discuss existing research gaps and important areas for future research on social support and health among HIV-positive caregivers of children. This discussion will be based not only on the literature review presented in this chapter, but also on the theoretical and empirical work outlined in Chapter 2, and the systematic review with HIV-positive caregivers of children discussed in Chapter 3. The aim is to comprehensively define the existing research gaps to which this study aims to contribute.

4.1 Health risks associated with HIV and caregiving

An HIV diagnosis and/or living with the disease may be considered a key stressor for health. HIV-positive individuals have heightened physical and mental health risks, especially as the severity of the disease increases. Similarly, caring for children has been shown to be associated with increased stress and mental health risks, especially when the caregiving burden is high and/or caregivers are looking after foster children. Adults caring for children who are also living with HIV may be especially at risk for poor physical and mental health, as they would be dealing with stressors related both to caregiving and living with HIV. This section will review the published literature(s) on HIV and child caregiving as respective risk factors for health, and consider the implications of the combined experience of child caregiving and HIV.

4.1.1 Physical health effects of HIV

Since the physical health risks and implications of living with HIV/AIDS are well documented (see for example: Barnett & Whiteside, 2006; Schneider et al., 2008; Schoub, 1999; World Health Organisation, 2005) they will only be briefly discussed in this section, and greater attention will be afforded to the mental health implications of the disease.

Once contracted, the Human Immunodeficiency Virus attacks and destroys human immune system cells known as CD4 cells, thus progressively debilitating the immune system and allowing for opportunistic infections, such as tuberculosis, to attack the body. AIDS, Acquired Immunodeficiency Syndrome, refers to the late stage of HIV infection, when a

person's immune system is severely damaged and has difficulty fighting diseases. The progression of HIV to AIDS usually takes about 8- 10 years, but may be as short as 2 or 3. While HIV-status is usually determined by diagnostic (blood) tests and AIDS by a CD4 count below an indicated threshold, these clinical parameters may be difficult to determine in resource-limited settings with limited laboratory access. As a result, organisations such as the World Health Organisation and the US Centers for Disease Control have introduced clinical staging systems, which identify various stages of disease progression, based on the presence of HIV-related symptoms and, where available, CD4 count (Centers for Disease Control and Prevention, 1992; World Health Organisation, 2005).

In the absence of treatment, once HIV progresses to AIDS, infections will become more frequent and severe until the infected person dies; this will occur over a period of approximately 12 – 24 months. However, the introduction of ART (antiretroviral therapy) in the mid-2000s has increased the life expectancy of many people living with HIV who are able to access treatment, thus decreasing AIDS-related mortality (UNAIDS, 2010). For many, HIV has therefore been transformed from a 'death sentence' into a chronic disease. However, the limited available data from resource poor settings (Buyondo, Batamwita, Featherstone, & Mills, 2011; Myezwa, Buchalla, Jelsma, & Stewart, 2011; Myezwa, Stewart, Musenge, & Nesara, 2009) and experiences from resource rich settings (Nixon et al., 2011; O'Brien, Bayoumi, Strike, Young, & Davis, 2008; O'Brien, Wilkins, Zack, & Solomon, 2009) indicate that living longer with the HIV is often accompanied by the experience of morbidity and HIV-related disability. This is the result of both the disease itself and the side-effects of treatment, and represents one of the most significant 'secondary' health-related impacts of the epidemic in a post-ART era. Thus, while ART has changed the trajectory of the disease and the type and experience of physical and mental conditions, living with HIV and on treatment continues to represent a significant stressor for health.

Moreover, the pace of disease progression and the intensity of the physical health effects of the disease are likely to be greater in many communities of Southern Africa and the developing world, which are facing situations of widespread poverty, food insecurity, difficult access to quality health care and other livelihood stressors (Barnett & Whiteside, 2006; Belue, et al., 2008; Casale, 2011; Howard, et al., 2006; Ssengonzi, 2009).

4.1.2 Mental health effects of HIV

Literature showing associations between HIV and worse mental health. Various studies, conducted in both the developed and developing world, provide evidence of worse mental health among HIV positive individuals, compared to HIV-negative control groups or normative population data. These findings are not surprising, since poorer mental health has been associated with the presence of many other serious medical illnesses (see for example: Ciesla & Roberts, 2001; Rodin & Voshart, 1986). For example, the World Health Organisation reported that HIV prevalence rates in mentally ill inpatients and outpatients in the USA were estimated to be between 5% and 23%, compared to the 0.3 – 0.4% in the general population (World Health Organisation, 2008).

The existing global literature on HIV and mental health points most strongly to a relationship between HIV infection and depression or psychological distress, as studies in both high and low income countries have found higher rates of psychological distress and depression among HIV positive individuals (Folkman, et al., 1993; Sherr, et al., 2011; World Health Organisation, 2008). There is a smaller body of literature showing significant relationships between a positive HIV status and other mental health conditions, such as

anxiety, PTSD and suicidal ideation. For example, a review of the US and global literature on psychosocial factors and HIV revealed a significant body of evidence highlighting a greater prevalence of depression, anxiety and PTSD among HIV-positive individuals than in the general population (Whetten, Reif, Whetten, & Murphy-McMillan, 2008). A 2001 systematic review conducted by Sherr et al showed that the prevalence of PTSD among people living with HIV ranged from 5% to 74%, significantly greater than the prevalence (7–10%) in the general population (Sherr et al., 2001). A more recent systematic literature review on HIV infection and suicidal behaviour revealed a high suicidal burden among people with HIV (Catalan et al., 2011); autopsy studies showed that 9.4% of HIV-positive study participants had committed suicide, 26.9% reported suicidal ideation and 22.2% had a suicide plan. Though these reviews identified the existing global literature on these themes, it should be noted that the large majority of papers found and reviewed were from North America and Europe.

There are also numerous studies showing associations between worse physical health status, including severity of symptoms and disease progression, and worse mental health of HIV positive individuals. For example, higher rates of psychological distress or depression among HIV positive individuals have also been shown to be related to the severity of HIV-related symptoms and/or disease progression (Folkman, et al., 1993; Leserman, 2003; Linn, et al., 1995; Sherr, et al., 2011; World Health Organisation, 2008). There is also evidence that individuals with more HIV-related symptoms and infected for a longer time are more at risk for mental health conditions such as depression, anxiety and PTSD (Whetten, et al., 2008; Zinkernagel et al., 2001).

Despite key differences in the nature and trajectory of the epidemic in Southern Africa versus the developed world, the smaller body of literature from the Southern African region highlights similar associations between HIV and mental health outcomes. A 2011 systematic

review of 104 papers on HIV/AIDS and mental health research in sub-Saharan Africa showed high overall prevalence levels of mental illness among people living with HIV, with most studies reporting over 19% prevalence of mental health conditions (Breuer, et al., 2011). Studies reviewed clearly revealed higher frequencies of depression among PLWHIV in relation to the general population, however findings on anxiety and PTSD were less clear, in part due to study limitations (e.g. absence of control groups). It was also shown that mental disorders such as depression were higher in people with more HIV symptoms and late stage disease (Breuer, et al., 2011).

Explaining observed associations between HIV/AIDS and worse mental health.

An HIV diagnosis and the experiences of living with the disease can be a source of significant stress, leading to worse mental health (Sherr, et al., 2011). Infected individuals face multiple potential HIV-related stressors, including experiences of physical illness, financial stressors, fear of disclosure, social isolation or stigma and fear of death (Clucas, et al., 2011; Sherr, et al., 2011; World Health Organisation, 2008). A 2001 meta-analysis of (ten) published studies showed that HIV-infected individuals had higher rates of depressive disorder (Ciesla & Roberts, 2001) than the general population, but lower rates than those observed in medical inpatients; this led the authors to conclude that it might not be the HIV infection itself, but associated factors such as stigma and environmental stressors, accounting for these findings (Ciesla & Roberts, 2001). Brandt's (2007) qualitative work with HIV-infected mothers in South Africa supported quantitative findings on the impact of HIV on psychological distress, but highlighted poverty as an 'underlying narrative' that 'filtered' their experience of living with HIV; at times this poverty had greater importance as a stressor for these women than HIV in itself (Brandt, 2007). More generally, there is strong evidence to show that poverty is associated with worse mental health (Brandt, 2009; Patel & Kleinman,

2003; World Health Organisation, 2001), and that poverty can be a driver of HIV (Casale & Whiteside, 2006; Eaton, Flisher, & Aaro, 2003; Hallman, 2004) pointing to risks for mental health among HIV-infected individuals living in poor Southern African communities.

Apart from the potential psychological impact of living with HIV, the disease can also directly affect the central nervous system and cause neuropsychiatric conditions such as depression, mania, cognitive disorder and dementia (World Health Organisation, 2008). Neuropsychiatric and psychological problems among PLWHIV cannot be completely dissociated, however, as the one may influence the other; for example, conditions of people with neurological disease may worsen as a result of depression and distress (Gibbie et al., 2006; Rackstraw, 2011).

While this research is interested primarily in HIV as a stressor for health, and therefore the effects of HIV/AIDS on physical and mental health outcomes, it is important to note that the causal relationships explaining associations between HIV status, disease progression and mental health may be complex and/or bidirectional. For example, it has been shown that persons with mental health disorders (e.g. substance-use disorders and risky sexual behaviours) are more at risk of contracting HIV (Brandt, 2009; World Health Organisation, 2008); this is reinforced by studies showing mental health conditions, such as anxiety, to predate infection (Clucas, et al., 2011). It is also possible that greater distress among HIV-positive individuals may adversely affect disease progression and symptoms, for example through effects on immune functioning. For example a study with 40 HIV-positive gay men affected by a hurricane in the USA found greater optimism to be associated with better cellular immunologic control; this relationship was partially mediated by lower depression levels (Cruess et al., 2000). A treatment trial conducted by Ferrando et al (1997) showed that treating depression among HIV-positive men and women with medically symptomatic HIV or AIDS led to significant reductions in both affective and somatic

symptoms, some of which had been attributed to HIV rather than depression; findings suggest that the contribution of depression to perceived somatic symptoms in HIV-positive individuals may be considerable, even in later stages of the disease.

Thus, evidence of positive associations between mental health outcomes such as depression, and disease progression (measured, for example, by the rate of decline of CD4 count) may indicate that these mental health conditions are causes or results of disease progression, or, more likely, that they have “a complex interaction in both” (Sherr et al., 2011; p. 494). Not surprisingly, given links between mental health and disease progression, worse mental health status in HIV-infected individuals has also been associated with higher mortality rates (Antelman et al., 2007; Ickovics et al., 2001; Sherr, et al., 2011).

Mental health implications of ART for HIV-positive individuals. Given the extent to which the introduction of antiretroviral treatment (ART) of HIV has changed the trajectory of the epidemic, at both a macro and individual level, it is useful to briefly consider the mental and physical health implications of ART for people living with HIV. In fact, the relationship between mental health and ARV uptake is also potentially complex and bidirectional. On the one hand, mental health disorders (e.g. depression or cognitive impairment) have been shown to affect health-seeking behaviour and treatment uptake/adherence (Brandt, 2009; Mellins, Kang, Leu, Havens, & Chesney, 2003; Pence, 2009; World Health Organisation, 2008). On the other hand, ART may have a positive effect on mental health among HIV-positive individuals on treatment, as HIV-related stress and mental health may improve with a decrease in HIV-related symptomology. For example, Brandt (2007) assessed depression and anxiety among 80 South African HIV-positive mothers before and six months after receiving antiretroviral therapy; while the therapy

appeared to not have an impact on anxiety, depression among these women was found to have declined (Brandt, 2007). Successful treatment adherence and reduced symptomology may also lead to HIV becoming less of a stressor compared to other life challenges. For example Brandt's qualitative work also revealed that among women on HAART who were relatively asymptomatic, HIV was not the key source of stress, compared to poverty-related stressors.

Yet while anti-retroviral therapy can be effective in reversing neurocognitive deficits, there is also evidence that the therapy itself can have negative side effects on the nervous system, including depression, nervousness and psychosis (Gibbie, et al., 2006; Rackstraw, 2011; World Health Organisation, 2008). As indicated above, data from both the developed and developing world show that living longer with HIV is accompanied by the experience of increased physical and mental illness and disability. This is the result of both the disease itself and the side-effects of treatment.

4.1.3 Health effects and risks related to child caregiving

Research deriving mainly from the developed world shows that stress related to caregiving responsibilities and strain can negatively affect the mental and physical health of caregivers (Pinquart & Sorensen, 2007; Schofield et al., 1999). More specifically, there is substantial evidence that stressors related to child caregiving responsibilities can have adverse health effects for carers of children. This may be true for both biological parents and relatives or other foster caregivers. For example, a cross-sectional study with 846 low-income mothers of young children in the UK revealed a high prevalence of depressive symptoms among this sample, with approximately one third of mothers suffering from depression,

associated with high levels of reported stress (Reading, 2005). An Australian study with 354 single and 1689 partnered mothers found a high prevalence of mental disorders among single mothers, especially single mothers facing financial hardship (Crosier, Butterworth, & Rodgers, 2007). A study conducted in the USA with 486 Ohio grandmothers, including caregivers of grandchildren, showed that primary caregivers had worse self-reported mental and physical health than non-caregivers (Musil, et al., 2009). Other research with grandparent child carers in the USA showed that grandparents with higher parenting stress reported lower levels of physical, social, and mental health (Leder, et al., 2007).

Focusing specifically on the Southern African region, various quantitative and qualitative studies highlight how the demands of caregiving can negatively impact physical, emotional, financial and even social stress among foster and biological caregivers of children in HIV-endemic areas (Belue, et al., 2008; Casale, 2011; Howard, et al., 2006; Ssengonzi, 2009). Once again, this is especially true in a context of widespread poverty, food insecurity, displacement, stigma and other stressors these carers are having to face, often in the absence of adequate public sector or community safety nets (Drimie & Casale, 2009; Howard et al., 2006; Kipp, Matukala Nkosi, Laing, & Jhangri, 2006). In many Southern African communities, the burden of care for children falls primarily on women for various reasons, including traditionally accepted gender roles of women as principal care providers and the absence of men in the homes (Akintola, 2006; Campbell & Foulis, 2004; Freeman & Nkomo, 2006; Kipp, et al., 2006). Moreover, given high rates of young adult mortality and morbidity in HIV-endemic areas, caregiving responsibilities are being increasingly taken on by older adults, who are at higher risk of caregiving-related fatigue and health conditions (Pinquart & Sorensen, 2007; Ssengonzi, 2009; World Health Organization, 2002).

There is also evidence, from both the developed and developing world, that providing care for orphaned and/or foster children may be particularly stressful and demanding (Linsk

& Mason, 2004), with consequences including poorer use of health facilities, greater concern with and neglect of one's own health, stress-related somatic complaints and chronic health conditions (Joslin & Harrison, 1998, 2002; Kuo & Operario, 2009; Linsk & Mason, 2004). This is particularly relevant in many HIV-endemic areas of Southern Africa, where individuals (mainly grandparents or other members of extended families) are increasingly taking responsibility for non-biological children, given high mortality of prime age adult parents (Freeman & Nkomo, 2006; Howard, et al., 2006; Mudavanhu, Segalo, & Fourie, 2008; Ssengonzi, 2009). For example, two community surveys from HIV-endemic communities in the KwaZulu-Natal province of South Africa point to a greater caregiving burden and worse mental and general physical health outcomes of orphan (versus non-orphan) caregivers (Bachman DeSilva et al., 2008; Kuo & Operario, 2011). Reasons for this may include HIV-related stigma and stresses related to addressing the children's health needs (in the case of HIV-affected children), and concern regarding guardianship and care for the children after the caregiver's death (Casale, Drimie, Quinlan, & Ziervogel, 2009; Chazan, 2008; Hejoaka, 2009; Kanya & Poindexter, 2009; Mellins & Ehrhardt, 1994). Household poverty has also been shown to exacerbate caregiver health risks, and some studies have found that financial stressors are greatest in AIDS-impooverished households caring for orphans or HIV-affected children (Howard, et al., 2006; Lv et al., 2010).

Moreover, while this research focuses on the health status of caregivers, versus the children in their care, it should be noted that research also shows that caring for a child with a particular health condition or disability may be especially stressful. Parents of children with chronic medical conditions and disabilities may experience physical and emotional strain, financial challenges and social isolation, that can influence their physical and mental health (Kuster & Merkle, 2004). There are, in fact, numerous empirical studies, conducted primarily in North America, showing greater parenting stress and worse health outcomes among carers

of children with illness or disability, including children with HIV (Brehaut et al., 2009; Brown, 2007; Jessop, Riessman, & Stein, 1988; Ray & Ritchie, 1993; Vasquez, 2003). There is also qualitative evidence to support these findings. For example, in a qualitative study exploring caregiver perspectives of the health implications of long-term informal caregiving for children with disabilities (N. Murphy, Christian, Caplin, & Young, 2007), caregivers described their stress related to caregiving, their worry about the future and the negative physical, emotional and functional health consequences of long-term, informal caregiving (N. Murphy, et al., 2007).

Lastly, although this thesis focuses on caregiving burden as a stressor and health risk, it should not be forgotten that caring for children has also been shown to be a source of support, joy, pride and affection for caregivers in general, and for HIV-positive caregivers more specifically. Affection and responsibility for the children in one's care may also represent a source of resilience and a reason to live. For example, a meta-synthesis of qualitative literature documenting experiences of HIV-positive mothers showed that, despite the increased burden of motherhood (including disclosure, child care and custody issues), being a mother also provided women with support, self-esteem, and a reason to live and fight HIV infection (Gillespie, 2004).

4.1.4 Potential cumulative effects of caregiving and HIV on caregiver health

The health risks of caregiving are likely greater for caregivers of children who are also HIV-positive, as they would face both stressors deriving from living with HIV/AIDS and stressors associated with caregiving. These stressors may include HIV-related stigma and

social isolation (Akintola, 2008; Campbell & Foulis, 2004; Madavahnu, Segalo, & Fourie, 2008; Orner, 2006; Thomas, 2006), concern about their children's status (Bennetts et al., 1999) fear of disclosure of their own illness (Brandt, Dawes, & Bray, 2006; Demmer, 2011; Tompkins, Henker, Whalen, Axelrod, & Comer, 1999), AIDS-related physical symptoms, anxiety and fear of death or loss (Mudavanhu, et al., 2008; Thampanichawat, 2008) and concern around permanency planning for children (Tompkins, et al., 1999).

There is a fairly large body of literature, once again mainly derived from North America, that reveals the challenges and health risks for HIV-positive individuals who are also biological parents and/or primary caregivers of children. First, qualitative evidence highlights caregiving-related challenges and strain experienced by HIV-positive caregivers of children. For example, a qualitative study with HIV-positive female child caregivers in the USA and Canada showed that child concerns and caretaking roles were among the primary challenges these women faced in their daily life (Hackl, Somlai, Kelly, & Kalichman, 1997; Ndlovu, Jon, & Carvalhal, 2010). Another USA qualitative study with 28 grandparents and other relatives caring for children of HIV-positive biological parents (Linsk & Mason, 2004), highlighted the multiple stresses of these foster caregivers, which also differed according to their own status: HIV affected caregivers had more concern about parenting stress related to their own health and multiple tasks, while non-infected caregivers were more likely to report financial stress linked to caregiving.

Various empirical quantitative studies have found elevated rates of health disorders, especially depression, among HIV-positive biological or foster parents of children. For example, a quantitative study with HIV-positive mothers and fathers in the USA found increased parental role strain to be associated with increased depressive symptoms among both HIV-positive fathers and mothers (Semple et al., 1997). A study with 40 American and Latina HIV-infected mothers of small children in the USA found that prevalence rates of

lifetime psychiatric diagnoses were close to 90% and that histories of major depression and PTSD were most common (Mellins, Ehrhardt, & Grant, 1997). Another USA study exploring patterns of disclosure among 40 mothers infected with or affected by HIV showed that over 50% of these mothers met the DSM-IV diagnostic criteria for a psychological disorder in the preceding year, the most common conditions being PTSD and depression; perceived stress was shown to explain 43% of the variance in psychological adjustment (L. Murphy, Koranyi, Crim, & Whited, 1999).

Health risks for HIV-positive caregivers of children have also been shown to be higher for carers with greater activity limitation and more difficulty carrying out caregiving tasks. For example, Murphy et al (2002) found depression to be elevated among a sample of 135 mothers of young children (in the USA) diagnosed with HIV/AIDS, particularly for mothers who had greater difficulties performing regular daily tasks (D. Murphy, et al., 2002). Likewise, a study with 220 low-income HIV-positive mothers in the USA found that these mothers had high levels of psychiatric disturbance (Silver, et al., 2003) and that a higher level of symptoms was experienced by mothers with greater activity limitation and more difficulty carrying out caregiving activities due to ill health.

Nevertheless, in the absence of multiple comparison groups it is often difficult to distinguish between stresses related to caregiving burden and those related to living with HIV, or to determine different outcomes across specific groups (e.g. HIV positive, HIV-negative, caregivers of children versus non caregivers). Smith et al (2001), for example, find no statistically significant difference in levels of psychological stress between HIV-positive and HIV-negative recent mothers recruited from clinics in South-Eastern USA (L. Smith et al., 2001).

4.2 Social support as a protective factor for health among HIV-positive individuals and caregivers of children

Empirical evidence, from both the developed and developing world, indicates that social support can be an important resource for adult health, including adults who are caregivers of children and/or HIV-positive. The section below summarises findings of the existing literature on social support as a protective factor for the health of HIV-positive individuals and for individuals caring for children respectively. Since quantitative studies assessing the support-health relationship among HIV-positive caregivers of children have been discussed previously in the systematic review section of this thesis (Chapter 3), they will not be discussed again. However, the last part of this section will highlight findings of qualitative studies, conducted with HIV-positive caregivers of children, which underscore the perceived protective role of social support for caregiver health.

4.2.1 Social support as a protective factor for the health of HIV-positive individuals

Early studies on social support and health with HIV-positive populations. Evidence of the importance of social support for the health of individuals living with HIV/AIDS is not surprising, given that social support has been repeatedly shown to be associated with better physical health more generally (see for example Pinquart & Sorensen, 2007) and with better mental health among the chronically ill (see for example: Bennett et al., 2001; Primomo, Yates, & Woods, 1990; Uchino, et al., 1996).

Up until the early 1990s, research on social support and health among people living with HIV focused mainly on populations of homosexual men in the USA (Green, 1993). A review of the existing literature on social support and HIV conducted in 1993 identified only 8 published papers based on empirical studies (Donlou, Wolcott, Gottlieb, & Landverk, 1985; Hart, Fitzpatrick, McLean, Dawson, & Boulton, 1990; Namir, Alumbaugh, Fawzy, & Wolcott, 1989; Namir, Wolcott, et al., 1989; Namir, et al., 1987; Ostrow et al., 1991; Wolcott, Namir, Fawzy, Gottlieb, & Mitsuyasu, 1986; Zich & Temoshok, 1987). All studies were conducted with men, most with homosexual or bisexual men, most were conducted in the USA and most included participants at the symptomatic stage of the disease, recruited from treatment settings. Findings showed evidence of a positive relationship between more social support, particularly instrumental support, and active coping (Namir, et al., 1987), more social support and better psychological wellbeing (e.g. less hopelessness and depression) (Wolcott, et al., 1986; Zich & Temoshok, 1987) and more social support and better perceived health status (Wolcott, et al., 1986). There was also evidence that outcomes could differ across different populations. Ostrow et al (1991), for example, found a positive association between social support and mental health for white gay men and a negative association for black gay men; these differences were attributed to stigmatizing attitudes linked to differences in the structure and composition of social networks (Green, 1993; Ostrow, et al., 1991). However, given the narrow population focus and recruitment mainly through health facilities, it was argued that review findings were likely not representative of the broader HIV-infected population and HIV-positive populations in different settings (Green, 1993).

Over the two decades that have since passed, numerous empirical quantitative studies on social support and health among HIV positive individuals have been conducted, mainly in the developed world. Overall, this research points to a positive association between various

social support dimensions and better health outcomes among HIV-positive individuals, with most studies finding evidence of main (versus stress-buffering) effects. Moreover, consistent with the broader social support literature, findings suggest that perceived support (versus actual enacted support) and the quality of relationships (versus mere size of network) are more important factors for health. Green's (1993) review of the literature included studies conducted up until 1991. Findings of more recent studies on social support and mental health and social support and physical health respectively with HIV-positive individuals are synthesized below.

Post-2001 studies on social support and mental health of people living with HIV.

The majority of studies investigating the relationship between social support and health among HIV-positive individuals focus on mental health outcomes. Many of the earlier studies on these themes continued to work with samples of homosexual male populations in the USA or Europe. The most common finding was of a positive relationship between more social support and better mental health. For example, social support was found to have a positive main effect (but not stress-buffering effect) on psychological distress at the asymptomatic stage of the disease (Blaney et al., 1991) and to reduce death-related anxiety at the symptomatic stage of the disease (Catania, Turner, Choi, & Coates, 1992), among homosexual males in the USA.

A larger and more recent body of research conducted with heterosexual and/or broader populations of HIV-positive individuals also points to a positive relationship between social support and mental health. Some of these studies show the relationship between social support and mental health outcomes to be linked to or mediated by coping processes. Here too most of these studies, especially the earlier ones, derive from the USA. For example,

structural equation analysis of data from a USA longitudinal study with 212 people living with HIV showed that social support availability and satisfaction were associated with less psychological distress both directly and indirectly, through more active and less avoidant coping (Schmitz & Crystal, 2000). A further study with 626 people living with HIV/AIDS in New York revealed that respondents with one or more important persons in their social network had better mental health than those with only general support and assistance or no support at all (Reich, Lounsbury, Zaid-Muhammad, & Rapkin, 2010). Research working specifically with HIV-positive North American women showed lower perceived social support levels to be predictors of distress (Hudson, Kathryn, Miramontes, & Portillo, 2001; Serovich, et al., 2001), loneliness and stress (Serovich, et al., 2001). Similarly, investigation with HIV-positive African American and Hispanic USA populations showed significant positive relationships between functional dimensions of perceived support (e.g. support satisfaction or availability) from various sources and better mental health outcomes (Simoni, Montoya, Huang, & Goodry, 2005; Song & Ingram, 2002; Stewart, Cianfrini, & Walker, 2005). Exploratory work has also highlighted the role of stigma, together with social support, in predicting mental health among HIV-positive individuals; for example, a study with 30 men and women recruited from two HIV outpatient clinics in the USA revealed that depressive symptoms were associated with less social support and also more perceived HIV-related stigma (Prachakul, Grant, & Keltner, 2007).

A smaller number of studies conducted in Asia, South America, Africa and the Middle East reveal similar findings regarding positive associations between more social support and better mental health among HIV-positive populations. For example, a 1997 study with 47 HIV-positive and HIV-negative patients in Japan showed that the HIV-positive patients had higher depressive symptoms and less social support than the HIV-negative control group; moreover, more social support and less avoidance coping were associated

with fewer depressive symptoms (Fukunishi et al., 1997). Work with both PLWHIV living in Northern Thailand (408) and Israel (56) has also shown reported social support to be a significant predictor of less psychological distress (M. Cohen, Arad, Lorber, & Pollack, 2007; Li, Sung-Jae, Thammawijaya, Jiraphongsa, & Rotheram-Borus, 2009). Research with 55 HIV-positive low-middle income adults living in Lima, Peru, found that both the presence of large social support networks and better satisfaction with support were inversely correlated with depression, especially for men (Fasce, 2008). The first known study to examine the effect of social support on depression outcomes in (272) AIDS patients on a public sector ART programme in rural South Africa showed that 33% of this population was depressed, and that having better quality and availability of (particularly instrumental) social support predicted a lower likelihood of depression (Yeji, 2009).

Similarly, research also indicates that rejection or avoidance following support seeking can negatively affect the psychological status of HIV-positive adults. For instance, besides showing a positive relationship between more social support and better mental health (measured by anxious or depressive mood), Song and Ingram's research with 116 HIV-positive African American adults also showed that HIV-related unsupportive responses predicted more disengaged/denial coping strategies and greater mood disturbance (Song & Ingram, 2002). Similarly, a survey with 125 HIV-positive men and women recruited from health facilities in the USA found that more 'avoidance behaviours' by a close friend, intimate partner or parent were positively associated with depressive symptoms of participants, pointing to the "potential for psychological harm in all types of relationships if a significant other dismisses or trivializes ones efforts at support seeking" (Derlega, Winstead, Oldfield, & Barbee, 2003, p. 127).

Consistent with the broader social support and health literature, perceptions of support have also been shown to be more important for mental health than actual support received.

For example, McDowell and Serovich's research, with 125 women and 232 men living with HIV in the USA, demonstrated that perceived social support was a significant predictor of better mental health (measured by indices of depression and loneliness) while the effect of actual social support (referring to the number of people available to provide support) was small (McDowell & Serovich, 2007).

Post 2001 studies on social support and physical health among people living with HIV. There is a smaller body of research showing significant associations between more social support and better physical health outcomes among HIV-positive individuals. Most studies worked with samples of HIV-positive homosexual populations in the USA. For example, a 1994 study with 47 HIV-positive homosexual men recruited from a clinic in Sweden showed measures of social network (social participation) and material social support to be associated with a lower CD4 count, suggesting that these psychosocial factors may have been affecting the participants' immune system (Persson, et al., 1994). Similarly, Pakenham et al's (1994) research with 96 HIV-positive gay or bisexual men showed that more social support was positively associated with better health-related indicators, such as number of HIV-related symptoms, CD4 count and social adjustment to illness; among persons still at the asymptomatic stage, emotional support was also associated with better subjective health status (Pakenham, et al., 1994). Among the first longitudinal data to reveal that more stress and less social support could accelerate HIV disease progression, were findings of a study by Leserman et al (1999) with 82 HIV-positive homosexual men in North Carolina; participants were asymptomatic at baseline and followed up every 6 months for 5.5 years. Faster progression to AIDS, as measured by lymphocyte counts and AIDS-indicator conditions, was associated with more cumulative stressful life events, more cumulative depressive symptoms and less cumulative social support. The authors found that the probability of HIV progressing

to AIDS was two to three times higher among participants with low social support (i.e. with social support levels below the median) than among participants with high social support, and highlighted that it would be important to better understand the mechanisms explaining this phenomenon (Leserman, et al., 1999).

Subsequently, research conducted with broader populations of HIV-affected individuals has revealed similar associations between social support and physical health indicators. For example, a USA 12-month longitudinal study with 65 men and women living with HIV found that individuals reporting more satisfying social support were more likely to report lower increase in their HIV-related health symptoms, after controlling for coping and baseline health status; the authors argued that findings pointed to social support as a robust predictor of physical health outcomes over time, independent of coping style and baseline medical status (Ashton et al., 2005). The above-cited Cohen et al (2007) study with HIV-positive individuals in Israel showed that better HIV indicators (e.g. lymphocyte count and viral load) were related to more social support and better treatment adherence (M. Cohen, et al., 2007). Atkins et al (2010) found a higher perceived level of social support among 357 HIV-positive individuals in Canada to be associated with a lower cognitive symptom burden, regardless of whether or not participants suffered from depression (Atkins et al., 2010). Research with HIV-positive individuals receiving treatment in KwaZulu-Natal, South Africa, found higher reported social support to be a predictor of better physical functioning; other predictors were greater length of time on medications and fewer comorbid health problems (McInerney et al., 2008).

There are also several studies showing a positive relationship between social support and better health-related quality of life, including measures of physical health. For example, Nunes et al (1995) found social support to be significantly correlated with quality of life in a population of 50 HIV-positive individuals in the USA, and better quality of life to be

associated with higher CD4 counts (Nunes, Raymond, Nicholas, Leuner, & Webster, 1995). A further study with 78 HIV-symptomatic adults receiving primary clinical care or community support in the USA showed that social support from friends, as well as regular weekly physical exercise, were significant predictors of better health-related quality of life (Clingerman, 2004). A cross-sectional study with 160 HIV-infected persons in Nepal, who were receiving treatment, care, and support from community-based NGOs, showed that perceived satisfaction with social support was significantly correlated with quality of life, including physical dimensions of quality of life (Yadav, 2010).

Evidence of mediating pathways between social support and health among people living with HIV. As indicated in many of the studies included above, the most researched and documented mediating processes explaining effects of social support on mental health among HIV-positive individuals are those related to coping. Overall, better mental health outcomes appear to be associated with active coping, and worse mental health outcomes with avoidance or disengagement coping. However, the literature also provides some evidence of further or alternative mediating processes explaining observed relationships between social support dimensions and specific health outcomes. First, various studies point to - potentially multiple - psychological mediating processes linking social support to better mental health, including individual resilience variables and feelings of being loved and understood. For example, Schmitz and Crystal's longitudinal study with 212 people living with HIV in the USA showed that feeling loved and understood was found to mediate the relationship between social support and the choice of active or avoidant coping styles (Schmitz & Crystal, 2000), which in turn predicted psychological distress, as described above. Findings of structural equation modelling conducted in the above-cited Simoni et al. study, with HIV-positive women in New York, suggested that psychological resourcefulness

variables, such as self-esteem and mastery, were mediating the relationship between social support and less depressive symptomatology (Simoni, et al., 2005). A cross-sectional study with 160 HIV-infected persons in Nepal, receiving treatment, care, and support from community-based NGOs, showed that the observed positive effects of social support on physical and psychological dimensions of quality of life were mediated mainly through hope (Yadav, 2010). Research also points to effects of social support on physical health through better mental health outcomes, which could be considered an example of psychological mediating processes. For instance, a study conducted with 226 HIV-positive males attending clinics in a southern USA state provides evidence of social support affecting health-related quality of life mainly through an intermediate depression variable (Jia et al., 2004).

Social support has also been found to be associated directly with positive health behaviours among adults living with HIV/AIDS, which could represent behavioural mediating processes (at least partly) explaining effects of social support on physical health. While most of these studies do not link health behaviours to health outcomes, one could reasonably assume that they will likely lead to better health. For example, greater availability of emotional support was found to be a predictor of combination therapy medical compliance among 179 HIV-positive clinical trial study participants in the USA (Cox, 2002). Analysis of data from a large 1994-1997 survey of a representative sample of people with HIV in New York also showed a positive relationship between more social support and the use of HAART or other ARV treatment therapies, though this depended on disclosure of HIV status within the family or broader social network (Waddell & Messeri, 2006). A qualitative study with 20 HIV-positive African American women on HIV treatment found that having supportive family members was perceived to facilitate adherence, whereas feeling unloved or uncared for was identified as one of the barriers to adherence (Edwards, 2006). In South Africa, a descriptive survey with 165 urban and 97 rural women living with HIV showed that higher

perceived social support availability was associated with support group attendance, condom use and taking vitamins; the research also showed that receiving counselling as well as participating in a support group were more strongly associated with positive health behaviour than social support on its own (Gaede et al., 2006). While Luszczyńska et al.'s study with 104 AIDS clinic patients in India did not show a direct relationship between social support and adherence, path and mediation analysis showed an indirect effect of social support on adherence mediated by greater self-efficacy (Luszczyńska, Sarkar, & Knoll, 2007). This suggests possible multiple mediating variables between social support and physical health, for example: positive support effects on personal resilience which may translate into better health behaviours (e.g. adherence), which in turn may lead to better physical health.

A longitudinal study conducted by Burgoyne (2005) in the USA linked social support to both adherence and better physical health outcomes. This research, assessing social support and its associations with virological outcome, over a 4-year period for 34 adults on highly active antiretroviral therapy (HAART), found that participants with consistent adherence, and higher perceived interpersonal, informational and emotional support, experienced better clinical benefit. Moreover, the study suggested causal directionality, with social support and/or improvements in social support over time leading to a greater likelihood of viral load suppression to an 'undetectable' level (whereas cross-sectional virological status did not predict subsequent levels of social support) (Burgoyne, 2005).

4.2.2 Social support as a protective factor for the health of caregivers of children

Quantitative research assessing the relationship between social support and caregiver health. There is a substantial body of research documenting positive associations between higher social support and better mental health among caregiver populations, including caregivers of children. The majority of studies with carers of children have been conducted in North America with low-income, recent and/or single biological mothers. For example, analysis of data from large Canadian and USA surveys showed that anxiety and distress among mothers of young children were negatively associated with more support from significant others (D'Arcy & Siddique, 1984; Meadows, 2011) and the community (D'Arcy & Siddique, 1984). Similarly, the analysis of a USA panel study over a period of one year showed that the cognitive experience of recent mothers' social support (but not the extent of their social network) was negatively associated with psychological distress (Stemp, Turner, & Noh, 1986). Analysis of data with a representative sample of low-income African American women, with children under 6 years, found a main effect of emotional social support on psychological distress and a buffering effect of instrumental support on the relationship between perceived levels of everyday discrimination and (higher) psychological distress (Ajrouch, Reisine, Lim, Sohn, & Ismail, 2010).

Similar findings have also been demonstrated from research with biological mothers conducted in other parts of the world. For example, a randomized control trial (RCT) with 846 low-income mothers of young children in the UK showed that a lack of social support and high levels of reported stress were strongly associated with depressive symptoms (Reading, 2005). The Crosier et al (2007) Australian study with 354 single and 1689 partnered mothers found a lack of social support and financial hardship to be the most

important predictors of poor mental health (Crosier, et al., 2007). Similarly, a survey with 595 randomly sampled mothers from nine low-income communities in Brazil showed that poor quality partner relationships, lack of support to resolve a conflict, and lack of material support (e.g. for food or money) were predictors of lower health status among these women (Surkan, O'Donnell, Berkman, & Peterson, 2009).

There are also several studies investigating the importance of social support for the health of grandparents caring for children. A study conducted in the USA with 486 Ohio grandmothers, including caregivers of grandchildren, showed that perceived social support, more active coping and less avoidant coping were associated with better caregiver health status (Musil, et al., 2009); specifically, perceived instrumental support and feelings of support and involvement with family and friends were found to moderate the effects of strain and family stresses on depression among this population (Musil, et al., 2009). A further investigation, with 133 grandparent primary caregivers of grandchildren in the USA, showed perceived informal and formal social support to be associated with less caregiving stress and more life satisfaction (Gerard, et al., 2006).

Lastly, while the health status of children cared for is not the key focus of this study, social support has also been shown to be a protective factor against stress and mental health conditions of adults caring for children with disabilities or chronic illness. This is important to note, as many caregivers of children in HIV-endemic communities are likely caring for orphans and/or children with (HIV-related or other) health conditions, which – as indicated previously – could be adding to caregiver stress and mental health risks. Examples of studies include Jessop et al.'s (1988) work with 209 inner-city mothers of chronically ill children in the USA; the authors found that mothers who did not have a confidant demonstrated higher levels of psychiatric symptoms; other predictors of poor maternal mental health were additional stressors in the family, poor physical health and worse functional status of the

child cared for (Jessop, et al., 1988). A more recent survey conducted with 127 mothers of school-aged intellectually disabled children in Taiwan revealed maternal social support to be a major predictor of (lower) caregiver strain, as were the mothers' health status, the amount of time spent on caregiving activities, and the children's level of dependency (Tsai & Wang, 2009). A South African study conducted with 110 mothers of children with various disabilities showed a significant correlation between a larger maternal social network and lower maternal stress (Molteno & Lachman, 1996). Similarly, protective effects of social support on caregiver mental health have been found among mothers of children in treatment for mental health conditions in the USA, mothers of children with cerebral palsy in Australia and caregivers of children with leukaemia in Turkey (Bozo, Anahar, Ates, & Etel, 2010; Gjesfjeld, 2009; Skok, Harvey, & Reddihough, 2006).

Qualitative research exploring the relationship between social support and caregiver health among HIV-affected caregivers of children. While existing quantitative studies investigating social support and health among HIV-positive caregivers have been included in the systematic review section of this thesis, it is worth noting the existence of several qualitative studies highlighting the perceived importance of social support as a coping resource by caregivers. For example, a qualitative case-study conducted with 3 HIV-positive mothers in the USA, through the clinical perspective of a clinician-researcher, showed that social support and social networks were considered important resources for these women who struggled to deal with their HIV diagnosis and the stigma associated with it (S. Andrews, 1995). Similarly, sixty HIV-positive Indian mothers who participated in focus groups, to discuss challenges in accessing health care services and dealing with mental health stressors, identified psychological support as a central element for future intervention plans (Nyamathi, Thomas, Greengold, & Swaminathan, 2009). Qualitative work with women living with HIV

in Canada showed that child-related concerns were among their primary reported stressors, and that seeking social support was the most common coping strategy used (Ndlovu, et al., 2010).

While not conducted specifically with HIV-positive primary caregivers of children, qualitative research conducted in HIV-endemic South African communities also suggests that informal social support is considered a key resource for coping with financial and emotional hardship among caregivers of children, many of whom are HIV positive and/or caring for orphaned children. For example, in-depth qualitative interviews with 30 guardians of children orphaned by AIDS, living in a South African township, revealed how scarce material resources posed a challenge to meeting household needs and how social and emotional support from friends in NGO-linked support groups helped these caregivers deal with the stress and challenges of caring for orphaned children (Kiggundu & Oldewage-Theron, 2009). Findings from an exploratory qualitative study in peri-urban KwaZulu-Natal (Casale, 2011) showed how reciprocity and informal support among friends and neighbours helped caregivers of biological and foster children, living in HIV-affected families, cope with the daily challenges they faced; this support usually took the form of money or food and, in some cases, assistance with caregiving tasks. A further qualitative study from South Africa revealed how the identified lack of adequate financial, physical and emotional social support was a central issue explaining the experiences and frustrations of women caring for children orphaned by HIV/AIDS (Hlabyago & Ogunbanjo, 2009).

4.2.3 Relationship between caregiver social support and child wellbeing

Though beyond the direct scope of this thesis, it is important to note that caregiver social support and effects of social support on caregiver health have also been shown to be important for child wellbeing, thus further highlighting the importance of better understanding the caregiver support-health relationship. Better caregiver mental health and physical health have been respectively associated with better parenting and child health (Lindsey et al., 2008; D. Murphy, Greenwell, Mouttapa, Brecht, & Schuster, 2006; Reading, 2005; Smith Fawzi, et al., 2010; Stein, et al., 2008). For example, seeking social support as a maternal coping strategy has also been found to be associated with more positive outcomes in parenting and child development (Sheppard, 1994; Stevens, 1988) and access to adequate social support has been associated with better quality of parenting (Oyserman, Bybee, Mowbray, & MacFarlane, 2002; Simons, Beaman, Conger, & Chao, 1993) and better mental health among children cared for (Lindsey, et al., 2008).

The analyses of two studies included in the systematic review of this thesis (Chapter 3), working with populations of HIV-positive mothers, also linked the relationship between maternal social support and maternal health to child outcomes. Hough et al (2003) showed that maternal social support was associated with less maternal emotional distress levels; in turn, maternal distress was found to be a predictor of psychosocial adjustment of HIV-negative school age children (Hough, et al., 2003), as measured by the presence of child behaviour problems. Gay (1995) found observational ratings of maternal positive affect and maternal engagement to be related to the mother's reported availability of social support.

4.3 Gaps in the research on social support and health among HIV-positive and caregiver populations: key foci for future research

Chapter 2 presented a review of the key theoretical and empirical work to date on the relationship between social support and adult health. Chapter 3 described the methodology and findings of a systematic review of the literature quantitatively assessing the relationship between social support and (mental and physical) health outcomes among HIV-positive caregivers of children specifically. The current chapter (Chapter 4) provided a synthesis of the broader empirical literature on the protective role of social support for health among HIV-positive and caregiver populations respectively. Each of these sections highlighted key findings and trends emerging from the literature reviewed, as well as gaps and scope for future research.

Overall, these literature reviews brought to light the importance of social support for health. They showed that there is a considerable amount of evidence of both main and stress-buffering positive health effects of social support for various mental and physical health outcomes among diverse adult populations, deriving mainly from the developed world. They also highlighted some of the biological, psychological and behavioural processes found to be mediating these effects, and the need for further research aimed at better understanding these processes. This is especially true with regards to mediating processes and pathways explaining the more frequently observed main effects, and effects of social support on physical (versus mental) health.

In particular, the systematic review on social support and health among HIV-positive caregivers of children (described in Chapter 3) exposed the dearth of empirical studies on social support and health conducted in HIV-endemic areas of the developing world. This

includes Southern Africa, which is the world's region most affected by HIV. The review highlighted the need for studies exploring the support-health relationship with representative samples of caregivers (both biological parents and foster caregivers), and with control or comparison groups of HIV-positive and HIV-negative caregivers. Lastly, the systematic review showed how studies conducted with HIV-positive caregivers provided little insight on the mediating variables and processes explaining observed effects, beyond the effects of social support on coping processes. This indicates a need for more research exploring mediating processes that explain the health effects of social support, as well as testing for the existence of these effects.

University of Cape Town

CHAPTER 5: QUANTITATIVE METHODOLOGY

The previous chapters (Chapters 2, 3 and 4) synthesized the theoretical and empirical literature on social support and health among PLWHIV, and more specifically caregivers of children living with HIV, and highlighted research gaps. These included the absence of quantitative studies investigating the protective effects of social support for health conducted in Southern Africa, and the limited understanding of mediating processes explaining observed relationships between more social support and better health outcomes. As explained in Chapter 1, the overall purpose of this research is to contribute to addressing this gap, by investigating the relationship between social support and the (mental and physical) health of caregivers of children, from two HIV-endemic South African communities, with a particular focus on HIV-positive caregivers. In order to do so it employs a mixed methods research design, which both quantitatively investigates associations between social support and caregiver health outcomes, and qualitatively explores perceived pathways explaining these associations.

This chapter comprises a description of the quantitative component of this study, consisting of a household survey with 2477 caregivers in two (rural and urban) HIV-endemic communities in KwaZulu-Natal. First, this chapter presents the general and specific research questions that the quantitative component aimed to address. It then describes the quantitative methodology, including the site selection and sampling for the survey research, instruments and tools used, management of the field research and related challenges, survey data

management, ethical considerations and a detailed description of the quantitative analysis approach.

5.1 General and specific research questions addressed through the quantitative component

The quantitative component of this study aimed to address the first three general research questions, indicated in Chapter 1. These are listed below, and broken down into the specific research questions addressed through the quantitative analysis.

1) Is living with HIV/AIDS a risk factor for anxiety and depression among caregivers of children, and how does this compare to living with other illness?

- What is the prevalence of symptomatic depression and anxiety for HIV-positive, other ill and healthy caregivers in the sample and are there statistically significant differences between these prevalence rates?
- Controlling for key socio-demographic factors, is living with HIV/AIDS associated with a higher prevalence of depression and anxiety among caregivers?
- Controlling for key socio-demographic factors, is living with other chronic illness associated with a higher prevalence of depression and anxiety among caregivers?

2) Does social support have a main effect on caregiver depression and anxiety and/or buffer against the effects of HIV/AIDS- and other illness- related stressors on depression and anxiety?

- Is there evidence of a direct relationship between more social support and a lower prevalence depression and anxiety?
- Does social support moderate the relationship between HIV/AIDS and depression and/or anxiety among caregivers?
- Does social support moderate the relationship between other chronic illness and depression and/or anxiety among caregivers?

3) Is social support associated with better self-reported general health and functioning among HIV-positive, other ill and healthy caregivers respectively?

- Is more social support associated with better self-reported aggregate general health and functioning (including mental and physical health components) for HIV-positive, other ill and healthy caregivers respectively?
- Is more social support associated with better self-reported mental health for HIV-positive, other ill and healthy caregivers respectively?
- Is more social support associated with better self-reported physical health for HIV-positive, other ill and healthy caregivers respectively?

5.2 Quantitative survey research design and field methodology

The quantitative component of this research is situated within the broader survey research of the Young Carers KwaZulu-Natal (KZN) project. The aim of the project was to generate data on the physical, psychological and sexual health of both primary caregivers of children 18 years or older and children aged 10-17 in their care, in resource-deprived high HIV-prevalence settings. A primary caregiver was defined as an individual who takes on primary childcare duties; care provision was envisaged to involve various responsibilities, including meeting the economic, social, and psychological needs of a child. A primary caregiver could therefore be a biological parent, other adult relative (e.g. grandparent, aunt, uncle, sibling) or non-relative.

The Young Carers Study is a collaboration between the Health Economics and HIV and AIDS Division (HEARD) at the University of KwaZulu-Natal, South Africa, the University of Oxford, Brown University, various South African national government departments and universities⁷, and the National Action Committee for Children affected by AIDS (NACCA). It comprises survey research undertaken in three South African provinces, namely KwaZulu-Natal, Mpumalanga and the Western Cape; however, KwaZulu-Natal was the only province in which data was collected from primary caregivers, as well as from children.

⁷ Partners for the Young Carers national study include: University of Cape Town, University of the Witwatersrand, the South African national government departments of Social Development, Education, Health and Agriculture, Forestry and Fisheries, Cape Town Child Welfare, Save the Children and UNICEF. Further detail on the national study can be found at: www.youngcarers.org.za. HEARD, at the University of KwaZulu-Natal, was the primary funder for the KwaZulu-Natal research component.

The data used for the quantitative component of this study is the data collected through Young Carers survey interviews with caregivers of children in the two KwaZulu-Natal research sites (the research sites are described in further detail below). The doctoral candidate was a co-investigator and co-project manager of the Young Carers KZN project, and therefore collaborated on the project and instrument design, and co-managed the survey field research. In particular, the social support section of the caregiver survey instrument was designed by the doctoral candidate.

5.2.1 Site selection

Survey data was collected from both an urban and rural site in KwaZulu-Natal. The urban site chosen was Lamontville Township (Wards 74 and 75) in the eThekweni Metropolitan Municipality, approximately 20 kilometres south of the city of Durban. The rural site chosen was the greater Manguzi area in the uMhlabuyalingana municipality, bordering with Southern Mozambique in Northern KwaZulu-Natal (see Figure 5.1 for a map of the KwaZulu-Natal province and its census districts).

A staged selection process, based on various logistic and scientific criteria, was adopted in the choice of final field sites. Firstly, due to the particular interest in populations of AIDS-affected caregivers and children, the first criterion adopted was high HIV prevalence (Department of Health, 2008). Of the nine provinces of South Africa, KwaZulu-Natal had the highest HIV prevalence among antenatal clinic attendees in 2008 at an estimated 37.4%, versus a 28% national prevalence estimate. Potential sites were limited to census districts within the province with $\geq 30\%$ HIV prevalence among antenatal clinic

attendees; all 11 census districts met this standard. Of these, eThekweni (antenatal prevalence: 41.6%) and Umkhanyakude (antenatal prevalence: 39.3%) (Department of Health, 2008) were selected for their representativity of urban and rural sites (urban and rural distinctions based on reasoning used in Statistics South Africa, 2003b). One municipality was then chosen within each census district. The eThekweni Metropolitan Municipality was chosen for the urban site, since the eThekweni district is composed entirely of this municipality. Within Umkhanyakude, the Umhlabuyalingana Municipality was selected for logistical considerations, since a research partnership had been developed with a well-established local home-based care NGO, Tholulwazi Uzivikele (<http://www.tuproject.org/>), which had the appropriate existing networks and local knowledge to assist with community access and logistics on the rural site. Additionally this site was highly representative of a deep rural area, as it was located several hours' drive from the closest urban centre, had a low population density and limited services.

Each municipality was then further stratified into operationally defined 'sub districts,' which varied between the two sites. For the purposes of site selection, sub districts were classified as the smallest locally recognised geopolitical unit (i.e., the smallest area with a recognised political distinction from other areas). Within eThekweni, the smallest recognised geopolitical areas were census wards. Using data on eThekweni ward homestead categorisations from the Statistics South Africa website (www.statssa.gov.za) and the Provincial Indices of Multiple Deprivation ranking data (Noble et al., 2006), wards within eThekweni were narrowed to those with only urban households and that fell within the 20% most deprived wards; the latter selection criterion served to avoid selection of a ward with 'pockets' of wealth, given the high level of socio-economic inequality within the greater Durban area. A ward was then randomly allocated for selection with an online random

number generator, in order to limit geographical and other selection bias. The selected urban ward, ward 74, was one of two wards composing Lamontville, the oldest township of Durban.

Within the ward, Enumeration Areas (EAs; workload-defined boundaries for census enumerators) were randomly selected for systematic stratified sampling. Geographic information systems (GIS) maps of the area were used to determine EA boundaries. Following the survey of every EA in Ward 74 it was decided to continue surveying into Ward 75, to meet desired numbers. The decision to continue interviewing in Ward 75 (versus randomly selecting an alternative ward) was based mainly on the fact that communities were mostly continuous, as Ward 75 comprised the remaining part of Lamontville. Though community members recognised geopolitical boundaries between wards 74 and 75, they did not recognise the wards as separate communities. Also, given the proximity of the wards and ward councillors' offices, the project team was already known to the Ward 75 councillor and other local authorities; this facilitated community buy-in and team safety.

On the rural site, *isigodi* or 'tribal areas' were the smallest recognised geopolitical units. Each *isigodi* is run by an *induna*, the local tribal leader. We chose to work with *isigodis* as units of stratification, rather than census wards, for various reasons. First, the census boundaries (wards and EAs) in Umhlabuyalingana were not recognised as meaningful boundaries between communities; second, tribal leaders were seen as the most important de facto 'authorities' by these communities, and their consent for us to work in their community was considered an important prerequisite for community participation; third, logistical factors such as dense bush coverage, out-of-date aerial photography maps, a lack of tarred 'roads' and a lack of landmarks made it very difficult to identify EA boundaries (further detail on these fieldwork challenges is provided below in the discussion of fieldwork challenges and ethics issues related to the research). *Isigodi* boundaries, on the other hand, were recognised

and could be identified by community members. Data was collected in twelve *isigodi*. These tribal communities were randomly chosen, although the ability of the research team to work within these depended on the consent of tribal leaders (see the fieldwork challenges paragraph below for further detail on this process). In most cases this access was granted, though obtaining buy-in and consent was a lengthier process for some communities than for others. This affected, to some extent, the order in which communities were visited, but not the selection of communities.

Figure 5.1: KwaZulu-Natal province census districts



5.2.2 Site descriptions

Urban site (Lamontville township). Situated approximately 20 km south of the Durban metropolitan area (see figure 5.2 showing the positioning of Lamontville within the greater Durban area), Lamontville is the oldest African township in eThekweni, with a rich history (Makhatini, 2009). Built in 1943, it was intended for members of the aspiring African middle class, while housing thousands of workers from the nearby south Durban industrial areas (Makhatini, 2009). Up until the late 1980s, houses in Lamontville were reserved for the occupancy of married couples, forcing single people to live in hostels; these included children over 18 and people who had lost their spouse (Makhatini, 2009). As with most South African townships, Lamontville has a history of segregation linked to migrant labour, unrest and political violence under apartheid, and was also an important centre of political activism and resistance. Lamontville was the home of several key political leaders and a place of struggle during apartheid, resulting in a high political consciousness among residents (Makhatini, 2009).

Ward-level data from the 2001 South African census shows a population of approximately 20,574 in Ward 74 and 19,900 people in Ward 75, the two respective wards covering the Lamontville area (Statistics South Africa, Census 2001. My Constituency: Ward Profiles 2003). The population density in the Lamontville area is estimated at 6 826 people per square kilometer (Statistics South Africa, 2003b). The population in both Ward 74 and 75 consists almost entirely of Black Africans (representing approximately 96% of the population in Ward 75 and almost 100% in Ward 74), which reflects the divisions from apartheid. The predominant language spoken is isiZulu (Statistics South Africa, Census 2001. My Constituency: Ward Profiles 2003).

Figure 5.2. Location of Lamontville in the greater Durban area (Mapstudio, 2009).

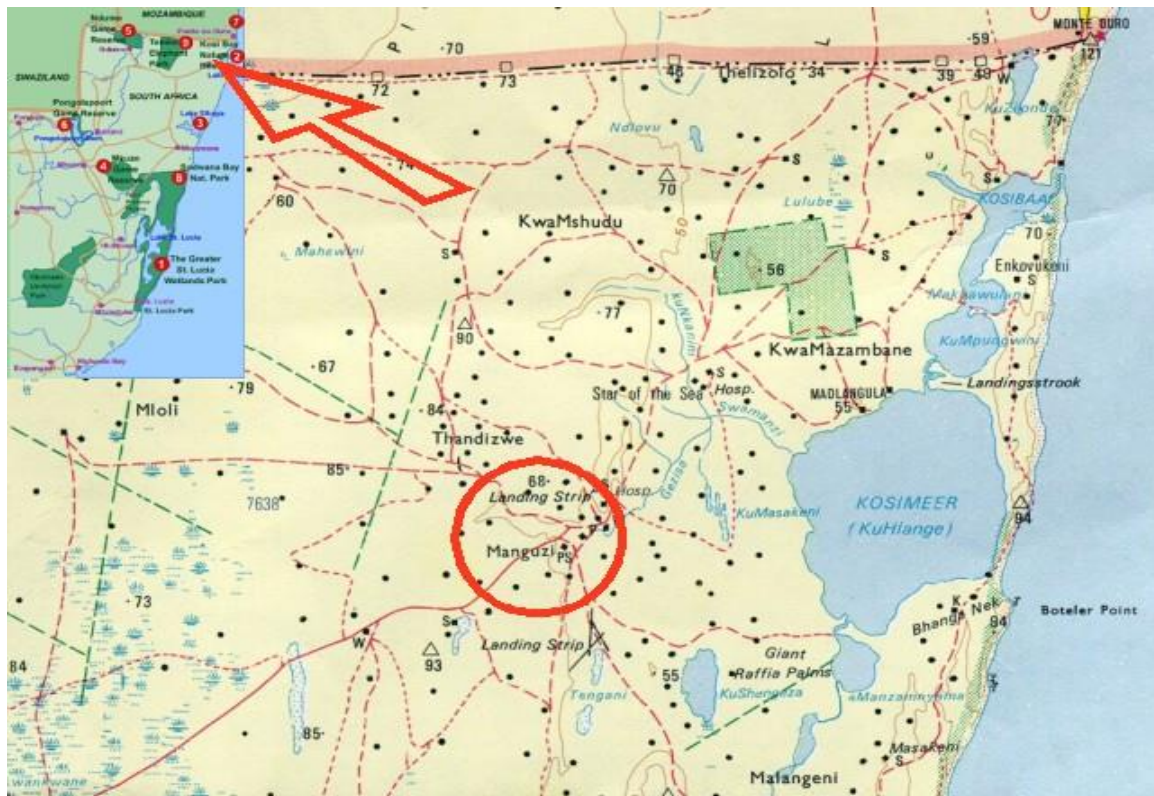


Available socio-demographic data highlights the social and economic challenges faced by households in Lamontville. The main industry in the area is reported to be manufacturing, but only approximately 40% of the labour force for Ward 74 and 45% for Ward 75 are employed, and around 30% of adults over 20 years in the two wards do not have any secondary education (Statistics South Africa, Census 2001. My Constituency: Ward Profiles 2003). About 34% of households in Wards 74 and 75 do not have formal housing; most of these households live in informal dwellings (e.g. shacks). Service coverage is quite

high however, as about 86% of households have access to electricity and 80% have running water within the dwelling or yard (Statistics South Africa, Census 2001. My Constituency: Ward Profiles 2003). It should also be noted that more than ten years have passed since the most recent available census data (2001) and these indicators may no longer entirely reflect the current reality of the area. For example, recent and on-going government-subsidised housing projects in the area, as well as anecdotal evidence, point to some improvement in living conditions.

Rural site (Manguzi). Manguzi is a rural community located in the Maputaland region of the KwaZulu-Natal province, in the Umkhanyakude District (see Figure 5.3 below). It is positioned about 15 km south of the Mozambique-South Africa border. Its lack of road infrastructure (90% consists of sandy tracks) and transport, along with limited service availability and communication, make this community largely rural (KwaZulu-Natal Department of Health, 2011). Consequently there is limited available data on the demographic profile of the area.

Figure 5.3: Map showing Manguzi in the KwaZulu-Natal province (CSIR, 2012).



The Umhlabuyalingana Local Municipality's online Integrated Development Plans (IDPs) appear to provide the most comprehensive aggregation of socio-demographic information on the area at a municipal level, as they draw from data provided by the 2001 census and a 2007 national community survey. The Umhlabuyalingana municipality spans an area of 3621 km² and was reported to have a population of approximately 164,000 people and an average household size of 6 people in 2007 (Statistics South Africa, 2007; Umhlabuyalingana Local Municipality, 2011). However, the population number in this area fluctuates due to cross border influx from Mozambique (KwaZulu-Natal Department of Health, 2011). Ninety-nine percent of the municipality is classified as rural and about 60% of the municipal area falls under traditional authority ownership, while the remaining 40% is constituted by commercial farms and conservation areas (Umhlabuyalingana Local

Municipality, 2011). The population consists almost entirely of Black Africans (accounting for more than 99% of the population) (Statistics South Africa, 2003a; Umhlabuyalingana Local Municipality, 2011) and while the predominant language is isiZulu, Tsonga is still widely spoken, especially among older inhabitants.

Available socio-demographic indicators highlight the high level of poverty and many social challenges in the area. In 2001, unemployment among the labour force was estimated to be 70% (Statistics South Africa, 2003a; Umhlabuyalingana Local Municipality, 2011). According to the 2010/2011 IDP, 47% of the economically active population within the municipality receives either no income or less than R1600 per month and only 8% of the population has obtained a grade 12 or higher education (Umhlabuyalingana Local Municipality, 2011). The local economy depends largely on tertiary (community) services (70% of municipal GDP) followed by agricultural production (20%) and manufacturing (10%) (Umhlabuyalingana Local Municipality, 2011). Based on our observation, many households also engaged in small-scale subsistence farming, although the sandy terrain and lack of irrigation systems rendered horticulture very difficult.

Nearly 50% of all residents in the municipality live in traditional dwellings (Umhlabuyalingana Local Municipality, 2011), typically consisting of reed and/or thatch huts. While almost 50% of households have access to piped water, access to electricity and fixed line telecommunication is still very low, with approximately 80% of the population dependent on energy sources such as candles and wood, and less than 1% accessing fixed communication lines (though about 70% of households have access to cellular telecommunication) (Umhlabuyalingana Local Municipality, 2011). The large majority of residents travel by foot to reach schools, clinics and other destinations (Umhlabuyalingana Local Municipality, 2011). Communicable diseases, including TB and HIV, accentuate health and social problems faced by communities in the greater Manguzi area (KwaZulu-Natal

Department of Health, 2011) and life expectancy in the province is estimated to be 43 years (Umhlabuyalingana Local Municipality, 2011). The municipality is served by two hospitals and 17 clinics (Umhlabuyalingana Local Municipality, 2011).

5.2.3 Community consultation and approval to conduct the research

The need for the broader quantitative survey research was identified in collaboration with key South African government stakeholders (including the Directorate of HIV/AIDS at the Ministry of Social Development, the Sector of Maternal and Child Health at the Department of Health and the Directorate of Health in Education at the Department of Education). The survey was then developed with the input of these South African government departments and the National Action Committee for Children Affected by AIDS (NACCA). Consultation with other stakeholders by the broader project team was also extensive; these included: local and international NGOs, service providers such as social workers, nurses and doctors, and HIV-affected groups of children.

At a local level, permission from gatekeepers in participant communities was obtained for the survey, as this was critical for the safety of the team and to facilitate community members' trust and willingness to participate. Communication with authorities and community stakeholders/members commenced months before the field research on each site and was on-going for the duration of the field research. The intention was to ensure a good understanding of the research's purpose, ensure and maintain community buy-in, and avoid creating expectations of material gain which is a common challenge in resource-deprived communities (Crigger, Holcomb, & Weiss, 2001). Before commencement of the field

research and during the fieldwork, the research team had multiple contacts with key political leaders in each site (e.g. ward counsellors, tribal leaders) to explain the research and obtain consent to work in specific communities. Contact was also made with stakeholders such as social services officers and policing structures (e.g. South African Police, community policing forums) to ensure their knowledge of the research and liaise with them on referrals and safety issues. Moreover, prior to the launch of the field research, the research team, in collaboration with the local authorities and their networks, coordinated the door-to-door dissemination of short hand-outs explaining the study, throughout participant communities.

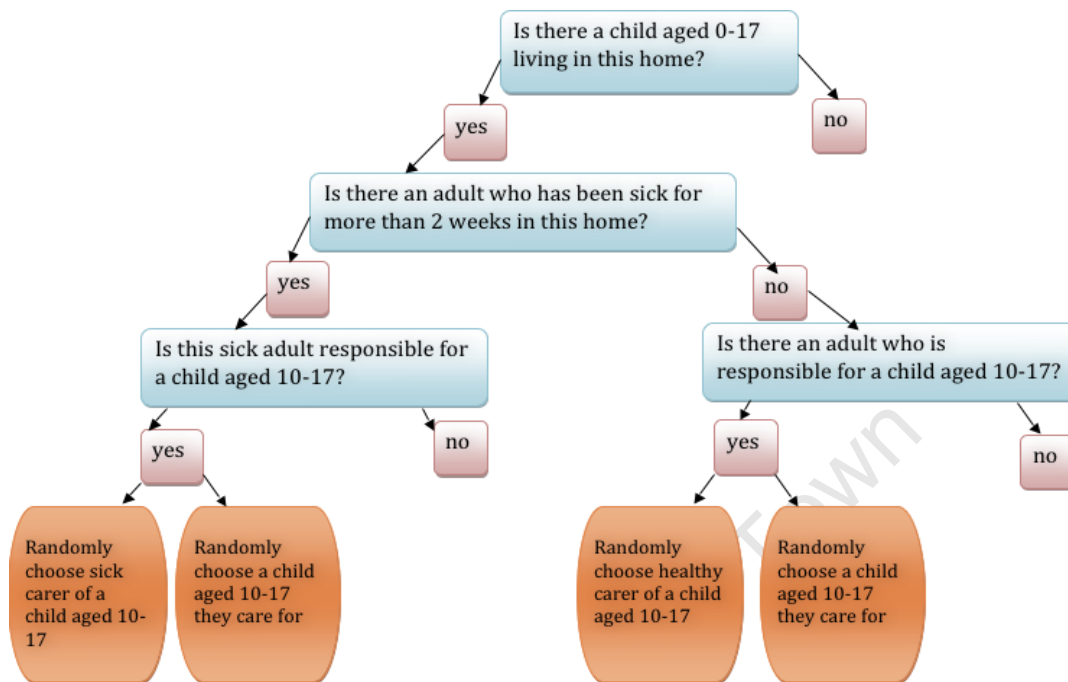
Approval to conduct research in Wards 74 and 75 was obtained from the respective Ward Councillors and eThekweni Municipality Speaker Councillor, following several meetings. Consent to work in the rural Manguzi site was obtained from the tribal chief for the Manguzi area, in part through the local NGO research partner's engagement at tribal authorities' meetings. In addition, approval to conduct the research was obtained from the tribal chief or *induna* of each tribal community. As explained in more detail in the 'Field research challenges and adaptive strategies' section below, obtaining this consent was a lengthy process, consisting of multiple interactions with each gatekeeper.

5.2.4 Sampling and recruitment of households

The survey recruitment strategy served to generate sufficiently large samples of ill and healthy caregivers in each site, in order to allow for comparisons between sub-groups of caregivers living with HIV, caregivers living with other illness and caregivers without a health condition. These minimum numbers were 1000 participants per site, and 250

participants in each sub-group. They were determined by the research team working on the broader Young Carers survey, based on available funding and statistical power needed to conduct core analyses for the broader survey. Households were sampled through stratified systematic random sampling. Interviewers approached every household in each designated area (*EA* or *isigodi*) and asked a set of pre-defined consecutive screening questions to determine each household's eligibility (see the *Identification of Dwelling and Sampling Sheet for Survey* in Appendix 2, and recruitment questions, illustrated in Figure 5.4). Households eligible to be interviewed were those in which an adult caring for at least one child between the ages of 10 – 17 was present. The intention was to prioritize interviews with ill adults caring for children, so an adult caregiver with self-reported illness was chosen to be interviewed in households where both ill and healthy caregivers were present. Also, in the case of more than one ill or healthy eligible adult in the same household and/or more than one child cared for, random selection was used to decide which carer-child pair to interview (e.g. by tossing a coin or throwing a dice). It is important to note that screening questions served to increase the proportion of sick caregivers included in the sample but were not used to classify caregivers as HIV-positive, other ill or healthy for analysis purposes; this classification was based on algorithms developed to analyse questionnaire data derived from responses to multiple questions (as will be described in detail further on).

Figure 5.4. Diagrammatic representation of recruitment screening questions



5.2.5 Survey instrument design and measures

Since this doctoral research is located within a broader health survey (the Young Carers KZN survey), questionnaires used in this study were designed to capture data for multiple analyses on child and carer health, beyond those relevant to this thesis. This section will describe the overall questionnaire design and criteria for the selection of psychometric tools. It will then describe in greater detail only those sections and tools from the caregiver survey instrument that are pertinent to the quantitative analysis of this doctoral work.

Overall questionnaire design. The design of the caregiver survey questionnaire was influenced by research gaps identified in the literature, previous studies on child and carer health conducted by project team members (see for example: Cluver & Gardner, 2007; Cluver, Gardner, & Operario, 2007; Kuo & Operario, 2009), and input from key stakeholders, such as South African national government departments, NGOs and AIDS-affected individuals. The 43-page questionnaire (see Appendix 3: Bilingual Adult Carer Survey) included standardized tools with strong psychometric properties, aimed at collecting data on various mental and physical health outcomes, as well as other indicators such as stigma, social support, parenting and child behaviour. Key caregiver and household socio-economic and demographic information was also collected, as well as information related to access to and use of health services.

The choice of which psychometric scales to include in the questionnaire was based on an extensive review of existing validated measurement tools, to determine the most suitable tools to be employed in this particular context. Primary considerations in choosing measurement tools were their psychometric properties, whether they had been validated in South Africa or – where not applicable - whether they had been used in South Africa or other developing countries and whether they had been validated with similar populations. Also, all tools included in the questionnaires had to be appropriate for administration via self-report through a non-clinician interview. As previously mentioned, the social support section of the caregiver questionnaire (pp. 31-35) was specifically designed by the doctoral candidate.

The questionnaire was translated into isiZulu, the local language, using standard back-translation procedures. An initial English version was translated into isiZulu by a first bilingual translator; this translated isiZulu version was then given to a second bilingual translator to be translated back into English. Throughout this process, conceptual and cultural

(versus literal or linguistic) equivalence were emphasised. The initial and translated English versions were then compared, and discrepancies addressed by the project managers, through consultation with the two translators and a third bilingual colleague. The questionnaire was piloted in July 2009 with a small sample of caregivers in Umlazi township, Durban; the survey instrument was shortened and slightly modified following responses and observation during the pilot study.

Indicators and measurement tools of relevance for the quantitative analysis of this doctoral research are described in detail below. These comprise measures of caregiver illness status, perceived availability of social support, general health and functioning, and symptomatic depression and anxiety. A description of socio-demographic variables used as control variables in the analysis is also included.

Caregiver illness status. The survey data collected allowed caregivers of children to be categorized with reference to their health status, specifically: as caregivers living with HIV/AIDS, caregivers living with other illness ('other ill' caregivers) and caregivers without a health condition ('healthy' caregivers). Caregiver HIV/AIDS was identified using an algorithm based on caregiver self-report of HIV-status, HIV-related illness and/or adherence to ARV treatment, as well as the verbal autopsy questionnaire (VA). This VA tool was developed to identify symptoms of HIV-related illness in areas with over 20% HIV-prevalence and where data on cause of death or illness is unavailable or unreliable (Hosegood, Vannestea, & Timæus, 2004; Lopman et al., 2006). A VA validation study conducted in Zimbabwe showed a sensitivity of 83% and specificity of 75% for AIDS death (Lopman, et al., 2006); a South African validation study showed a sensitivity of 89% and specificity of 93% of diagnoses for deaths caused by AIDS and other communicable diseases

(Kahn, Tollman, Garenne, & Gear, 2000). The use of the VA to identify HIV-related morbidity among living populations is, however, relatively new territory, and the broader Young Carers survey team (including Dr Lucie Cluver at Oxford University and Dr. Don Operario at Brown University) are currently assessing adult-child concordance and therefore inter-rater reliability of the VA tool for identifying adult HIV status among a living population, from the broader Young Carer survey dataset. Preliminary findings, recently presented at the 2013 American Public Health Association conference, show promising results, with 72% concordant child-adult reporting on HIV/AIDS illness status based on VA evaluation (Becker et al., 2013)

The ten VA signs and symptoms used to diagnose HIV-related illness or death are listed in Table 5.1 below, and included in section 2.17 and 2.18 (pp. 10 and 11) of the attached Adult Carers Survey Questionnaire (see Appendix 3); these include symptoms such as weight loss and wasting, and opportunistic conditions such as tuberculosis and oral candidiasis. The reported presence of three or more of these HIV-illness related conditions is used to determine HIV-related illness and/or AIDS-related death. The questions contained in the VA tool also allow for identification of HIV status less directly, minimizing risks of stigmatisation or inaccuracy of responses due to stigma around the disease.

Caregiver 'other illness' status was determined through questions on illnesses and symptoms pertaining to the most common causes of adult illness in South Africa, as identified in the South African Demographic and Health Survey (Department of Health, 2003) and the Health Systems Trust Annual Review (18 items) (Health Systems Trust, 2006). These included asthma, diabetes, arthritis, cancer, low or high blood pressure and epilepsy. Also, in consideration of the stigma surrounding HIV and AIDS, these questions on other illness and related symptoms were interspersed among the verbal autopsy questions, together

with questions on minor illness, e.g. common colds and flu (see sections 2.9 – 2.18 on pp. 9 – 11 of the attached Adult Carers Survey).

Table 5.1. Verbal autopsy: signs and symptoms predictive of AIDS-associated deaths

1. Weight loss	<ul style="list-style-type: none"> Moderate or severe weight loss with no other symptoms of malnutrition
2. Wasting	<ul style="list-style-type: none"> Moderate or severe weight loss with at least four of the following symptoms: paleness, changing hair colour, oedema of legs, burning sensations of the feet, dry scaly skin
3. Jaundice	<ul style="list-style-type: none"> Acute jaundice (yellowing of the whites of the eyes during the disease that lead to death) with fever and/or itching but without history of alcohol abuse
4. Herpes zoster	<ul style="list-style-type: none"> Ever suffered from zoster
5. Abscesses or sores	<ul style="list-style-type: none"> Had abscesses or sores
6. Oral candidiasis	<ul style="list-style-type: none"> Had two or three of the following: ulcers in the mouth, difficulty swallowing, white patches inside the mouth and tongue
7. Acute respiratory tract illness	<ul style="list-style-type: none"> Trouble breathing, cough lasting 3–27 d with fever but not recent TB, weight loss, or wasting, as above
8. Vaginal tumours	<ul style="list-style-type: none"> Vaginal tumour for at least one month with or without bleeding
9. Recent TB	<ul style="list-style-type: none"> Known to have suffered from TB in last five years
10. Acute diarrhoea	<ul style="list-style-type: none"> Loose stools lasting 3 – 27 days

Social support. The tool chosen to measure caregiver social support availability was the Medical Outcomes Study Social Support Survey (MOS-SSS; see questions 5.1a – 5.1s on p. 31 of the attached Adult Carers Survey and Figure 5.2 below). This scale measures dimensions of functional support, specifically: a) the overall level of social support perceived to be available and b) four specific types of social support, through the subscales measuring

emotional and informational support, tangible support, positive social interaction and affection (Sherbourne & Stewart, 1991).

Of the social support scales reviewed, the MOS-SSS was chosen as it appeared to best measure the types of constructs of interest to this analysis (i.e. perceived support availability and the functional dimension of support). It has also been shown to have strong psychometric properties ($\alpha=0.97$; 1-year test-retest reliability = 0.78) (Sherbourne & Stewart, 1991) and it is intended for self-administered survey research with general (ill or healthy) adult population samples. Though this tool has not been validated in South Africa, it has been widely applied in the developing world and used multiple times in South Africa. For example, it has been used in KwaZulu-Natal with urban and rural women living with HIV (Gaede, et al., 2006) and with Black South African male and female diabetes mellitus outpatients (Westaway, Seager, Rheeder, & Van Zyl, 2005). It should be noted that none of the possible alternative instruments identified, measuring similar constructs and/or applicable to a general adult population, had been validated in South Africa and none had been developed and tested specifically for caregivers of children. The Cronbach's alpha reliability statistic for the MOS-SSS scale in this sample was very high ($\alpha = 0.99$), in line with that of the original validation study (Sherbourne and Stewart, 1991) and the Westaway et al study in South Africa (0.97).

The MOS-SSS is a 19-item tool with 5-point answer scales. Respondents are asked to rate how often each type of support is available if they need it, and can choose one of five options ranging from 'none of the time' (1) to 'all of the time' (5). These responses are scored together to derive four subscales: emotional and informational support (8 items); tangible support (4 items); positive social interaction (4 items); and affection (3 items). These items, and the type of support they are intended to measure, are listed in Table 5.2. To obtain a score

of 1-5 for each subscale, the average of the scores for each item in the subscale is calculated. To obtain an overall support index, ranging from 1 – 5, the average is computed for all items.

The overall support index was of interest and used for this analysis. However, it should be noted that factor analysis showed that the MOS-SSS scale is in fact measuring one ‘perceived social support’ construct in this particular sample, as all items in the scale were highly correlated with each other. Principal component analysis of the 19 scale items in this sample extracted only one component (based on eigenvalues ≥ 1 ; total variance accounted for = 84%). This suggested that the perceived availability of types of emotional support in this caregiver population was closely associated with the perceived availability of tangible support. While it would have been beyond the scope of this particular study to investigate associations between different types of support and health outcomes, it should be highlighted that it would not have been possible to work with individual MOS-SSS subscales as distinct constructs in this population. It is also noteworthy that a previous South African study using the MOS-SSS, with a sample of 263 Black South African diabetes mellitus outpatients in Pretoria, identified two factors (as opposed to the four sub-scales identified by the original authors in their work with chronically ill adults in the USA); these appeared to be respectively representing sub-constructs of socio-emotional and tangible support (Westaway, et al., 2005).

Table 5.2. The MOS-SSS scale and subscales

5.1a Someone to help you if you were confined to bed	• Tangible support
5.1b Someone you can count on to listen to when you need to talk	• Emotional/informational support
5.1c Someone to give you good advice about a crisis	• Emotional/informational support
5.1d Someone to take you to the doctor if you needed it	• Tangible support
5.1e Someone who shows you love and affection	• Affectionate support
5.1f Someone to have a good time with	• Positive social interaction
5.1g Someone to give you information to help you understand a situation.	• Emotional/informational support
5.1h Someone to confide in or talk to about yourself or your problems	• Emotional/informational support
5.1i Someone to hug you.	• Affectionate support
5.1j Someone to get together with for relaxation	• Positive social interaction
5.1k Someone to prepare your meals if you were unable to do it yourself	• Tangible support
5.1l Someone whose advice you really want	• Emotional/informational support
5.1m Someone to do things with to help you get your minds off things	• Additional item
5.1n Someone to help with daily chores if you were sick	• Tangible support
5.1o Someone to share your most private worries and fears with	• Emotional/informational support
5.1p Someone to turn to for suggestions about how to deal with a personal problem	• Emotional/informational support
5.1q Someone to do something enjoyable with	• Positive social interaction
5.1r Someone who understands your problems	• Emotional/informational support
5.1s Someone to love you and make you feel wanted	• Affectionate support

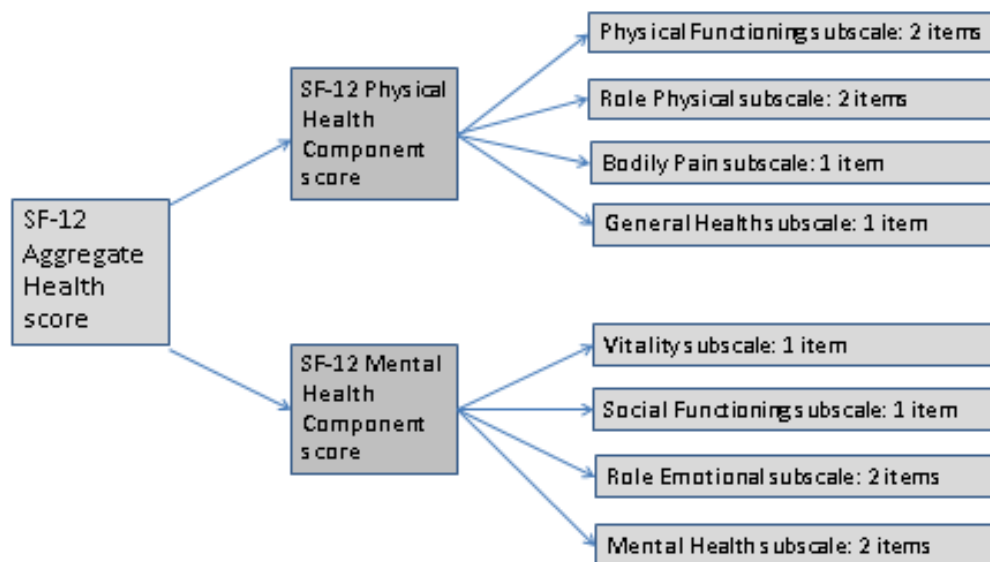
General health and functioning. Self-reported general (physical and mental) health and functioning was measured using the SF-12 tool. The SF-12 is a self-report questionnaire and general measure of health status, versus an indicator of the presence or absence of specific health conditions. The decision to choose a generic measure of overall health (rather than one specific to age, disease, or treatment group), was motivated by the intention to capture total burden of disease among this sample of caregivers of children; this is particularly relevant given the limited knowledge regarding the general health of this population.

The SF-12 is a shorter version of the SF-36 Health Survey (Ware, 2000, 2004), which measures how physical health impacts activities of daily functioning, and includes questions regarding the presence of chronic illness. SF-36 versions have been used in over 7,000 studies, in varying populations and cultural settings, including South Africa (Benitha & Tikly, 2007; O'Keefe & Wood, 1996), and have been translated into 60 languages, including isiZulu, Afrikaans and isiXhosa (O'Keefe & Wood, 1996; Ware et al., 2007). The Short Form 36 Version 2 (SF36v2) (36 items) was used in a study with caregivers in a similar HIV-endemic setting in the KwaZulu-Natal province (Kuo, 2010) and showed a high level of reliability ($\alpha=.94$). The SF-12 has been shown to be strongly correlated with the SF-36 scores, and to have good relative psychometric properties (Ware, Kosinski, & Keller, 1996). The Cronbach's alpha reliability statistic for the aggregate SF-12 scale in this sample was 0.84.

The SF-12 tool includes 12 questions from the SF-36 Health Survey (see questions 2.1 to 2.8 on pp. 7 and 8 of the attached Adult Carers Survey). Respondents rate each health and functioning item on three- or five-point scales. These items are used to compute 8 subscales, as indicated in Figure 5.5 below; these are: Physical Functioning (PF); Role Physical (RP; indicating activity limitations because of physical health problems); Bodily Pain (BP); General Health (GH); Vitality (V); Social Functioning (SF); Role Limitations (RL; indicating activity limitation because of emotional problems) and Mental Health (MH). Using original scoring guidelines (Ware, Kosinski, Turner-Bowker, & Gandek, 2002), specific items were recoded so that higher scores corresponded with better health. Where there were multiple items in a subscale, these were then summed to compute aggregate raw scores. Raw scores were then transformed to a 0-100 scale in order to standardize scores and allow for interpretation.

As indicated in Figure 5.5 below, four subscales are associated with the physical health component of SF-12 or SF-36 tools, and four with the mental health component. The original SF-12 scoring manual provides formulas for aggregating the 8 subscales to estimate physical and mental health summary scores, using score coefficients from 1990 general U.S. population data. In the absence of corresponding normative data and coefficients for South Africa, for the purpose of this analysis the physical and mental health sub-components of the SF-12 were computed by calculating respective summary scores for the four physical health subscales and the four mental health subscales. This is in line with the approach used by previous studies conducted with South African populations (Benitha & Tikly, 2007; Kuo, 2010). Cronbach's alpha coefficients showed an internal reliability of 0.84 for the Physical Health Component score, and 0.66 for the Mental Health Component score.

Figure 5.5. SF-12 components and subscales



Depression. Depressive symptoms were measured using the Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). The CES-D is one of the most widely used self-report tools designed to measure depressive symptomatology in the general population. It has been shown to have strong psychometric properties, with high internal consistency reliability among the general population ($\alpha = 0.85$) (Radloff, 1977). Validity was established by the original author through correlations with other self-report measures, and correlations with clinical ratings of depression and other variables that support its construct validity (Radloff, 1977). The CES-D has been validated in numerous samples internationally, including in South Africa (Pretorius, 1991), and the cultural validity of the tool has also been tested with South African populations (Smit, van den Berg, Bekker, Seedat, & Stein, 2006). Moreover, the CES-D has been widely used among populations in South Africa and other parts of Africa, including low-income populations and HIV positive individuals (Hamad, Fernald, Karlan, & Zinman, 2008; Kaharuzza et al., 2006; Kuo & Operario, 2011; Myer et al., 2008; Nduna, Jewkes, Dunkle, Jama Shai, & Colman, 2013; Poupard et al., 2007; Pretorius, 1991; Smit et al., 2006). Cronbach's Alpha coefficients reported for the above-cited studies with samples in Africa ranged between 0.88 and 0.92. The CES-D showed high internal reliability in this sample ($\alpha = 0.95$).

The CES-D is a 20-item tool through which respondents are asked to indicate how often they may have experienced symptoms of depression on a four-point scale ranging from 'Rarely or none of the time' (0) to 'Most of the time' (3). Responses are summed to compute a total score ranging from 0 to 60, with higher scores representing higher levels of depressive symptoms. A cut-off score of 16 or higher was used in this study to indicate the presence of depression as this is the generally accepted cut-off score for high risk of clinical depression, above which professional care is recommended (Cheung & Bagley, 1998; Hamad, et al., 2008; Radloff, 1977); this was the cut-off used by the original author (Radloff, 1977) and

previous studies successfully conducted in Africa, including South Africa (Hamad, et al., 2008; Kaharuzza, et al., 2006; Kuo & Operario, 2011; Nduna, et al., 2013).

Anxiety. Caregiver anxiety symptoms were measured by the Beck Anxiety Inventory (BAI), a tool used to assess common symptoms of clinical anxiety in adults (Beck & Steer, 1993). The BAI instrument was developed to produce an anxiety tool that would reliably distinguish anxiety from depression while also showing convergent validity with other anxiety instruments (Beck & Steer, 1993; Steele & Edwards, 2008). The BAI has been shown to have good psychometric properties, with a high internal consistency (ranging from .90 to .94) and test retest reliability of 0.75 (Beck, Epstein, Brown, & Steer, 1988; Beck & Steer, 1993; Steele & Edwards, 2008). The BAI has been widely used in many different cultural contexts and has been translated into many languages. An isiXhosa translation of the BAI was validated in South Africa (Steele & Edwards, 2008); this study showed high internal consistency ($\alpha = 0.92$) with a mean score comparable to international data. Moreover, the BAI is used regularly in South Africa both in research and clinical settings, and internal consistency has been shown to be comparable to the USA validation studies (Nel & Kagee, 2013; Pillay, Edwards, & Sargent, 2001; Pillay & Sargent, 1999; Spangenberg & Pieters, 1991). The Cronbach's Alpha coefficient for this sample was 0.95, indicating a high level of internal reliability.

The BAI is 21-item instrument through which respondents indicate the extent to which they have been bothered by anxiety symptoms experienced over the past month; responses are chosen from a four-point scale ranging from 'Not at all' (0) to 'Severely' (3). Responses are then aggregated to compute a total score ranging from 0 to 63. According the guidelines suggested by the original authors, scores of 0-7 indicating very low anxiety; 8-15

mild anxiety, 16-35 moderate anxiety and 26-63 high anxiety (Beck & Steer, 1993). A binary variable was created and used in this analysis to denote the presence (score of 8+) or absence (scores between 0 and 7) of some level of anxiety. The standardised cut-off scores for the BAI have been used widely, including in previous studies conducted in South Africa (Nel & Kagee, 2013; Pillay, et al., 2001)

Socio-economic and demographic variables. The caregiver survey questionnaire also included questions aimed at collecting caregiver and household demographic and socioeconomic data (see pp. 2-4 and 35-38 of the attached Adult Carers Survey). Caregiver age, gender, household size and other basic demographic information were collected using items from the South African National Census (Statistics South Africa, 2003a), South Africa's 2005 General Household Survey (Statistics South Africa, 2005), South Africa Demographic and Health Survey (Department of Health, 2007), and the KwaZulu-Natal Income Dynamics Study (KIDS) questionnaire (May, Carter, Haddad, & Maluccio, 1999). Selection of previously tested questions maximized chances of including culturally appropriate questions designed for a low literate population.

Household socioeconomic status was measured using Booysen's (2001) South African economic asset index (EAI). This economic asset index is based on factor and principal component analysis of variables from Demographic and Health Surveys (DHS) (Booyesen, 2001). Variables included indicators of ownership of consumer goods, access to services and resources (e.g., electricity and sanitation), dwelling characteristics, household size and household experiences of food insecurity (see questions 1.2 – 1.4, 6.1 - 6.5 and 7.1 in the attached Adult Carers Survey). Variables were normed and weighted based on scoring coefficients specific to South Africa (Booyesen, 2001). Weighted variables were then summed

to form a total score, which was then transformed into a categorical EAI variable with five quintiles, the lowest (first) quintile representing the lowest socio-economic group. This method of estimating economic status has been shown to be as or more reliable than other conventional measures (Filmer & Pritchett, 2001; Montgomery, Gagnolati, Burke, & Paredes, 2000). Preliminary analysis with this sample using variables for each quintile showed that only belonging to the two highest quintiles (40% wealthiest households in the sample) was significantly associated with the mental health outcomes of interest, as could be expected in similar resource-deprived communities where poverty is generalized; economic asset quintiles in this sample represent relative socio-economic status among households in communities with overall low socio-economic status compared to national indicators (Noble et al., 2006). A categorical binary variable was therefore created and used in this analysis to indicate relative socio-economic status, that is, whether or not a caregiver's household fell into the two highest socio-economic quintiles, based on the EAI.

The caregiver questionnaire also collected information on the children reported to be living in the household, including the whereabouts of their biological parents and/or whether the biological parents were still alive (see section 4 of the Adult Carers Survey questionnaire on pp. 22-27). In this way, it was possible to determine the presence and number of single and double orphans in the household.

5.2.6 Procedure: the field research process

Recruitment and training of field staff for the urban site survey research was carried out from June to September 2009, while fieldwork for the urban site was conducted from

September 2009 to March 2010, then for an additional month in November 2010. Recruitment and training for the rural site was conducted in March to April 2010, and the field research from May to October 2010. The section below describes the field team composition and the field research process.

Field team composition and roles. The urban field team consisted of two field coordinators, 15 interviewers and 4 security escorts. The rural field team consisted of two field coordinators (one local and one who had worked on the urban site and relocated to Manguzi), 14 interviewers (8 local and 6 from the Durban field team who relocated) and 5 community guides. All interviewers were fluent in both English and the local language, isiZulu; they went from home to home to introduce the project, ask eligibility questions and (in the case of eligible households) obtain informed consent and conduct the interview. Field coordinators provided supervision of the research process in the field by managing the research team together with the project managers, identifying selected recruitment sites, driving interviewers and security escorts from meeting spots to interview sites, and regularly checking the quality of interviews and paper questionnaires. In the urban site, security escorts had the role of safeguarding the security of the research team and assisting with community buy-in and dissemination of information on the project. Each security escort was 'assigned' a group of interviewers on field, who were to report to him/her and inform him/her of their whereabouts at all times. The role of community guides on the rural site was primarily that of introducing the team and facilitating community buy-in, as crime was less of a concern.

Recruitment and training. Field researchers on the urban site were recruited by means of a formal selection process through the Health Economics and HIV/AIDS Research

Division at the University of KwaZulu-Natal; this included advertising posts through the internal university mail system, reviewing and shortlisting CVs, conducting interviews with potential candidates and checking references. Security escorts were chosen by the Ward Councillor among members of the Community Policing Forum, a body that liaises between community members and the police service. These escorts were well known and respected throughout the community, and therefore provided the team with 'legitimacy' and facilitated access to households.

One field coordinator and six interviewers later relocated to the rural site to join the rural field team. In addition, a local field coordinator and eight local interviewers from the rural site were recruited in collaboration with the NGO partner, through local knowledge, CVs and interviews. On the rural site, 28 people who had completed a Life Skills course with the NGO were provided with a week's general and project-specific research training. Eight interviewers and five community guides were then selected to form part of the rural field team, based on verbal and written assessments following this training; selection criteria included retention and understanding of the course's content, spoken and written English and isiZulu, and communication skills. In particular, community guides selected were individuals with previous home-based care experience through the local NGO partner, who were familiar with the local communities and demonstrated good personal interaction.

On both the urban and rural field site, all fieldworkers received two to three weeks of both general research and project-specific training to prepare for the field research. General research training was provided on topics such as general health, research ethics, referrals, communication skills and questionnaire administration. Project-specific training included the use of GIS devices and administration of the specific survey instruments to be used. Training

was interactive and included role-play and simulation of interviews to allow interviewers to gain confidence and skill in administering the questionnaires.

Figure 5.6. Photograph of project managers providing research training for the field team in the rural site.



Supervision and quality control of data collection. Following the launch of the urban fieldwork, capacity building continued on field for both the research assistants and field coordinators. The fieldwork was initially launched with a small team, in order to allow for closer supervision, and then slowly scaled up during the first few weeks on field. The doctoral candidate and co-project managers worked closely with the field coordinators and interviewers during the first month of fieldwork, in order to support and further develop the team, control the quality of the data collection process and help deal with the challenges that

arose. Project managers randomly accompanied fieldworkers to the interviews, and provided feedback individually at the end of each field day. During the launch of rural fieldwork, the relocated urban team members, who had previous research experience and were more familiar with the questionnaire, assisted in training and mentoring team members from the rural site. During the first month of rural fieldwork, local interviewers were paired with a field coordinator, project manager, or urban team interviewer, who monitored their interviews and evaluated the quality of their questionnaires. Community guides received office-based and on-field training in project introductions and responding to questions from members of the community.

Throughout the field research, interviewers continued to be closely supervised by field coordinators, who randomly rotated with the interviewers to monitor data collection quality and provide individual feedback. Project managers continued to provide field supervision and quality control, but gradually reduced their presence on field to about 50% of their time, in order to better meet the varied needs of the project. However, daily debriefing meetings were held between the project managers and the field coordinators prior to fieldwork each day for the entire duration of the field research.

Each completed questionnaire was handed over to field coordinators the following day prior to commencement of fieldwork; these questionnaires were thoroughly quality checked by at least one other individual, either project manager, field coordinator or (on the rural site) one of the three office-based staff members, within two working days. The questionnaire responses were checked, question by question, for completeness and, in some cases, for coherence with responses to other related questions. In the case of errors or missing data, questionnaires were returned to fieldworkers so that the households could be revisited and corrections made; where this was not possible follow-up occurred telephonically.

Team meetings were held weekly at the office(s) with the project managers and entire field team, to discuss progress, fieldwork issues and challenges, and possible solutions to address these. Project managers were also regularly in telephone contact with principal investigators to discuss progress and corrective actions to deal with challenges. Moreover, job profiles were drawn up and signed by every team member at the onset of the project; subsequently regular performance appraisals were conducted with staff, during which feedback was provided in five key areas: utilisation of training, adherence to protocols, team and community interactions, speed of work and quality of work.

Figure 5.7. Photograph of a field coordinator, local interviewer and home-based carer discussing logistics in the rural site.



Field research challenges and adaptive strategies. Despite extensive discussions and planning, during the survey field research several challenges emerged that required adaptive strategies. Reconciling objectives and plans with the more fluid and unpredictable on-the-ground reality of conducting fieldwork is a common challenge for health researchers (Casale, Flicker, & Nixon, 2011; Mathee et al., 2010), especially for survey research of this dimension and duration, involving a considerable amount of logistics and staff coordination. Some of the key challenges experienced and strategies used to address these are briefly discussed below. A few are relevant for both research sites, while others are specific to the urban or rural areas. The fieldwork challenges encountered on the rural (Manguzi) field site and strategies used to address these have also been documented in more detail in a recently published manuscript prepared by the doctoral candidate and other members of the KwaZulu-Natal Young Carers project management team (Casale, Lane, Sello, Kuo, & Cluver, 2013).

The most prominent challenge to fieldwork in the urban field site was the team's security. While the crime levels in Lamontville were not as high as in many other townships in eThekweni, the prevalence of violent crime was still a concern⁸ and people who were clearly not from the area were considered a particular safety risk. Several approaches were used to address safety risks. These included: a) developing clear safety protocols and ensuring that they were respected by field team members; b) discussing safety issues and protocols during regular project meetings; c) leaving the fieldwork site early enough to allow

⁸ Crime statistics for Lamontville for April 2009 to March 2010, obtained from the South African Police Service, showed 191 cases of assault with intent to inflict grievous bodily harm, 121 cases of common assault, 100 cases of robbery, 63 cases of malicious damage to property, 92 cases of drug- or alcohol- related crimes, 109 cases of theft and 20 cases of carjacking. Data on crime in Lamontville and other townships in eThekweni, from 2003 to 2012, can be found at the following website: www.saps.gov.za/statistics/reports/crimestats/2012/provinces/kzn/kwazulu_natal.htm

staff to travel home before dark; d) making contact with local policing authorities to advise them of our presence and work in the area and e) recruiting four members of the local community policing forum (CPF) as security escorts to accompany field staff around the sites. Fortunately we did not have major security problems, besides a few incidents of petty theft.

Figure 5.8. Photograph of one of the CPF security escorts approaching a dwelling in an informal settlement in Lamontville, to introduce the project and interviewer.



Each field site also presented its own logistics challenges related to the terrain, topography and changing patterns of settlement. Sampling strategies and field plans needed to be adapted to take into account logistical constraints and the reality of political boundaries on the ground. This was especially the case for the rural site, given the area's limited

infrastructure and difficult terrain. For example: visibility was restricted in many areas due to flat terrain and dense bush; roads, road signage and/or road access to homes were absent in most areas; and aerial photos and maps were outdated and inadequate for our purposes. These challenges prompted re-assessment of both the sampling strategy in the rural site and the fieldwork logistics coordination. As explained above, it was decided to work with 'isigodi' as the smallest geopolitical boundaries, versus census EAs, as this allowed us to refer to local knowledge and political structures to determine community boundaries. We worked with local drivers familiar with the area and terrain, a majority of local field assistants and our CBO partner's local network of home community-based carers, present in each *isigodi*. To avoid households being visited multiple times, the HCBCs 'scouted' the area beforehand, in order to familiarise themselves with the area and subsequently direct RAs to homes. Given the significant distances between homesteads in certain areas, staff were often dropped off in different locations and later fetched by the same drivers.

Figure 5.9. Photographs illustrating logistics difficulties.



The image on left shows a field interviewer who resorted to climbing a tree in order to locate the next household in the rural site. The image on the right illustrates how interviewers often had to walk long distances on sand paths to reach homesteads.

Ensuring privacy and confidentiality was also very challenging on both sites, given the area and household characteristics. For example, many of the urban dwellings were one-roomed shacks or houses inhabited by multiple family members who would be present in the dwelling or pass through the dwelling during interviews. In some cases the only barriers between ‘rooms’ or spaces in the dwelling were curtains or sheets. We adopted multiple creative strategies through-out the fieldwork process to ensure confidentiality of interviews, following various project team discussions on this issue. These included: explaining the importance of privacy upfront to respondents or parents of respondents, requesting a private space before the interview, conducting the interview outside, speaking softly, allowing

literate respondents to fill in more sensitive sections themselves rather than answer verbally and providing concerned or curious family members with a blank questionnaire copy while the interview was being conducted.

Figure 5.10. Field researchers interview a caregiver in a quiet, shady spot under a tree in her homestead.



Finally, while the community consultation and buy-in process on the urban site involved only a few political leaders (i.e. ward councillors and municipal representatives), this process proved to be a major challenge for the rural site, where distances between households were greater and each community (*isigodi*) was governed by a local tribal leader (*induna*). Despite buy-in activities conducted by our local NGO partner prior to our arrival and the consent obtained from the tribal chief in the area, on our arrival in the area knowledge

of the project had not reached some communities and/or households. As a result we encountered much distrust and many refusals, and in extreme cases were chased out of communities. We learnt that not all community leaders had attended tribal meetings and/or advised their community members about the project; moreover some communities were temporarily without tribal leaders due to succession processes in course. We decided to rethink and intensify our community dissemination, in close collaboration with our NGO partner. Our team liaised with the NGO staff to contact the local schools and *induna* from each community to explain the purpose of our research and how this would be carried out. The consultation process involved multiple meetings with both community leaders and community members planned well in advance, during which these stakeholders would have the opportunity to ask for further clarification regarding our project. In most cases approval was granted, however in the few exceptional cases where community leaders could not be contacted, the project could not work in those specific *isigodi*. Also, to reach people in communities who were temporarily without leaders, we liaised with the NGO's existing network of home community-based carers (HCBCs) from those particular communities, to advise households of the research project and tribal chief's approval prior to the team's arrival. These strategies appeared to be extremely successful, as they significantly improved the reception of our team members in communities, and reduced the number of refusals to a negligible amount. The final refusal rate for both sites was less than 0.5%.

5.3 Survey data management

5.3.1 Data team, data entry and quality control

Survey data entry took place from October 2009 to February 2011; it was therefore on-going while the fieldwork was in course and lasted for two months after the completion of data collection. The data was captured in SPSS 18 by four data enterers based at HEARD's Durban office at the University of KwaZulu-Natal. Members of the data team were also recruited, by the doctoral candidate and colleagues, through job advertisements, CV review and interviews as per the University of KwaZulu-Natal's HR procedures. Data team members had prior data capturing experience and were familiar with SPSS; however two days' additional data training, including research ethics training and project-specific training, was provided by a colleague at the University of KwaZulu-Natal, who was an expert in quantitative data management and databases. The data team was supervised by the doctoral candidate and received performance appraisals in areas including: utilisation of training, adherence to protocols, team interactions, speed of work, and quality of work.

The data entry process was coordinated by the doctoral candidate and a co-project manager, as well as a data manager. The data manager was responsible for managing the data team on a daily basis, regularly merging SPSS databases, controlling the quality of data entered by rechecking a random subset of the data, and altering database variables where needed. Project managers also randomly quality controlled a subset of questionnaires entered in the database. Where missing data, inconsistencies or further errors were picked up during the data entry process, questionnaires were sent back to field for correction via the project

managers and field coordinators. In the case of minor errors and non-sensitive questions, the data team members would phone respondents to make corrections directly to the questionnaires; in this way they also contributed to follow-up with respondents and a further level of data collection quality control.

5.3.2 Data handover and storage.

Strict protocols were developed to regulate hardcopy submission, transportation, and handover of questionnaires in field, as well as data storage. On both the urban and rural sites questionnaires were stored in locked offices, and could only be accessed by authorised senior team members who had signed confidentiality agreements. During rural fieldwork, completed questionnaires were transported from the rural site to the urban offices on a bi-weekly basis by field coordinators or project managers driving a project vehicle. All stages of handover and recovery were recorded with modules detailing who had completed each questionnaire, who had submitted and who had received it, and the dates on which this handover had occurred.

After being entered into the databases by the Durban-based data team, paper survey questionnaires were catalogued and placed in a double-secured archive room at HEARD's UKZN office; they could be accessed only by the project managers or PIs, who had to sign an archive register on retrieving and returning them. Electronic databases and files were stored on password-protected computers attached to desks with computer locks in a locked office, accessible only to the data manager, project managers and PIs. All identifying information

was excluded from the final project database to be used for analysis, and cases were identified using unique identification numbers (UINs).

5.3.3 Data cleaning

Data cleaning was carried out over a period of approximately seven months, from March to September 2011, by the doctoral candidate and other Young Carers KZN project managers. The work was divided so that each team member was assigned a specific number of variables from the databases to be cleaned. This was done through syntax that was saved separately, cross-checked and shared with the team, and then finally run on the database. The data cleaning process involved addressing missing values, and checking for and correcting outliers and inconsistencies.

Levels of missing data were very low (< 1%) and appeared to be randomly distributed throughout the dataset (Schlomer, Bauman, & Card, 2010). The broader Young Carers survey research team checked for patterns in the missing data, and did not identify any (e.g. social desirability in answering sensitive questions; correlations with key outcome variables). For key variables (e.g. age, gender, scale items) missing data was addressed by: a) (where possible) reverting back to the original paper questionnaires to check for possible data entry errors; and b) in the case of psychometric tools, substituting the missing value with the mean of the remaining relevant scale or subscale items (mean imputation) (Carter, 2006; Schlomer, et al., 2010). In the remaining cases a discrete missing value ('666') was assigned to the case variable to indicate that it was missing.

5.4 Ethics approval and considerations related to the quantitative field research and data management

5.4.1 Formal ethics approval

Ethics approval for the quantitative component of this study was obtained from both the University of KwaZulu-Natal and the University of Oxford, as part of the broader Young Carers study. Approval to conduct the survey research was also requested and received from the South African national Department of Social Development, and the KwaZulu-Natal provincial departments of Health and Education. Letters of approval received for the quantitative research are included in Appendix 5.

5.4.2 Key ethics considerations

Extensive discussion and thought was given to ethical considerations related to the quantitative research component, during the research design phases. Ethical guidelines were informed by a broad literature review and the Young carer project team members' considerable previous experience in this area of research. Obtaining consent from local authorities and other gatekeepers has already been discussed. Below is a summary of other key ethics issues considered and measures adopted to address these.

Measures to protect autonomy. All attempts were made to ensure that participants fully understood the research, and that consent was both voluntary and informed. Informed consent was obtained from each caregiver survey participant. All caregivers that agreed to participate signed ‘opt-in’ consent forms (see Appendix 4: Adult Carer Consent Form For Survey). Information sheets and consent forms were read to participants in their preferred language to prevent illiteracy from hindering a participant’s understanding of the study purpose and methods. All participants were told they had the right to decline to participate or terminate their participation at any time, and that all results would remain confidential. Following the interview, participants were encouraged to ask any questions they may have had regarding the research, and were given an opportunity to have their data destroyed rather than included in the study. Only caregivers capable of providing their own consent were included in the survey.

Measures to minimize potential harm or stress. This study did not involve any procedures which may have unpleasant or have harmful side effects and it was not anticipated that the interviews would cause distress. However, in order to reduce any risk of participants becoming distressed, a number of measures were taken. All interviewers were trained and experienced in both research ethics and in working with HIV-affected families. Where there was a need for a particular participant to access more extensive support (such as seeing a counsellor or attending a clinic) referrals were made. A referral system was set up on each of the two sites, in collaboration with the appropriate local social services and child welfare offices. Field interviewers were trained to complete referral modules, which were then

delivered to the appropriate authorities. On the rural site, referrals were made in conjunction with the NGO partner organisation, which had an existing referral system set up.

Incentives. There is much debate in the literature on the appropriateness of incentives in health research. On the one hand, incentives (e.g. monetary compensation) may be seen as an indication of respect for participants' time and contribution; on the other hand, there is the risk of undue inducement that may compromise voluntary participation and the quality of responses (Bentley & Thacker, 2004; Grady, 2001; Grant & Sugarman, 2004; Singer & Bossarte, 2006). For this study a decision was taken to not provide any form of financial rewards to participants, to avoid the risk of jealousy within the community or households, undue influence on the decision to participate in the study and the quality of responses (given the low socio-economic status of households) and the safety risks associated with interviewers carrying money or other items. However, each caregiver participant received a colour Certificate of Participation following the interview (regardless of completion) as a token of appreciation (see Appendix 6: Carer Certificate of Participation). These were well received.

Measures to protect confidentiality. Various measures were taken to protect the confidentiality of participants' identities and information. As previously indicated, these included exploring creative ways to obtain privacy when conducting each interview (such as conducting interviews outside, or in local libraries). Staff entering data and/or translating and transcribing interviews were made to sign confidentiality agreements. Electronic data was stored on password-protected computers or back-up drives, and paper data was stored in locked cabinets. Completed surveys were stored in a secure archive at the Health Economics

and HIV and AIDS Research Division's offices at the University of KwaZulu-Natal's Westville campus, with availability of this data limited to the doctoral candidate and other members of the research management team, and managed through a log book. Moreover, only aggregate results of this study will be reported in dissemination of any kind; all participant names will be omitted and only locations in which the study took place will be included.

5.5 Analysis Approach

Survey data were analysed using SPSS 18. The paragraphs below describe the approach and methods used for the quantitative analysis of this research. Results of the quantitative analysis will be presented in the next chapter of this thesis (Chapter 6).

5.5.1 Descriptive statistics for the whole sample and sub-groups of interest

Descriptive statistics were generated for the whole sample, and for respective sub-samples of HIV-positive, other ill and healthy caregivers. These included percentages (in the case of categorical variables) or mean values and standard deviations (in the case of continuous variables) for key socio-demographic variables, health outcomes of interest for this analysis and the social support score. The health outcomes of interest were: symptomatic anxiety (as measured by the BAI), symptomatic depression (as measured by the CES depression scale), the SF-12 aggregate health score, and the SF-12 mental and physical health subscale scores.

Key socio-demographic variables included an indicator of location (that is whether the caregiver was living in the urban or rural site) as well as variables shown to be predictors of mental health among HIV-positive individuals and adult caregivers (Crosier, et al., 2007; Patel & Kleinman, 2003; Pinguart & Sorensen, 2007; Whetten, et al., 2008; World Health Organisation, 2001; Zinkernagel, et al., 2001); these are: age, gender, education and socio-economic status. Descriptive statistics were also generated for several selected socio-demographic variables included in the overall Economic Asset Index, in order to provide further – and more immediate – indicators of relative socio-economic household conditions for caregiver groups. These included household size, members of the household reportedly experiencing hunger at least occasionally, and household access to services such as running water, electricity and a flush toilet.

Moreover, given previously-cited evidence of negative effects of caregiving burden on health outcomes, indicators for the number of children in the household and the presence of orphaned children in the household were also included among the descriptive data and socio-demographic control variables in the regression analyses. The definition used for an orphaned child was a child (aged 0-17) that had lost one or both biological parents, as per the definition adopted by UNICEF and linked global development partners (UNICEF, 2013); it therefore included both single and double orphans. It should, however, be noted that these variables cannot be considered reliable indicators of caregiver burden or dependency for the specific caregiver interviewed, as they refer to the number of children and presence of one or more orphans in the entire household, which could include multiple caregivers⁹.

⁹ It was not possible to determine *which* or *how many* children in the household were the direct responsibility of the specific caregiver interviewed, as the survey did not collect this data.

Significant differences between the three caregiver sub-groups of interest (caregivers with HIV, caregivers with other illness and healthy caregivers) for these socio-demographic, health and social support variables were assessed using one-way ANOVAs and chi-square tests.

5.5.2 Multiple regression analyses

Two separate sets of regression analyses were conducted to address the three research questions guiding the quantitative analysis section of this thesis, specifically:

- 1) Is living with HIV/AIDS a risk factor for depression and anxiety among caregivers of children, and how does this compare to living with other illness?
- 2) Does social support have a main effect on caregiver depression and anxiety, and/or buffer against the effects of HIV/AIDS- and other illness- related stressors on depression and anxiety?
- 3) Is more social support associated with better self-reported general health and functioning among HIV-positive, other ill and healthy caregivers respectively?

Hierarchical logistic regression analyses with the entire sample of caregivers were conducted to address the first two research questions; categorical (dependent) variables were used for anxiety and depression, given the generally accepted and validated cut-off values for these variables (as described in Section 5.2.5). Linear regression analyses were conducted with each sub-sample of interest (HIV-positive, other ill and health caregivers) in order to address the third research question; the decision to work with the continuous SF-12 scores as

dependent variables was motivated by the absence of meaningful validated cut-off values for these scales. The choice of variables to include in the regression analyses as key variables of interest (stressors and social support) was driven by the research questions to be addressed; the choice of socio-demographic control variables was based on theory and previous empirical studies (previously cited) showing associations between these variables and mental health outcomes. More detail on the regression analyses approaches and methodologies are provided below.

Main and stress-buffering effects of social support on depression and anxiety.

Hierarchical logistic regression analyses with interaction terms were conducted to assess the relationship between HIV/AIDS and other illness, and mental health outcomes (depression and anxiety), as well as test for both main and stress-buffering effects of social support on depression and anxiety. This analytic approach is in line with that of previous studies, included in the systematic literature review of this thesis, assessing main and stress-buffering effects of social support on mental health with similar populations in the developed world (Klein, et al., 2000; Mellins, et al., 2000). The presence of main effects of social support was tested by determining whether there was a direct relationship between the social support score variable and the mental health outcome, while the presence of stress-buffering effects was tested by determining whether social support moderated the relationship between the specific stressors of interest (HIV/AIDS and other illness) and the mental health outcome of interest.

In order to conduct moderation analysis, interaction terms were created by multiplying each individual stressor by the protective resource (social support). The two stressors included in this first part of the analysis were HIV/AIDS and other illness,

respectively indicating whether the caregiver was living with HIV/AIDS or a non-HIV related illness (as opposed to a reference group of caregivers who had not reported a health condition). Dichotomous variables were created for each of these stressors, whereby '1' indicated the presence of the stressor and '0' the absence of the stressor. Interaction terms were created by multiplying each respective binary stressor variable by the mean-centred continuous social support score; mean-centring of continuous variables is suggested in order to reduce multi-collinearity when using interaction terms (Holmbeck, 1997; Mellins, et al., 2000).

First, bivariate tests (independent *t*-tests and Chi-square tests) were used to assess associations between each dependent mental health variable, and the socio-demographic, illness and social support variables to be included as independent variables in the logistic regressions. Second, hierarchical logistic regressions were conducted separately for each mental health outcome (depression and anxiety). After controlling for socio-demographic variables (block 1 of regression models), the two potential stressors (HIV/AIDS and other illness) were entered first in the regression models (block 2), social support as a potential protective factor was entered second (block 3), and the interaction of stressors and social support third (block 4). All independent variables were entered in SPSS as covariates, and categorical variables were entered as 'categorical covariates', specifying '0' as the reference category. For each independent variable entered in the regressions, Wald values and odds ratios were reported, together with significance levels. Associations were reported as statistically significant where the *p* value was less than 0.05. For each regression, the model chi-square and its significance level were reported, to indicate whether variables added significantly improved the models' ability to predict the independent variable outcome.

Associations between social support and general health and functioning for HIV-positive, other ill and healthy caregivers. In order to address the third research question on associations between social support and general health and functioning, three sets of multiple linear regressions were conducted for each of the three sub-samples of interest, that is: for HIV-positive, other ill and healthy caregivers. The decision to conduct this analysis separately for the three sub-groups, as opposed to conducting a regression with the whole sample using interaction terms (as for the regressions investigating anxiety and depression as dependent variables), was motivated by the specific research questions of interest to this analysis. The aim was to assess whether there were significant positive associations between more social support and better general health and functioning among caregivers who were already living with HIV or other illness. Also, stress-buffering effects of social support are more commonly assessed and understood within the mental (versus physical) health domain.

For each sub-group of caregivers, a correlation matrix was produced, showing Pearson's product-moment correlation coefficients for bivariate correlations between all SF-12 independent variables, and the socio-demographic, social support and health dependent variables to be included in regressions. Four linear regressions were then conducted for each sub-group of caregivers, to test direct associations between social support and general (aggregate), mental and physical self-reported health, as measured by the SF-12 aggregate health scale and its respective mental and physical health sub-components.

In the first model for each sub-group of caregivers, the SF-12 general health and functioning aggregate score was regressed against the socio-demographic control variables and social support, to determine the relationship between social support and an indicator of overall mental and physical health. Three further regressions were then run for each sub-group of caregivers to test the relationship between social support and the respective physical and mental sub-dimensions of the general health indicator. The intention was to isolate these

respective mental and physical health sub-components of the SF-12 aggregate health score, and regress each of these against social support. However, considering the methodological challenges related to the scoring of the SF-12 mental and physical health subscales, previously explained, two separate approaches were taken in order to achieve this.

The first approach consisted of regressing the SF-12 mental health subscale and the SF-12 physical health subscale separately against the social support score (last four columns in regression tables) for each sub-group of caregivers, after controlling for socio-demographic variables. The second, alternative approach, aimed at isolating the physical health component of the SF-12 aggregate health score, consisted in regressing SF-12 aggregate health score against social support for each sub-group of caregivers, this time controlling for mental health by including the depression and anxiety categorical variables (second and third columns in regression tables). Differences in the effect size and significance of the social support variable between the two (model 1 and model 2) SF-12 aggregate score regressions – that is, before and after controlling for anxiety and depression - were observed. The results of these two approaches, aimed at observing associations between social support and separate mental and physical health components of the SF-12 tool, were then compared.

Standardized coefficients (B), standard errors (SE(B)) and unstandardized coefficients (β) were reported for each independent variable, as well as significance levels. While the primary focus of these analyses was on the associations between social support and SF-12 health outcomes, rather than the total variance explained by the models, the R-square, adjusted R-square, and F values were also reported for each linear regression as indicators of the amount of explained variance and model fit. It should also be noted that, although not reported in the tables, collinearity diagnostics were checked for each of the linear regressions; tolerance statistics were well within the acceptable range of 0.4 – 1, VIF values between 1

and 2 and Durbin-Watson statistics greater than 1 for all regressions, indicating the absence of multicollinearity problems.

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CHAPTER 6. QUANTITATIVE RESULTS AND DISCUSSION

The previous chapter provided an overview of the objectives and methodology for the quantitative component of this research. This included a description of the quantitative analysis approach used to address the following (first three) general research questions of this study:

- 1) Is living with HIV/AIDS a risk factor for anxiety and depression among caregivers of children, and how does this compare to living with other illness?
- 2) Does social support have a main effect on caregiver depression and anxiety and/or buffer against the effects of HIV/AIDS- and other illness- related stressors on depression and anxiety?
- 3) Is social support associated with better self-reported general health and functioning among HIV-positive, other ill and healthy caregivers respectively?

Descriptive statistics and bivariate tests were used to present characteristics of the entire sample of caregivers, and sub-samples of interest for this analysis, as well as to identify significant differences in socio-demographic variables and key health outcomes across sub-groups (i.e. between caregivers with HIV/AIDS, other illness and without a health condition). Multiple regression analyses were then conducted to investigate the relationship between social support and the (mental and physical) health outcomes of interest.

This chapter describes and discusses the results of this quantitative analysis. The first section (6.1) describes the characteristics of the entire sample and sub-groups of interest, and highlights significant differences between these. The second section (6.2) presents the results

of hierarchical logistic regression analyses investigating main and stress-buffering effects of social support on depression and anxiety for the entire sample of caregivers. The third section (6.3) presents results of linear multiple regression analyses conducted to assess whether social support was significantly associated with the physical and mental components of self-reported general health and functioning, for sub-groups of HIV-positive, other ill and healthy caregivers. The last section (6.4) discusses these quantitative findings, in relation to the existing literature and research questions they aimed to address.

6.1 Characteristics of the entire sample and key sub-groups

6.1.1 Descriptive statistics for the entire sample

Table 6.1 contains selected descriptive statistics for the entire sample of caregivers. Almost the entire sample (99.8%) defined themselves as Black African, and isiZulu was the mother tongue of 96% of participants. The large majority (89%) of caregivers in the sample were female. This is not surprising given that in the Southern African context care responsibilities for children fall primarily on women (Kuo & Operario, 2009). The mean caregiver age was 44 years, indicating the increasingly important role of older adults as caregivers in the context of HIV and young adult mortality (e.g. grandparents versus biological parents) (Freeman & Nkomo, 2006; Howard, et al., 2006). Descriptive variables also draw attention to the difficult socio-economic conditions of households in these communities. Only 18% of caregivers reported having completed high school. Approximately 40% of the sample reported members of their household experiencing hunger at least

occasionally; 44% did not have access to running water in their dwelling or yard, and about half of participants (49%) did not have access to electricity. The data also highlight the presence of orphaned children in the large majority of households in these communities. The average number of children in the household was 3, and orphaned children were present in 72% of households. The data also show high rates of mental and physical health conditions in this sample of caregivers. Twenty-eight per cent of caregivers were defined as HIV-positive, 37% other ill and the remaining 35% as healthy. Just under 36% of caregivers were experiencing depression and 49% some level of (mild, moderate or severe) anxiety.

Table 6.1. Socio-demographic and health characteristics for the whole sample

Variables	Total sample (n = 2477)
<i>Socio-demographic variables</i>	
Age (mean, SD) ¹⁰	44.2 (13.9)
Gender (% female)	88.8
Higher education level (completed high school) (%) ¹¹	18.1
Household size (mean, SD)	6.0 (2.8)
Household members experience hunger at least occasionally (%)	40.4
Access to running water on property (%)	56.0
Access to electricity (%)	50.8
Access to flush toilet (%)	41.3
Higher socio-economic status (two highest quintiles) (%)	40.0
Urban (%)	48.4
<i>Child and orphan presence in home</i>	
Number of children in household (mean, SD)	3.1 (1.7)
Orphaned children in household (%)	71.6
<i>Caregiver health outcomes</i>	
HIV/AIDS (%)	27.7
Other illness (%)	36.7
Anxiety (%)	49.4
Depression (%)	35.6
SF-12 aggregate health score (mean, SD)	68.1 (19.8)
SF-12 mental health score (mean, SD)	65.5 (18.9)
SF-12 physical health score (mean, SD)	70.6 (24.8)
<i>Social support</i>	
Social support score (mean, SD)	3.6 (1.3)

¹⁰ n = 2473 for this variable, due to 4 missing values

¹¹ n = 2461 for this variable, due to 16 missing values

6.1.2 Descriptive statistics for sub-samples of HIV-positive, other ill and healthy caregivers

Table 6.2 contains descriptive statistics of socio-demographic and health variables for sub-samples of caregivers living with HIV/AIDS, caregivers living with other (non-HIV-related) illness and caregivers who did not report a health condition. There were a number of significant differences across groups. For example, a much lower proportion of (HIV or other) ill caregivers had completed high school ($p < .001$) compared to healthy caregivers. HIV-positive caregivers had lower socio-economic status than both other ill and healthy caregivers; this is indicated by the difference in proportions of sub-groups that fell into the highest two socio-economic quintiles ($p < .001$), but also from reports of household members experiencing hunger and access to services ($p < .001$). For example, approximately 56% of HIV-positive caregivers reported members of their household going hungry at least occasionally, compared to 37% of other ill caregivers and 31% of healthy caregivers. A larger proportion of HIV-positive caregivers were from the rural site (approximately 67%) whereas a larger proportion of caregivers with other illness were from the urban site (61%). Also, the percentage of households with one or more orphaned children was highest for HIV-positive caregivers (75%), followed by other ill caregivers' households (72% versus 68% for healthy caregivers; $p < .05$).

All mental and physical health indicators were worse for HIV-positive caregivers compared to other ill caregivers, while indicators for other ill caregivers were in turn worse than those for healthy caregivers; all differences across groups were significant at the .001 level. For example, the proportion of HIV-positive caregivers experiencing anxiety (66%) was higher than the proportion of other ill caregivers with anxiety (54%) which was in turn

considerably higher than the prevalence of anxiety among healthy caregivers (31%). Even more striking were the differences in depression rates among HIV-positive caregivers and the other two groups of caregivers: around 56% of HIV-positive caregivers were categorised as depressed, compared to 34% of other ill caregivers and approximately 22% of healthy caregivers. Not surprisingly, all SF-12 health scales' scores were considerably higher for healthy caregivers than for caregivers living with HIV/AIDS or other illness ($p < .001$). There were no significant differences in the mean social support scores across the three groups.

6.2 Main and stress-buffering effects of social support on mental health

6.2.1 Bivariate associations for depression and anxiety

Results of bivariate tests (chi-square and independent sample T-tests) between the independent variables and each of the categorical dependent variables (depression and anxiety), for the entire sample of caregivers, are illustrated in Table 6.3. In bivariate analysis, age (being younger), a higher level of education (having completed high school), higher socio-economic status, and being from the urban (versus rural) site were significantly associated with less anxiety and depression. The presence of one or more orphaned children in the household was associated with a lower likelihood of depression but a slightly higher likelihood of anxiety. Living with HIV/AIDS was also significantly associated with more anxiety and depression, though living with other illness was only significantly related to more anxiety (not depression). A higher mean social support score was associated with less anxiety and depression.

Table 6.2. Differences in socio-demographic characteristics, social support and caregiver health variables for HIV-positive, other ill and healthy caregivers

Variables	HIV-positive (n= 685/ 27.7%)	Other ill (n=910/36.7%)	Healthy (n = 882/ 35.6%)	Chi-square value	F - value ¹²	p value for differences between groups
<i>Socio-demographic variables</i>						
Age (mean, SD)	42.3 (11.57)	51.2	38.5 (11.9)		236.31	<.001
Completed high school (%)	10.3	12.2	30.2	136.34		<.001
Household size (mean, SD)	6.0 (2.8)	6.2 (2.9)	5.9 (2.5)		4.20	<.05
Household members experience hunger at least occasionally (%)	56.4	37.2	31.2	109.23		<.001
Access to running water on property (%)	40.8	67.0	56.5	108.03		<.001
Access to electricity (%)	34.5	63.6	50.3	133.22		<.001
Access to flush toilet (%)	50.9	52.8	40.8	109.00		<.001
Higher socio-economic status (higher 2 quintiles) (%)	28.0	48.2	40.8	66.90		<.001
Urban (%)	33.1	61.2	46.9	124.42		<.001
Female (%)	88.8	90.8	86.7	7.32		<.05
<i>Child and orphan presence in home</i>						
Number of children in household (mean, SD)	3.2 (1.7)	3.0 (1.7)	3.1 (1.7)		2.95	ns
Orphaned children in household (%)	75	72.2	68.1	8.80		<.05
<i>Caregiver health outcomes</i>						
Anxiety (%)	66.0	54.4	31.4	198.71		<.001
Depression (%)	56.1	34.0	21.5	202.03		<.001
SF-12 aggregate health score (mean, SD)	59.3 (19.3)	62.4 (19)	80.8 (13.6)		374.36	<.001
SF-12 mental health score (mean, SD)	58.8 (18.8)	62.3 (18)	74.0 (16.5)		165.96	<.001
SF-12 physical health score (mean, SD)	59.7 (24)	62.4 (24.4)	87.6 (14.8)		435.77	<.001
<i>Social support</i>						
Social support score (mean, SD)	3.53 (1.29)	3.65 (1.23)	3.6 (1.32)		1.7	ns

¹² F -value associated with One-Way ANOVAs

Table 6.3. Bivariate associations between anxiety and depression and independent socio-demographic and illness variables for the whole caregiver sample

	Depression				Anxiety			
	CES-D score	M (SD) or %	Chi-square or <i>t</i> value	<i>p</i>	BAI score	M (SD) or %	Chi-square or <i>t</i> value	<i>P</i>
<i>Socio-demographic variables</i>								
Age (mean, SD)	score < 16	43.4 (13.9)	-7.97	<.01	score < 8	42.1 (13.2)	-8.00	<.01
	score ≥ 16	45.6 (13.7)			score ≥ 8	46.5 (14.2)		
Completed high school (%)	score < 16	77.1%	38.74	<.001	score < 8	72.6%	106.30	<.001
	score ≥ 16	22.9%			score ≥ 8	27.4%		
Higher socio-economic status (%)	score < 16	72.6%	48.43	<.001	score < 8	57.4%	30.84	<.001
	score ≥ 16	27.4%			score ≥ 8	42.6%		
Urban (%)	score < 16	72.5%	66.39	<.001	score < 8	55.7%	24.05	<.001
	score ≥ 16	27.5%			score ≥ 8	44.3%		
Number of children in household (mean, SD)	score < 16	3.0 (1.7)	-3.38	<.01	score < 8	3.0 (1.6)	-1.43	ns
	score ≥ 16	3.2 (1.7)			score ≥ 8	3.1 (1.7)		
Orphaned children in household (mean, SD)	score < 16	62.6%	8.33	<.01	score < 8	49.3%	4.12	<.05
	score ≥ 16	37.4%			score ≥ 8	50.7%		
<i>Caregiver illness</i>								
HIV/AIDS (%)	score < 16	43.9%	171.94	<.001	score < 8	34.0%	104.01	<.001
	score ≥ 16	56.1%			score ≥ 8	66.0%		
Other ill (%)	score < 16	66.0%	1.80	ns	score < 8	45.6%	14.28	<.001
	score ≥ 16	34.0%			score ≥ 8	54.4%		
<i>Social support</i>								
Social support score (mean, SD)	score < 16	3.7 (1.3)	3.45	<.01	score < 8	3.8 (1.2)	6.59	<.001
	score ≥ 16	3.5 (1.3)			score ≥ 8	3.4 (1.3)		

6.2.2 Results of hierarchical logistic regression analyses for depression

Results of hierarchical logistic regressions with depression as the dependent variable are shown in table 6.4. Additional variables added to the regression in each model have been highlighted with bold text, for ease of reference.

Model 1 shows that being older was significantly associated with higher odds of depression ($p < .01$), while higher socio-economic status ($p < .05$) and living in the urban (versus rural) site ($p < .001$) were associated with lower odds of depression. After controlling for socio-demographic variables, both HIV/AIDS and other illness were found to be significant stressors associated with depression. HIV/AIDS appeared to be a greater risk factor for depression than other illness, as the odds of caregivers with HIV falling into the 'depressed' category were more than four times greater than the odds for healthy caregivers (OR = 4.13, $p < .001$), while the odds of caregivers with other illnesses experiencing depression were 1.75 times higher than the odds for healthy caregivers (OR = 1.75, $p < .001$).

When the social support score variable was added to the regression (model 2), it was found to be significantly associated with a lower likelihood of depression, indicating a main effect of social support (OR = 0.92, $p < .05$). However, when the interaction variables were added to the model (model 3), the main effect of social support was no longer significant and a significant interaction effect for 'Other Illness x Social Support' was observed (OR = 0.79, $p < .01$). The direction of the association was consistent with the stress-buffering hypothesis, as being HIV-positive and having more social support was associated with a lower likelihood of depression. Since the interaction of HIV/AIDS and social support was not significant, and the main effect of social support lost significance in the interaction model, findings suggest

that the association between (more) social support and lower odds of depression was significant only for the sub-group of caregivers with chronic non-HIV-related illness.

Odds ratios for each of the two relevant subgroups of caregivers (other ill and HIV-positive) were then calculated, using the unstandardized (beta) coefficients for the main effects and interaction term generated by the SPSS regression output (indicated in model 3). Similarly, standard errors and confidence intervals were computed for each of the two recalculated coefficients¹³. These confirmed the significance of the social support-depression relationship for the subgroup of caregivers with other illness, but not with HIV-related illness (for the HIV/AIDS-ill subgroup: OR = 0.93, CIs = [1.05 – 0.82]; for the Other ill subgroup: OR = 0.83, CIs = [0.94-0.73]).

The Nagelkerke R² statistic increased from 0.14 for model 1 to 0.15 for models 2 and 3, suggesting a slight increase in the amount of variance explained by the model once the social support indicator was added. This suggests a relationship of 15% between the predictors and the prediction¹⁴ (Burns, & Burns, 2008).

¹³ An odds ratio was calculated for each of the subgroups, by computing the exponential function (EXP) of the sum of the unstandardized coefficients for the main effect (social support score variable) and the relevant interaction variable, generated by SPSS. Standard errors were calculated for each of these subgroups by taking the square root of the following equation: variance social support variable + variance interaction variable + 2* covariance social support score and interaction variable.

¹⁴ It is noted that the R² coefficients in logistic regression should be interpreted with caution, as they are not analogous to the coefficient of determination R-square in linear regression; they represent attempts to approximate the R-square based on likelihoods (Burns, & Burns, 2008).

6.2.3 Results of hierarchical logistic regression analyses for anxiety

Results of hierarchical logistic regressions with anxiety as the independent variable are shown in table 6.5. Model 1 shows that being older ($p < .001$) and female ($p < .01$) were significantly associated with higher odds of anxiety, while a higher education level ($p < .001$) and better socio-economic status ($p < .05$) were associated with lower odds of anxiety. After controlling for socio-demographic factors, both HIV/AIDS and other illness were found to be positively associated with more caregiver anxiety, though odds ratios show that HIV/AIDS was the stronger predictor (OR for HIV/AIDS = 3.52; $p < .001$; OR for other illness = 2.06; $p < .01$).

A higher social support score (included in model 2) was found to be significantly associated with lower odds of anxiety, indicating a main effect of social support on anxiety (OR = 0.84; $p < .001$). However, neither of the illness x social support interaction terms (included in model 3) were significant, suggesting that social support was not moderating the effects of HIV- or other- illness related stress on anxiety for this sample of caregivers.

The Nagelkerke R^2 statistic increased from 0.15 in model 1 to 0.16 in model 2 to 0.17 in model 3, suggesting a slight increase in the amount of variance explained in the model. This suggests a relationship of 17% between the predictors and the prediction in the final (interaction) model.

Table 6.4. Results of hierarchical logistic regression analyses predicting caregiver symptomatic depression (n = 2457)

	Model 1		Model 2		Model 3	
	Wald	OR (CI)	Wald	OR (CI)	Wald	OR (CI)
<i>Socio-demographic variables</i>						
Age	10.85**	1.01** (1.01-1.02)	11.10**	1.01** (1.01-1.02)	11.23**	1.01** (1.01-1.02)
Higher socio-economic status	6.23*	0.75* (0.60-0.94)	4.96*	0.78* (0.62-0.97)	5.35*	0.77* (0.61-0.96)
Completed high school	0.58	0.88 (0.68-1.18)	0.25	0.93 (0.71-1.20)	0.44	0.91 (0.67-1.17)
Urban	13.34***	0.66*** (0.53-0.83)	13.24***	0.66*** (0.53-0.83)	12.54***	0.67*** (0.54-0.84)
Gender (female)	2.01	1.20 (0.90-1.61)	1.19	1.18 (0.88-1.58)	1.20	1.18 (0.88-1.58)
Number of children in household	1.44	1.04 (0.98-1.10)	2.09	1.04 (0.99-1.10)	2.11	1.04 (0.99-1.11)
Orphaned children in household	0.97	1.11 (0.90-1.37)	0.83	1.10 (0.89-1.36)	0.80	1.10 (0.89-1.36)
<i>Stressors related to illness</i>						
HIV/AIDS	149.17***	4.13*** (3.29-5.18)	150.37***	4.16*** (3.31-5.23)	150.75***	4.18*** (3.32-5.25)
Other illness	21.95***	1.75*** (1.39-2.21)	22.61***	1.77*** (1.40-2.23)	23.41***	1.79*** (1.41-2.26)
<i>Social support</i>						
Social support score			5.30*	0.92* (0.86-0.99)	0.46	1.04 (0.92-1.18)
<i>Interactions</i>						
HIV/AIDS x Social support score					1.79	0.89 (0.75-1.06)
Other illness x Social support score					7.49**	0.79** (0.67-0.94)
<i>Model statistics</i>						
Nagelkerke R ²	0.14			0.15		0.15
Chi-square		271.11***		276.40***		283.98***

* p < .05; ** p < .01; *** p < .001

Table 6.5. Results of hierarchical logistic regression analyses predicting caregiver symptomatic anxiety (n = 2457)

	Model 1		Model 2		Model 3	
	Wald	OR (CI)	Wald	OR (CI)	Wald	OR (CI)
<i>Socio-demographic variables</i>						
Age	20.16***	1.02*** (1.01-1.02)	20.85***	1.02*** (1.01-1.02)	20.85***	1.02*** (1.01-1.02)
Higher socio-economic status	6.01*	0.77* (0.62-0.95)	3.31	0.82 (0.66-1.02)	3.33	0.82 (0.66-1.02)
Completed high school	21.99***	0.54*** (0.42-0.70)	16.52***	0.58*** (0.45-0.75)	16.66***	0.58*** (0.45-0.76)
Urban	1.27	0.88 (0.72-1.09)	1.34	0.87 (0.71-1.09)	1.30	0.88 (0.71-1.09)
Number of children in household	0.00	1.00 (0.95-1.06)	0.31	1.02 (0.96-1.08)	0.31	1.02 (0.96-1.08)
Orphaned children in household	0.07	1.03 (0.84-1.25)	0.02	1.01 (0.83-1.24)	0.02	1.01 (0.83-1.24)
Gender (female)	7.76**	1.48** (1.12-1.95)	6.20*	1.42* (1.09-1.89)	6.23*	1.43* (1.08-1.88)
<i>Stressors related to illness</i>						
HIV/AIDS	126.20***	3.52*** (2.83-4.39)	129.54***	3.62*** (2.90-4.51)	128.70***	3.60*** (2.89-4.50)
Other illness	43.24***	2.06*** (1.66-2.55)	45.99***	2.12*** (1.71-2.63)	46.41***	2.13*** (1.71-2.65)
<i>Social support</i>						
Social support score			25.15***	0.84*** (0.79-0.90)	7.13**	0.86** (0.77-0.96)
<i>Interactions</i>						
HIV/AIDS x Social support score					0.00	1.00 (0.84-1.18)
Other illness x Social support score					0.56	0.94 (0.81-1.10)
<i>Model statistics</i>						
Nagelkerke R ²	0.15			0.16		0.17
Chi-square	297.49***			322.91***		323.57***

* p <.05; ** p < .01; *** p < .001

6.3 Associations between social support and general health and functioning for HIV-positive, other ill and healthy caregivers

6.3.1 Results for the HIV-positive caregiver sub-sample

Results of Pearson correlations between all variables included in the linear regression for the sub-sample of HIV-positive caregivers are illustrated in Table 6.6. As could be expected, the SF-12 scales were significantly correlated with each other (for the association between the SF-12 mental health and physical health subscales $r = 0.62, p < .001$) and symptomatic anxiety and depression were also significantly correlated ($r = 0.40, p < .001$). However, although all associations between anxiety and depression respectively and the SF-12 scales were significant at the .001 level, correlation coefficients were below 0.30, suggesting that the shared variance between these health indicators was low to moderate. Age (being younger) was significantly associated with better outcomes for all health indicators, except for depression. Living on the urban site was associated with less depression and having completed high school was associated with better SF-12 aggregate and physical health scores. As could be expected, some of the socio-demographic indicators were significantly correlated with each other although, with the exception of living on the urban site and higher socio-economic status ($r = 0.49, p < .001$), correlation coefficients were below 0.3. A higher number of children in the home was associated with better SF-12 health outcomes, lower caregiver age, lower socio-economic status, and living on the rural site. Caregivers who were female and/or living on the rural site were more likely to have orphaned children living in their household. Bivariate associations between the social support score and less anxiety ($p < .01$), as well as a higher SF-12 mental health score ($p < .05$), were significant. A higher social

support score was also significantly associated with higher socio-economic status, living on the urban site, being male and having completed high school.

Results of linear regressions with the SF-12 general health and functioning scores as dependent variables, for HIV-positive caregivers, are included in Table 6.7. Model 1 aimed to assess whether there was a positive significant relationship between more social support and better overall health and functioning, as measured by the SF-12 aggregate health scale. Model 3 aimed to assess whether there was a positive significant relationship between more social support and better self-reported mental health, as measured by the SF-12 mental health subscale. Model 4 aimed to assess whether there was a positive significant relationship between more social support and better self-reported physical health, as measured by the SF-12 physical health subscale. Model 2 also aimed to assess the relationship between more social support and better physical health, using an alternative approach: that is, by repeating the regression with the SF-12 aggregate score as the independent variable (as in model 1) and controlling for mental health (anxiety and depression) in order to isolate the physical health dimension of the SF-12 aggregate score.

Model 1 shows how a more advanced age predicted worse general health ($\beta = -0.27, p < .001$) and a larger number of children in the household predicted better general health ($\beta = 0.08, p < .05$), as measured by the SF-12 aggregate score, among HIV-positive caregivers (see model 1 in Table 6.7). Higher social support was not significantly associated with better general health.

A higher age was the only significant socio-demographic predictor of (lower) self-reported mental health (as measured by the SF-12 mental health subscale) among HIV-positive caregivers ($\beta = -0.17, p < .001$). A higher social support score was also a significant positive predictor of better self-reported mental health ($\beta = 0.12, p < .01$).

A lower age ($\beta = -0.03, p < .001$) and higher number of children in the household ($\beta = 0.09, p < .05$) were the only significant predictors of better self-reported physical health (as measured by the SF-12 physical health subscale) among HIV-positive caregivers. Social support was not significantly associated with physical health. This result was reinforced by results of the SF-12 aggregate scale regression controlling for anxiety and depression (see SF-12 aggregate scale model 2 in Table 6.7).

Overall, the results of multivariate linear regression analysis with the SF-12 scales for HIV-positive caregivers suggest that more social support was significantly associated with better self-reported mental health, but not with self-reported physical health or overall general health and functioning, among this sub-sample of HIV-positive caregivers.

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Table 6.6. Bivariate correlations for the HIV-positive caregiver sub-sample (n=685)

	Anxiety	Depression	SF-12 aggregate health	SF-12 physical health	SF-12 mental health	Age	Higher SES	Urban	Female	Completed high school	Number of children in household	Orphaned children in household	Social support score
Anxiety	1	-	-	-	-	-	-	-	-	-	-	-	-
Depression	.40 ^{***}	1	-	-	-	-	-	-	-	-	-	-	-
SF-12 aggregate health	-.27 ^{***}	-.27 ^{***}	1	-	-	-	-	-	-	-	-	-	-
SF-12 physical health	-.28 ^{***}	-.21 ^{***}	.93 ^{***}	1	-	-	-	-	-	-	-	-	-
SF-12 mental health	-.19 ^{***}	-.27 ^{***}	.87 ^{***}	.62 ^{***}	1	-	-	-	-	-	-	-	-
Age	.11 ^{**}	.03	-.28 ^{***}	-.32 ^{***}	-.17 ^{***}	1	-	-	-	-	-	-	-
Higher SES	-.03	-.04	.01	0	.02	.02	1	-	-	-	-	-	-
Urban	.01	-.08 [*]	-.04	-.02	-.05	.02	.49 ^{***}	1	-	-	-	-	-
Female	.05	.01	.03	.03	.04	-.10 [*]	-.06	-.07	1	-	-	-	-
Completed high school	-.07	-.01	.08 [*]	.11 ^{**}	.03	-.20 ^{***}	.26 ^{***}	.22 ^{***}	-.01	1	-	-	-
Number of children in household	-.01	.01	.11 ^{**}	.10 ^{**}	.09 [*]	-.09 [*]	-.10 [*]	-.26 ^{***}	.07	-.06	1	-	-
Orphaned children in household	.00	.04	-.02	-.04	.00	.02	.02	-.10 [*]	.10 ^{**}	-.00	.34 ^{***}	1	-
Social support score	-.11 ^{**}	-.06	.06	.02	.09 [*]	.04	.13 ^{**}	.14 ^{***}	.14 ^{***}	.08 [*]	.03	-.05	1

* p < .05; ** p < .01; *** p < .001

Table 6.7. Multivariate linear regression results for the SF-12 aggregate scale, mental health subscale and physical health subscale for the HIV-positive caregiver sub-sample (n=685)

	SF-12 aggregate scale model 1			SF-12 aggregate scale model 2 (controlling for anxiety and depression)			SF-12 mental health subscale			SF-12 physical health subscale		
	B	SE (B)	Beta (β)	B	SE (B)	Beta (β)	B	SE (B)	Beta (β)	B	SE (B)	Beta (β)
<i>Socio-demographic variables</i>												
Age	-0.45***	0.06	-0.27***	-0.41***	0.06	-0.24***	-0.27***	0.06	-0.17***	-0.63***	0.08	-0.30***
Gender (female)	0.58	2.29	0.01	0.99	2.19	0.02	1.39	2.28	-0.02	-0.24	2.83	0.00
Higher socio-economic status	1.72	1.86	0.04	1.64	1.77	0.04	2.42	1.85	0.06	1.00	2.29	0.02
Completed high school	1.77	2.50	0.03	1.49	2.38	0.02	-0.48	2.49	-0.01	4.01	3.08	0.05
Urban	-2.30	1.80	-0.06	-2.66*	1.73	-0.07*	-3.20	1.80	-0.08	-2.21	2.22	-0.03
Number of children in household	0.96*	0.47	0.08*	0.93*	0.44	0.08*	0.71	0.47	0.06	1.21*	0.58	0.09*
One or more orphaned children in household	-2.13	1.76	-0.05	-1.92	1.67	-0.04	-1.02	1.75	-0.02	-3.24	2.16	-0.06
<i>Social support</i>												
Social support score	1.01	0.57	0.07	0.57	0.54	0.04	1.58**	0.56	0.12**	0.44	0.70	0.02
<i>Mental Health</i>												
Anxiety				-6.45***	1.58	-0.16***						
Depression				-7.68***	1.50	-0.20***						
<i>Model Statistics</i>												
R square	0.09			0.18			0.05			0.11		
Adjusted R square	0.08			0.17			0.04			0.10		
F	8.66***			14.82***			4.42***			10.55***		

* p < .05; ** p < .01; *** p < .001

6.3.2 Results for the other-ill caregiver sub-sample

Results of bivariate correlations between all variables included in the linear regression for the sub-sample of caregivers living with non-HIV-related illness are illustrated in Table 6.8. As was the case for HIV-positive caregivers, SF-12 health scores were highly correlated with each other, as were symptomatic anxiety and depression ($r = 0.38, p < .001$). Anxiety and depression were respectively correlated with all three SF-12 scales, although absolute values of correlation coefficients remained within a range of 0.19 – 0.32. Age was highly significant for all health outcomes, except for depression, though both higher socio-economic status and living on the urban site were significantly associated with less depression. A higher education level (having completed high school) was associated with better health outcomes for all health scales. There were also positive, although quite weak, relationships between gender (being male) and better anxiety and SF-12 aggregate and physical health outcomes. As was the case for HIV-positive caregivers, the only strong relationship highlighted between socio-demographic variables was between higher socio-economic status and living on the urban site ($r = 0.55, p < .001$). A higher number of children in the home was significantly correlated with a lower age, lower education level and lower socio-economic status, and living in the rural site, as well as a higher likelihood of depression. The presence of an orphaned child in the home was instead associated with being older, being female and having a lower level of education. A higher social support score was significantly correlated with less depression and less anxiety, better SF-12 aggregate health and mental health scores, a higher education, higher socio-economic status, a greater number of children in the household and living on the urban site.

Results of linear regressions with the SF-12 general health and functioning scores as independent variables, for caregivers living with a non-HIV-related illness, are included in Table 6.9. Age was significantly associated with all SF-12 health outcomes in this subsample of caregivers experiencing non-HIV-related illness, and in particular for physical health ($\beta = -0.40$ for the general health scale, -0.25 for the mental health subscale and -0.44 for the physical health subscale, $p < .001$ for all three health outcome dependent variables). Better socio-economic status was also significantly associated with higher scores for all SF-12 scales ($p < .05$), while having completed high school predicted better self-reported general ($p < .05$) and physical ($p < .01$) health, although coefficients were smaller compared to those for caregiver age. Gender (being female) was associated only with worse SF-12 physical health scores, however, regression coefficients show that the contribution of gender to the variance was quite low ($\beta = 0.07$, $p < .05$). A higher number of children in the home was associated with worse outcomes for all SF-12 scales, although the presence of an orphan in the home was not significant.

A higher social support score was significantly associated with higher scores for both the SF-12 aggregate health scale ($p < .05$) and the SF-12 mental health subscale ($p < .01$), but not for the SF-12 physical health subscale, for this sub-group of other ill caregivers. The absence of a significant relationship between social support and subjective physical health was reinforced by the results of the SF-12 aggregate scale model 2 regression in Table 6.9: after controlling for the mental health outcomes (anxiety and depression), the association between social support and the SF-12 aggregate scale score was no longer significant.

In sum, as was the case for HIV-positive caregivers, the results of multivariate analysis with SF-12 scales for caregivers experiencing other (non HIV-related) illness suggest that more social support was significantly associated with better self-reported mental health, but not physical health.

Table 6.8. Bivariate correlations for the other-ill caregiver sub-sample (n=910)

	Anxiety	Depression	SF-12 aggregate health	SF-12 physical health	SF-12 mental health	Age	Higher SES	Urban	Female	Completed high school	Number of children in household	Orphaned children in household	Social support score
Anxiety	1	-	-	-	-	-	-	-	-	-	-	-	-
Depression	.38***	1	-	-	-	-	-	-	-	-	-	-	-
SF-12 aggregate health	-.29***	-.27***	1	-	-	-	-	-	-	-	-	-	-
SF-12 physical health	-.23***	-.19***	.93***	1	-	-	-	-	-	-	-	-	-
SF-12 mental health	-.30***	-.32***	.86***	.60***	1	-	-	-	-	-	-	-	-
Age	.12***	.05	-.38***	-.43***	-.23***	1	-	-	-	-	-	-	-
Higher SES	-.05	-.14***	.05	.03	.07*	.21***	1	-	-	-	-	-	-
Urban	-.08*	-.18***	.05	.06	.04	.10**	.55***	1	-	-	-	-	-
Female	.07*	.01	-.07*	-.08*	-.03	.03	.03	.02	1	-	-	-	-
Completed high school	-.20***	-.07*	.20***	.23***	.13***	-.25***	.13***	.16***	-.09**	1	-	-	-
Number of children in household	.02	.08*	-.06	-.05	-.06	-.09**	-.10**	-.24***	.06	-.10**	1	-	-
Orphaned children in household	.05	.06	-.04	-.06	-.01	.12***	.06	.00	.08*	-.15***	.30***	1	-
Social support score	-.15***	-.13***	.09**	.06	.11**	-.01	.14***	.07*	.04	.12***	.08*	.01	1

<.05; ** p < .01; *** p < .001

* p

Table 6.9. Multivariate linear regression results for the SF-12 aggregate health scale, SF-12 mental health subscale and SF-12 physical health subscale for caregivers living with non HIV-related illness (n = 910)

	SF-12 aggregate scale model 1			SF-12 aggregate scale model 2 (controlling for anxiety and depression)			SF-12 mental health subscale			SF-12 physical health subscale		
	B	SE (B)	Beta (β)	B	SE (B)	Beta (β)	B	SE (B)	Beta (β)	B	SE (B)	Beta (β)
<i>Socio-demographic variables</i>												
Age	-0.53***	0.04	-0.40***	-0.49***	0.04	-0.37***	-0.31***	0.04	-0.25***	-0.75***	0.06	-0.44***
Gender (female)	-3.03	2.02	-0.05	-2.47	1.94	-0.04	-0.51	2.03	-0.01	5.55*	2.53	0.07*
Higher socio-economic status	3.66*	1.42	0.10*	3.35*	1.37	0.09*	3.69*	1.43	0.10*	3.63*	1.79	0.07*
Completed high school	4.34*	1.90	0.07*	3.11	1.84	0.05	2.01	1.91	0.04	6.66**	2.39	0.09**
Urban	0.02	1.46	0.00	-1.29	1.41	-0.03	-1.18	1.46	-0.03	1.21	1.83	0.02
Number of children in household	-1.09**	0.38	-0.10**	-0.94**	0.36	-0.08**	-1.08**	0.38	-0.10**	-1.09*	0.47	-0.08*
Orphaned children in household	1.80	1.38	0.04	2.11	1.32	0.05	1.85	1.39	0.05	1.75	1.73	0.03
<i>Social support</i>												
Social support score	1.07*	0.48	0.07*	0.48	0.46	0.03	1.47**	0.48	0.10**	0.67	0.60	0.03
<i>Mental Health</i>												
Anxiety				-5.93***	1.23	-0.16***						
Depression				-7.06***	1.28	-0.18***						
<i>Model Statistics</i>												
R square	0.18			0.25			0.08			0.22		
Adjusted R square	0.18			0.25			0.07			0.21		
F	25.14***			30.31***			10.04***			31.39***		

*p < .05; ** p < .01; *** p < .001

6.3.3 Results for the healthy caregiver sub-sample

Results of bivariate correlations between all variables included in the linear regression for the sub-sample of healthy caregivers are illustrated in Table 6.10. As for the other two sub-groups of caregivers, all three SF-12 scales were highly correlated, although the correlation coefficients for relationship between the SF-12 mental and physical health subscales were lower than the coefficients for (HIV or other) ill caregivers ($r = 0.52, p < .001$). Depression and anxiety were also significantly correlated with each other ($r = 0.44, p < .001$) and with the SF-12 scales (absolute values of correlation coefficients ranged from 0.22 to 0.34). Age was significantly associated with worse health outcomes, while higher education and higher socio-economic status were associated with better health outcomes for all health variables, and living on the urban site with better outcomes for all health variables except for the SF-12 mental health scale. Similarly to results for the other two sub-groups, higher socio-economic status and living on the urban site were strongly related ($r = 0.58, p < .001$), though in this case the association between a higher socio-economic status and a higher education was also strong ($r = 0.43, p < .001$). A larger number of children in the home was significantly related to more depression, a lower socio-economic status and education level, living in the rural site and being female; the presence of orphaned children in the home was associated with living in the urban site and being female. A significant relationship was found between a higher social support score and better health for all health outcomes except depression; these relationships were clearly stronger than those between social support and the health variables for (HIV or other) ill caregivers (absolute values of coefficient sizes ranged from 0.14 to 0.25; $p < .001$). Higher social support was also significantly associated with a lower age, higher levels of socio-economic status and education, and more children in the home.

Results of linear regressions with the SF-12 general health and functioning scores as independent variables, for caregivers without a reported health condition, are included in Table 6.11. As was the case for the HIV-positive and other ill sub-samples of caregivers, a higher age was a significant predictor of worse scores on all SF-12 scales among healthy caregivers; this was especially the case for the SF-12 physical health subscale (see models 1, 3 and 4; for the general health scale: $\beta = -0.22$, $p < .001$; for the mental health subscale: $\beta = -0.11$; $p < .01$; for the physical health subscale: $\beta = -0.28$, $p < .001$). Higher socio-economic status was also significantly associated with better health scores for all three SF-12 scales, though the significance levels and β coefficients were lower ($p < .05$).

A higher social support score was a highly significant predictor of better scores on all three of the SF-12 health scales for this sub-sample of healthy caregivers (see models 1, 3 and 4 in Table 6.11), although the relationship appeared to be stronger for mental health and aggregate (general) health than for physical health (for the general health scale: $\beta = 0.21$, $p < .001$; for the mental health subscale: $\beta = 0.21$; $p < .001$; for the physical health subscale: $\beta = 0.15$, $p < .001$). The physical health results were reinforced by the outcome of the SF-12 aggregate scale regression which controlled for anxiety and depression (model 2 in Table 6.11): both anxiety and depression were significant predictors of worse general (mental and physical) health, and the social support score remained significant in the model ($p < .001$), after controlling for these mental health outcomes.

In sum, the results of multivariate linear regression analysis with the SF-12 scales for the sub-sample of caregivers categorized as 'healthy' (without a reported physical health condition), suggest that more social support was significantly associated both with better self-reported mental health and better self-reported physical health for this sub-sample.

Table 6.10. Bivariate correlations for the healthy caregiver sub-sample (n = 882)

	Anxiety	Depression	SF-12 aggregate health	SF-12 physical health	SF-12 mental health	Age	Higher SES	Urban	Female	Completed high school	Number of children in household	Orphaned children in household	Social support score
Anxiety	1	-	-	-	-	-	-	-	-	-	-	-	-
Depression	.44 ^{***}	1	-	-	-	-	-	-	-	-	-	-	-
SF-12 aggregate health	-.34 ^{***}	-.32 ^{***}	1	-	-	-	-	-	-	-	-	-	-
SF-12 physical health	-.29 ^{***}	-.22 ^{***}	.86 ^{***}	1	-	-	-	-	-	-	-	-	-
SF-12 mental health	-.30 ^{***}	-.33 ^{***}	.89 ^{***}	.52 ^{***}	1	-	-	-	-	-	-	-	-
Age	.10 ^{**}	.11 ^{**}	-.24 ^{***}	-.30 ^{***}	-.12 ^{***}	1	-	-	-	-	-	-	-
Higher SES	-.21 ^{***}	-.16 ^{***}	.17 ^{***}	.16 ^{***}	.13 ^{***}	-.02	1	-	-	-	-	-	-
Urban	-.18 ^{***}	-.13 ^{***}	.12 ^{***}	.14 ^{***}	.07	-.11 ^{**}	.58 ^{***}	1	-	-	-	-	-
Female	.08 [*]	.08 [*]	-.04	-.05	-.02	.03	-.08 [*]	-.10 ^{**}	1	-	-	-	-
Completed high school	-.17 ^{***}	-.13 ^{***}	.16 ^{***}	.19 ^{***}	.09 ^{**}	-.26 ^{***}	.43 ^{***}	.40 ^{***}	.12 ^{**}	1	-	-	-
Number of children in household	.05	.09 ^{**}	.02	.01	.03	-.02	-.18 ^{***}	-.31 ^{***}	.15 ^{***}	-.18 ^{***}	1	-	-
Orphaned children in household	.01	.03	-.03	-.02	-.03	.05	-.02	-.09 ^{**}	.07 [*]	-.04	.34 ^{***}	1	-
Social support score	-.14 ^{***}	-.00	.25 ^{***}	.21 ^{***}	.23 ^{***}	-.08 [*]	.23 ^{***}	.06	.02	.25 ^{***}	.08 [*]	.03	1

* p < .05; **p < .01; *** p < .001

Table 6.11. Multivariate linear regression results for the SF-12 aggregate scale, SF-12 mental health subscale and SF-12 physical health subscale for caregivers without a reported health condition (n = 882)

	SF-12 aggregate scale model 1			SF-12 aggregate scale model 2 (controlling for anxiety and depression)			SF-12 mental health subscale			SF-12 physical health subscale		
	B	SE (B)	Beta (β)	B	SE (B)	Beta (β)	B	SE (B)	Beta (β)	B	SE (B)	Beta (β)
<i>Socio-demographic variables</i>												
Age	-0.25***	0.04	-0.22***	-0.21***	0.04	-0.18***	-0.15**	0.05	-0.11**	-0.35***	0.06	-0.28***
Gender (female)	-0.57	1.30	-0.01	0.27	1.22	0.01	-0.14	1.62	-0.00	-1.00	2.53	-0.02
Higher socio-economic status	2.88*	1.15	0.10*	1.48	1.09	0.05	3.07*	1.43	0.09*	2.69*	1.79	0.09*
Completed high school	-0.10	1.13	-0.00	-0.56	1.06	-0.02	-0.97	1.41	-0.03	0.78	2.39	0.02
Urban	0.73	1.12	0.03	0.27	1.06	0.01	0.13	1.40	0.00	1.34	1.83	0.06
Number of children in household	0.31	0.30	0.04	0.40	0.28	0.05	0.31	0.37	0.03	0.32	0.47	0.04
Orphaned children in household	-0.97	0.99	-0.03	-0.97	0.93	-0.03	-1.50	1.23	-0.04	-0.44	1.73	-0.01
<i>Social support</i>												
Social support score	2.15***	0.35	0.21***	2.08***	0.33	0.20***	2.59***	0.43	0.21***	1.71***	0.60	0.15***
<i>Mental Health</i>												
Anxiety				-5.69***	0.99	-0.19***						
Depression				-6.99***	1.11	-0.21***						
<i>Model Statistics</i>												
R square	0.13			0.24			0.07			0.14		
Adjusted R square	0.12			0.23			0.07			0.14		
F	15.79***			26.74***			8.65***			18.06***		

* p < .05; ** p < .01; *** p < .001

6.4 Discussion of quantitative findings

6.4.1 Overall prevalence of mental health conditions

The prevalence of mental health conditions in this sample of caregivers was considerably high, at 49% for anxiety and 36% for depression. While a comparison of exact rates found by other studies is not possible, due to different sample populations and instruments used¹⁵, it should be noted that the proportions of caregivers experiencing symptomatic anxiety and depression in our sample were considerably higher than the estimated national prevalence rates for South Africa (these are approximately 16% for lifetime anxiety disorders and just under 10% for major depressive disorder, and around 30% for any mental health disorder, including mood and substance use disorders) (Herman, et al., 2009). Our findings are more in line with those of South African studies conducted with samples of HIV-positive or chronically ill adults and/or caregivers living in similar resource-deprived HIV-endemic communities. For example, two studies carried out in South Africa with patients living with HIV found that between 33 and 35% of these patients were experiencing depression (Hughes, Jelsma, Maclean, Darder, & Tinise, 2004; Olley et al., 2003), while a study with South African patients attending public health clinics for the treatment of other chronic illness (hypertension and diabetes), showed that nearly 40% were

¹⁵ For example, Herman et al (2009) reported on the South African Stress and Health study that measured anxiety and depression using the Composite International Diagnostic Interview (CIDI). Kuo and Operario (2011) measured anxiety using the Kessler scale (K10) and depression using the CES-D (the same instrument used in this study). Olley et al (2003) used the MINI International Psychiatric Interview, while Kagee et al (2008) used the Beck Depression Inventory.

distressed and over 20% were experiencing moderate to severe depression (Kagee, 2008). A recent survey conducted with a similar population of caregivers in HIV-endemic KwaZulu-Natal (Kuo & Operario, 2011) showed that around 60% of caregivers were experiencing anxiety and 30% depression.

The descriptive data for this study's sample suggest that the high rate of mental health conditions in this population may in part be explained by the effects of (HIV-related and other) illness. However, even for healthy caregivers, the prevalence of anxiety and depression is substantially greater than the national survey figures for the general population.

6.4.2 Associations between HIV- and other illness- related stressors and depression and anxiety

Consistent with a substantial body of existing empirical literature, findings of this analysis show that experiences of HIV/AIDS and other illness are significantly associated with greater odds of depression and anxiety among primary caregivers of children in these two HIV-endemic communities (Ciesla & Roberts, 2001; Folkman, et al., 1993; Rodin & Voshart, 1986; Sherr, et al., 2011; World Health Organisation, 2008). Our results also show that HIV/AIDS is a stronger predictor of depression and anxiety than other non-HIV related chronic illness. These findings highlight the particular risks of HIV/AIDS for mental health among this population of caregivers, which likely reflect both the physical health impact of the disease and its social dimension (Ciesla & Roberts, 2001).

6.4.3 Main and stress-buffering effects of social support on mental health

The results of this analysis show that higher social support is directly associated with lower odds of anxiety for caregivers. These findings are consistent with previous empirical work showing predominantly main effects of social support on adult mental health (House, Umberson, et al., 1988). These results suggest that social support is a protective factor for anxiety for all caregivers in this community, whether or not facing HIV- or other-illness-related stressors.

Results of this analysis also indicate that social support may be buffering against the negative effects of stressors resulting from other (non-HIV-related) illness on depression. It should be noted, however, that this does not appear to be the case for HIV/AIDS-related stressors. One possible explanation for this outcome, as argued by previous authors, is that protective resources such as social support may be insufficient to protect individuals caring for children from the particular effects of HIV, especially when living in difficult social conditions; in other words the impact of HIV-related stressors on mental health outcomes may simply be too large to observe the support impact (Mellins, et al., 2000). These hypotheses are, however, beyond the scope of this analysis and would need to be further explored through future research.

6.4.4 Associations between social support and general health and functioning for HIV-positive, other ill and healthy caregivers

Findings of multiple linear regressions exploring SF-12 general health and functioning scales confirm a significant relationship between more social support and better self-reported mental health, overall in line with findings of the logistic regressions for symptomatic anxiety and depression, reported above. Significant associations between higher social support scores and higher scores on the SF-12 mental health subscale were found for all three sub-groups of caregivers, that is: HIV-positive, other ill and healthy caregivers.

Findings were, however, less conclusive for the physical health dimension of the SF-12 tool. Results of linear regression analysis suggest that social support is positively associated with better self-reported physical health among the sub-sample of healthy caregivers, but not for caregivers living with HIV/AIDS or other illness. This may indicate that for caregivers already living with a health condition (whether or not HIV-related) and experiencing the physical effects of this condition, social support is not able to act as a positive health resource for general physical health, as it does in the absence of a health condition. Findings of this analysis therefore do not support research showing associations between more social support and better subjective physical health among HIV-positive individuals (Leserman, 2003; Pakenham, et al., 1994; Persson, et al., 1994). However, this may (in part) be explained by the limitations of the physical health measure used in this survey and the nature of this analysis. Studies investigating effects of support on (HIV and other) disease progression or physical health status among individuals with a health condition should ideally use biological indicators, control for factors such as years living with the disease, and collect longitudinal data to control for initial health status. This was not possible

to achieve through this analysis, given the available quantitative indicators and cross-sectional study design.

6.5 Synthesis of quantitative findings

Results of the quantitative component of this study highlight the overall protective role of social support for health, particularly for mental health. Main effects were found for symptomatic anxiety, some evidence of stress-buffering effects of social support were found for depression, and positive associations were found between more social support and higher scores for the SF-12 self-reported mental health indicator, among sub-samples of HIV-positive, other ill and healthy caregivers. A positive relationship between more social support and better self-reported physical health (as per the physical health dimensions of the SF-12 tool) was, however, found only for the sub-sample of 'healthy' caregivers, and not for caregivers living with HIV/AIDS or other illness.

Findings of the quantitative analysis contribute to addressing the 'first order' questions related to the existence and direction of associations between social support and health outcomes, and embodied in the general research questions 2 and 3 of this study (see Table 1.1). They cannot, however, provide us with further insight regarding the 'second order' questions of *why* and *how* social support is linked to better caregiver health (Sarason & Sarason, 2009; Uchino, et al., 2012), embodied in the fourth general research question guiding this work. These 'second order' questions will be addressed in the following two chapters (Chapters 7 and 8), which describe the methodology and findings of the qualitative component of this study.

CHAPTER 7: QUALITATIVE COMPONENT METHODOLOGY

The previous chapter of this thesis (Chapter 6) presented findings of the quantitative analysis, from survey data with 2477 primary caregivers of children living in HIV-endemic communities in KwaZulu-Natal. Overall, the analysis showed a positive relationship between more social support and better mental health outcomes. It provided evidence of main effects for symptomatic anxiety and depression, and suggested some stress-buffering effects for symptomatic depression (for stressors related to other illness, but not HIV). A positive direct relationship was also found between social support and self-reported mental health for all caregivers, as measured by the SF-12 general health and functioning tool. The quantitative analysis also showed a direct positive association between social support and better self-reported physical health (based on the SF-12 tool), though only for caregivers without a (HIV-related or other) health condition.

This chapter describes the methodology of the qualitative component of this study, aimed at further qualifying and exploring the quantitative findings summarized above. It aims to address the fourth general research question guiding this research, by exploring the perceived mediating processes that may be explaining observed effects of social support on caregiver health. The qualitative investigation consisted of in-depth semi-structured interviews with 24 HIV-positive and HIV-negative caregivers who had participated in the quantitative survey. The objectives and methodology of the qualitative component are described in further detail in this chapter; this includes the study design and sampling, data

collection and analysis. Findings of the qualitative analysis will be presented in the following chapter (Chapter 8).

7.1 Objectives of the qualitative component

The primary objective of the qualitative component of this research was to further explain associations between social support and caregiver health outcomes observed through the quantitative analysis, presented in previous chapters. Specifically, the qualitative work aimed to address the fourth general research question guiding this work (indicated in Chapter 1), and related specific research questions:

What are the perceived pathways and mediating processes explaining the relationship between social support and caregiver health?

- What does the qualitative data tell us about caregivers' experiences and key sources of anxiety and depression?
- How do caregivers perceive social support to be affecting their psychological health?
- How do caregivers perceive social support to be affecting their physical health?
- Are there key differences in the experiences and perceptions of HIV-positive, versus HIV-negative (other ill or healthy) caregivers, or of male versus female caregivers?

The main purpose of the qualitative work was therefore to explore mediating processes and pathways through which social support was perceived to be affecting health among this sample of caregivers of children. With reference to the House et al theoretical framework presented above (House, Umberson, et al., 1988), this work therefore aimed to shed light on the potential biopsychosocial mediating variables explaining main or stress-buffering effects, represented by Box D and the *b/c* and *b/d* pathways (see Figure 1.1 in Chapter 1). The identification of possible, potentially co-existing, explanations for observed associations between social support and (mental and physical) health outcomes investigated was intended to both contribute to existing theory and empirical work, and identify possible mediating variables to be explored in future quantitative work.

Given the particular interest in HIV-positive caregivers, differences between perceptions of HIV-positive and HIV-negative (other ill or healthy) caregivers were to be identified through the analysis of qualitative data. Moreover, although the quantitative analysis of this thesis did not explore outcomes by gender (as almost 90% of caregivers in the sample were female), differences in experiences/perspectives between male and female caregivers emerging from the qualitative work were also identified. Previous studies have shown gender differences relating to both support networks and various aspects of the social support – health relationship. For example, in some populations differences have been found between men and women regarding the type or size of their networks, the ways in which they seek or utilise support to deal with stress and distress and the extent of the protective nature of social support for their health (Schraedley, Gotlib, & Hayward, 1999; Tamres, Janicki, & Helgeson, 2002; Walen & Lachman, 2000).

7.2 Sampling and qualitative research design

The qualitative component design and field research took place between July and December 2011. Given its objectives and links to the larger quantitative survey data, the qualitative study design and instrument were informed by the review of both theoretical and empirical literature on social support and health, presented in Chapters 2 and 3, and by findings of the preliminary analysis of the quantitative survey data (highlighting associations described in Chapter 6).

A sample size of 20-25 individuals was decided on based on resource availability (particularly funding for the field research, transcription and translation¹⁶) and the number of caregiver sub-groups of interest. Participants were caregivers who had taken part in the quantitative survey in the urban site (Lamontville township). Sampling for this study was purposive or criterion based (J. Mason, 2002; Patton, 2002), based on specific characteristics of caregivers which were considered the most important to help explore the key questions and themes (Ritchie & Lewis, 2006). The key selection criteria were health status and gender. Stratified purposive sampling was conducted (Patton, 2002) in order to compare sub-groups with variation on these specific characteristics (Ritchie & Lewis, 2006). The primary criterion was HIV status, and the intention was to recruit an equal number of caregivers who were HIV-positive (10 – 12) and HIV-negative; among the HIV-negative caregivers, the intention was to recruit both healthy caregivers and caregivers with other illnesses. The aim was also to

¹⁶ The qualitative component of this doctoral work was funded by a research grant awarded to the doctoral candidate by the Health Economics and HIV and AIDS Research Division (HEARD) at the University of KwaZulu-Natal. The analysis presented in this thesis is therefore part of a broader qualitative study, designed and implemented by the doctoral candidate, and funded by the HEARD research grant.

include both male and female caregivers in the sample. This would allow the analysis to identify possible differences in the experiences and perceptions of HIV-positive caregivers, versus other ill and healthy caregivers, and between male and female caregivers. Given the relatively small sample size and the number of sub-groups (2 for gender; 3 for illness status), there were not intended to be nested criteria for this analysis (i.e. differences were not explored by illness status for each gender separately); however, in order to ensure variation within gender groups, the same proportions of HIV-positive, other ill and healthy caregivers were recruited.

The choice of HIV status as the main selection criterion was motivated by the specific interest in the protective effects of social support for the health of caregivers living with HIV. One of the aims of both the quantitative and qualitative analyses was to identify whether social support could be affecting the health of HIV-positive caregivers in different ways compared to other (ill and healthy) caregivers. As indicated above in the quantitative methods section, HIV-status was determined in the survey by the use of algorithms applied to the quantitative data set, taking into account self-report of HIV status and responses for the verbal autopsy (VA) tool. However, given the relatively small numbers needed for the qualitative study, HIV-positive participants for the qualitative component were selected from the list of participants who had self-reported their HIV status in the quantitative survey; in this way the identification of HIV status in the qualitative sampling would not be affected by the margin of error linked to the VA tool. As indicated in the description of the quantitative survey tools (in Chapter 5), caregiver 'other illness' status was determined in the survey through questions on illnesses and symptoms pertaining to the most common causes of adult illness in South Africa, as identified in the South African Demographic and Health Survey (Department of Health, 2003) and the Health Systems Trust Annual Review (18 items)

(Health Systems Trust, 2006); these included asthma, diabetes, arthritis, cancer, low or high blood pressure and epilepsy.

Existing lists and information derived from the broader quantitative survey data allowed for refined purposive sampling, to identify the study group based on specific, and in some cases sensitive, information that would otherwise be difficult to obtain among this population (e.g. HIV status). Sampling was conducted by generating lists of survey participants with the specific set of characteristics for each desired sub-group for the qualitative study (e.g. HIV-positive and female; HIV-positive and male). Individuals were then randomly chosen from each list and contacted telephonically to enquire about interest in participating and potentially set up an appointment for the consent process. Random selection continued until appointments were made with the desired minimum number of participants from each sub-group of interest. Where interviews could not be conducted (e.g. where participants cancelled appointments, were unwilling to participate or could not be found), additional names were then randomly chosen from the relevant lists.

Despite the initial intention to interview an equal number of male and female participants, this proved challenging given the smaller number of male caregivers overall and in each sub-group, their lower willingness to participate, greater difficulty tracing them and more limited availability to be interviewed during the day. Taking this into account, and considering that females represent the large majority of caregivers in these communities, it was decided to work with a larger number of females in the qualitative sample (the final number was 16 females, versus 8 males). Considering the gendered nature of caregiving in this community, female caregivers were considered the priority group for the qualitative investigation.

The final sample consisted of 24 caregivers of children with the following characteristics (as illustrated in the table below): 16 female and 8 male; 12 HIV-positive, 12 HIV-negative, of which 6 healthy and 6 other ill. Male and female participants were distributed evenly across the three illness categories. Each participant was assigned an identification number, ranging from F1-F16 for female participants and M1-M8 for male participants.

Table 7.1. Characteristics of the final qualitative study sample

HIV status	HIV-positive	Other ill	Healthy	Total
	12	6	6	24
Gender				
Female	8	4	4	16
Male	4	2	2	8

7.3 Instrument design

The qualitative research tool, the interview topic guide, is included in Appendix 8. It is important to note that, as for the quantitative survey, this tool was designed by the doctoral candidate for a broader qualitative study, linked to the KwaZulu-Natal Young Carers quantitative survey, and funded by the Health Economics and HIV/AIDS Research Division at the University of KwaZulu-Natal. It therefore includes questions aimed at collecting additional data beyond the focus of this doctoral research. The questions specific to the aims of this doctoral research have been highlighted in bold in the attached questionnaire.

The qualitative instrument was designed as a topic guide for face-to-face in-depth semi-structured interviews. As such, broad questions were included to cover key topics to be addressed during the interview. Its application was intended, however, to be flexible enough to permit topics to be covered in a different order if appropriate, in order to maintain the logical flow of the conversation (e.g. where the issue already came up spontaneously and was being discussed by the respondent) (Ritchie & Lewis, 2006). The interview was also intended to be interactive, with themes probed and explored through follow-up questions, based on participants' responses, in order to obtain a better understanding of their meaning and resemble an everyday conversation as much as possible (Ritchie & Lewis, 2006). For the core questions, key themes around which to construct follow-on questions were indicated under specific broad questions in point form on the topic guide as a reminder to the interviewers. The intention was also to allow for some discussion of unforeseen emergent topics that could be relevant to the purpose of the investigation.

The first English version of the interview guide was discussed during a group session with the three bilingual (isiZulu-English) research assistants who were to conduct the field

research for the qualitative component of the study, in order to ensure their understanding of the intentions and meaning of the questions. The tool was subsequently translated by the research assistants during a group session, and later back-translated by a bilingual Masters level student with good knowledge of both spoken and written English and isiZulu. The instrument was then piloted in isiZulu with the research team and bilingual colleagues from the research division (HEARD) during the training sessions. While there did not appear to be major challenges with any of the broad questions asked, it emerged that the wording of several questions should be slightly modified to more effectively convey the intended meaning. It also became clear that it was important to include multiple generic introductory questions on the respondent's key support providers and types of support received, in order to contextualise the subsequent questions on the relationship between support and health, and allow the respondents to better respond by relating questions to their own experiences of support, as opposed to abstract notions or constructs which participants would have difficulty relating to. The topic guide was refined accordingly, based on this feedback.

As illustrated by the qualitative tool, the interviews were to commence with simple socio-demographic questions aimed at putting the participant at ease, including the number of children cared for and how long the carer had been living in the area. Questions on key sources of support and types of support received by the respondents were not essential for the research questions to be answered by the qualitative component (they had been explored quantitatively through the survey), but were included to contextualise and facilitate responses to the subsequent questions on the relationship between social support and health outcomes. These questions were followed by the core part of the interview, containing questions on how social support was perceived to affect (mental and physical) health; these were included early in the interview in order to ensure that respondents would be relatively fresh when addressing them. They were followed by questions aimed at qualifying some further descriptive findings

from the survey (e.g. on sources of support and access to social support), which were beyond the scope of this doctoral research. Finally, the interview closed with questions on recommendations for future interventions as well as an opportunity to express any issues of importance to the respondent that hadn't been covered. The interviewee was then thanked and given the opportunity to ask further questions about the study or interview. The intention of the last part of the interview was also to wind down the conversation, that is, to allow the respondent to return to 'the level of everyday social interaction' and move away from strong feelings that may have emerged during the more sensitive parts of the interview (Ritchie & Lewis, 2006, pg 146).

7.4 Training and field research

The two research assistants (RAs) who conducted interviews for the qualitative study were selected from the larger group of research assistants who had worked on the quantitative component. This selection was based on their previous experience with qualitative research and the quality of their participant interaction during the quantitative survey. These RAs had previously received training for the quantitative work on research methods and ethics more generally, from the doctoral candidate and broader research team. They were provided with additional specific training for the qualitative work by the doctoral candidate, conducted over two days; this training included principles and approaches to qualitative interviewing and familiarisation with the aims and instrument for this particular study. Group sessions and role-play served to allow the RAs to practice simultaneous translation and provide each other with feedback on their translation.

The qualitative field research consisted of one semi-structured in-depth interview (Burgess, 1982) with each of the 24 caregivers. Each participant was contacted telephonically and arrangements were made to visit him/her at his/her home and explain the consent process. As was the case for the quantitative survey, isiZulu consent forms were prepared (an English version is attached in Appendix 7), read and discussed with each participant by the bilingual field research assistants, to ensure participants' understanding of the content and allow for questions. Where verbal and written consent was provided, the interviewer would enquire whether he/she could proceed with the interview or make an appointment to return and conduct the interview. Prior to commencing the consent process and the interviews, the doctoral candidate and RAs spent some time in participants' homes making general conversation to put the participant at ease, then introducing themselves and the project.

The duration of the interviews was approximately 1 to 1 ½ hours. Each interview was conducted by the doctoral candidate and one of the isiZulu field research assistants in the local language (isiZulu). Simultaneous isiZulu-English translation was carried out during the interview, in order to allow the doctoral candidate to participate directly in the conversation and probe where appropriate. While this approach had the disadvantage of lengthening the interviews and interrupting the conversation flow to some extent, it had the advantage of allowing for more flexible and in-depth exploration of the key themes, given the doctoral candidate's familiarity with the existing empirical and theoretical work in this area and the preliminary quantitative findings. It should also be noted that the doctoral candidate had been conducting qualitative research with caregivers in urban and rural communities in KwaZulu-Natal since 2006, using similar approaches (see for example: Casale, 2011; Casale, Drimie, Quinlan, & Ziervogel, 2009); as such she had a good knowledge of the social and cultural context.

Given the smaller, more manageable nature of the qualitative field research (in relation to the quantitative survey field research), this field research did not present significant challenges. The team experienced some difficulty only in tracing respondents from the survey lists and identifying the homes, especially where contact details or addresses had changed. In the case of several unsuccessful attempts to contact individuals, further potential participants were randomly chosen from relevant lists.

7.5 Ethical approval and considerations related to the qualitative research

Ethics approval for the qualitative component of this research was obtained from the University of KwaZulu-Natal, as part of the larger study funded by HEARD, and from the University of Cape Town (see Appendix 9 for ethics approval letters for the qualitative research). Many of the key ethical issues relevant to the qualitative research, and measures taken to address them, were similar to those relevant to the quantitative research, which have been previously discussed. These include measures to protect autonomy, measures to minimize potential harm or stress and measures to protect confidentiality.

Since the qualitative component of the study was carried out in one of the urban Wards in which the survey research had been conducted (Lamontville, Ward 74), a referral system with the area's social services had already been set up, and the doctoral candidate had already-established relationships with the Councillor and other key local stakeholders. As a result, obtaining consent from gatekeepers to conduct the qualitative interviews did not present any challenges. Also, the field research assistants who conducted the qualitative

interviews had previously worked on the quantitative survey; they had therefore undergone research ethics training and were familiar with the existing referral system.

As was the case for the quantitative study, written informed consent was obtained from each caregiver participant, after reading the consent form aloud in the caregivers' mother language, isiZulu, and allowing time for questions and discussion (see Appendix 7 for the English version of the consent form for the qualitative study). Caregivers participating in the qualitative interviews did not receive incentives; they were, however, offered juice and biscuits during the interview, as a small token of appreciation for their time and for allowing the researchers into their home once again.

Similar measures to those for the quantitative survey were also employed to ensure the confidentiality of participants' identities and interview data. Staff translating and transcribing interviews signed confidentiality agreements. Electronic data was stored on password-protected computers or back-up drives, and paper data was stored in locked cabinets. Completed surveys were then transferred for storage to a secure archive at the HEARD offices at the University of KwaZulu-Natal's Westville campus; availability of this data was limited to the doctoral candidate. Lastly, in reporting the findings of the qualitative analysis, all participant identifying data were omitted; caregivers were attributed numbers or pseudonyms, or simply referred to in a generic manner, e.g. as a 'female caregiver'.

7.6 Data transcription and analysis

Interviews were transcribed and translated into English by three bilingual research assistants, with previous transcription and translation training and experience through

HEARD at the University of KwaZulu-Natal. Quality control of translations and transcriptions for each interview conducted was subsequently carried out by a bilingual Masters-level student, who had a good command of both spoken and written English and isiZulu and previous transcription and translation experience.

The data was analysed by the doctoral candidate, in consultation with the RAs who had participated in the interviews. The doctoral candidate's direct involvement in all interviews facilitated her familiarisation with the data. The main analytical approach employed was thematic analysis; themes were identified from the transcript content and attention was paid to the way the themes were treated and presented and the frequency of their occurrence (Berelson, 1952; Ritchie & Lewis, 2006). These themes were later linked to sub-group criteria variables, specifically gender and illness status.

Thematic analysis of the data was conducted through a multi-staged process, incorporating aspects of framework approaches and aspects of inductive approaches (Corbin & Strauss, 1990; Miles & Huberman, 1984; Neuman, 2006; Ritchie & Spencer, 1994). Nvivo software was used to support the coding and management of the data. Data reduction was carried out with the help of an analytical or 'coding' framework to break the text down into meaningful and manageable segments (Lee & Fielding, 1996; Miles & Huberman, 1984). An initial analytical framework was developed based on the theoretical interests and topic guide questions; this was, however, iteratively refined taking into account relevant and recurrent issues emerging from the text (Attride-Stirling, 2001). The transcript content was indexed electronically using Nvivo software. An inclusive approach was adopted in terms of indexing the data, at the expense of some repetition; that is, where the same text segments were deemed relevant to more than one theme or subtheme, they were 'multi-indexed' or indexed within each of those themes.

The thematic framework was refined multiple times to add, collapse or subdivide categories in order to create a hierarchy of themes. This process included both grouping initial themes into broader 'higher order' categories, representing larger, shared issues, as well as subdividing key themes of interest for the analysis into sub-codes or –themes. For example, text relating to explanations for effects of social support on physical health or mental health was subdivided based on the types of mechanisms identified.

At the first stages of the data analysis, emerging themes were described in terms close to the language used by respondents to allow the process to be grounded in the data (Ritchie & Lewis, 2006). The intention was to avoid imposing a preconceived structure upfront, so as to allow themes to be later related to the existing theory, and for new unforeseen pathways to potentially emerge. This was considered important to allow for some level of theoretical generalization and potentially contribute to existing theory on mediating processes of social support. The doctoral candidate then re-read through the themes, in order to extract common or significant ideas relevant to the theory and explore underlying patterns (Attride-Stirling, 2001; Ritchie & Lewis, 2006). More abstract classifications were thus made, based on research questions and concepts from the existing theoretical literature underlying these (Attride-Stirling, 2001), and themes were re-categorised based on these. The final thematic framework is illustrated in Table 7.2.

The final step in the analysis was to create explanatory accounts (Ritchie & Lewis, 2006) through associative analysis, in order to address the key research questions and allow for theoretical deduction. As indicated above, the main objective of the qualitative component was to identify and explore explanations or potential pathways for the effects of social support on health. In this study, explanations were built mainly on explicit reasons given by participants themselves. However, implicit reasons inferred from the data were also

considered; this was achieved by searching for underlying logic in responses given, using common sense, comparing findings with those in other studies and relating findings to the theoretical framework (Ritchie & Lewis, 2006).

As previously indicated, the House et al (1988) theoretical framework constituted the overarching theoretical framework to which findings could be related. These included recurrent (dominant and less dominant) themes identified in the data, but also the silences. For example, this framework was useful in identifying processes or mediating variables not supported by the data or for which the data provided less insight. Patterns and differences relating to these categories across key sub-groups within the study population were also explored and recorded where relevant, that is, whether and how particular views or experiences were associated differently with particular sub-groups, and possible reasons for this. Where specific themes were taken up entirely or predominantly by one particular sub-group of caregivers (e.g. male versus female, HIV-positive versus HIV-negative) this was highlighted in the analysis¹⁷; similarly, if there were clear differences in the perspectives and experiences of different sub-groups of caregivers in relation to a particular theme, these differences were indicated.

¹⁷ Given the nature of this qualitative explanatory research and the differences in sub-group sizes (specifically for the male versus female sub-groups) a cautious approach was adopted to highlighting differences across groups. Differences in the frequency of themes raised or number of participants who raised a particular theme were not in themselves considered sufficient to highlight differences across groups. These were only identified when a particular theme was highlighted entirely/almost entirely and repeatedly by one sub-group (i.e. when it was clearly dominant among one sub-group but not the other) and/or taken up differently across sub-groups (for example where there were clear opposing views or experiences on a particular theme).

Table 7.2. Final thematic framework for qualitative data analysis

CAREGIVER MENTAL HEALTH	Caregiver experiences of anxiety
	Caregiver experiences of depression
SUPPORT CONTEXT	Types of support important for health
	Sources of support
IMPORTANCE OF SOCIAL SUPPORT FOR CAREGIVER HEALTH	Negative effects of support seeking on mental health
	Positive effects of social support on mental health <ul style="list-style-type: none"> ▪ Direct positive effects, through communication and social interaction ▪ Indirect effects by reducing stress/stressors ▪ Indirect effects through mediating processes <ul style="list-style-type: none"> ○ Psychological resilience factors: hope, optimism, self-esteem, self-efficacy ○ Coping processes: distraction, rumination and more active problem-solving
	Positive effects of social support on physical health <ul style="list-style-type: none"> ▪ Positive effect on physical health through better mental health ▪ Positive effect on physical health through more positive health behaviour
	Importance of social support beyond coping with stressors <ul style="list-style-type: none"> ▪ Comfort and greater psychological resilience through regular interaction ▪ Positive influence on social and health behaviour ▪ Maintaining relationships to secure support for difficult times ▪ Comfort in the knowledge that support would be available ▪ Personal development and knowledge gain through support
	Importance of specific support providers

CHAPTER 8: QUALITATIVE RESULTS AND DISCUSSION

The previous chapter (Chapter 7) described the design, data collection and analysis for the qualitative component of this research, consisting of in-depth semi-structured interviews with 24 primary caregivers of children who had participated in the quantitative survey. This chapter presents the results and discussion of the qualitative data analysis. As previously explained, the purpose of this qualitative analysis was to provide further insight on the quantitative findings, that showed social support to be a protective resource for health, and in particular for mental health. The qualitative analysis aimed to explore perceived mediating processes explaining the relationship between social support and caregiver (mental and physical) health. Moreover, it intended to highlight differences in experiences and perspectives between sub-groups of caregivers based on illness status (HIV-positive, other ill and healthy) and gender. As such, this analysis aimed to address the fourth general research question, and related specific research questions, guiding this study, listed in Chapter 7.

First, to provide some background for the main findings on pathways explaining the support-health relationship, this chapter will present findings on caregivers' support context. This includes a brief summary of the main stressors or sources of anxiety and depression identified by participants, and the types of support participants considered to be most important for their health. It will then go on to present key themes emerging from participants' explanations of how they perceived social support to affect their mental and physical health, with particular attention afforded to the importance of social support for caregivers living with HIV. Moreover, although the qualitative data is not able to effectively distinguish between mediating processes explaining main versus stress-buffering effects, this

chapter will explore these themes to some extent, by highlighting caregivers' perceptions of why social support is important for their health more generally, even when they are not coping with specific stressors or stressful situations. Where themes were taken up entirely or predominantly by specific sub-groups of caregivers (e.g. males versus females; HIV-positive caregivers versus other caregivers) this will be highlighted, as will emerging differences in perspectives and experiences across groups. Finally, the implications of these qualitative findings will be discussed, in relation to the broader literature and theoretical framework.

8.1 Caregivers' experiences of anxiety and depression

As indicated by the qualitative interview topic guide (included in Appendix 8), caregivers were asked whether they ever felt anxious or depressed. All caregivers reported some experience of anxiety, and the large majority (all but two) caregivers interviewed reported experiencing depression. While interviewers referred to specific symptoms to clearly distinguish between depression and anxiety (e.g. "feeling sad" versus "feeling worried"), interview data suggest that constructs of anxiety and depression were perceived to be closely related for many caregivers, and sometimes used interchangeably. Moreover, reported reasons for caregivers experiencing anxiety overlapped to a large extent with those for depression.

The most common sources of anxiety identified were concerns related to caregiving and the behaviour or wellbeing of children cared for; this was the case for all groups of (ill and healthy, male and female) caregivers. Stressors included children's "bad" behaviour and/or delinquency, for example: children being influenced by peer pressure; showing a lack

of respect for traditions; not helping in the home; and disrespecting the caregiver. However, caregivers also reported worrying about not being able to meet the children's basic needs, especially food and school fees, and about what would happen to the children when they passed away. A few caregivers also spoke about their concern for (older) children who had left the home and were involved in difficult and/or abusive marriages.

Other sources of anxiety for caregivers included having to live with and manage one's own illness (in the case of caregivers who had HIV or another health condition), caring for an elderly parent, having experienced the illness or death of loved ones, and being discriminated against by other community members (this was, for example, the case of a female caregiver with Albinism). More general financial difficulties were also mentioned by multiple respondents as a key source of anxiety, for example: being unemployed, not having adequate shelter or means to meet the family's needs, and not being able to pay the bills. One caregiver reported the lack of support from family and a sense of abandonment as the main stressor she experienced.

The quotes below illustrate some of the sources of anxiety highlighted above.

I am just worried about life, thinking about my children and school fees and to buy them clothes for Christmas, and bills that come at the end of the month on debts from stores, and water and electricity bills - it's things like that that worry me (healthy male caregiver, M1).

There is only one thing that makes me worried. My illness doesn't worry me, but what makes me worry is that I have two daughters who are married. The eldest daughter is happy in her marriage but the other daughter is not happy. Her husband is very abusive, he ill-treats my daughter but my daughter loves him. In my heart, I always say I prefer my daughter to come back home because her husband is not working but my daughter is working (HIV-

positive female caregiver, F6).

As a sick person I think about what might happen to my children if I can die, that is what worrying me (HIV-positive female caregiver, F9).

Many of the reasons given for depression mirrored those given for anxiety. The most frequently indicated source of depression was children's disobedience and/or bad behaviour; for example: children dropping out of school or falling pregnant, or children not helping enough in the household. Other sources included: thoughts of one's own illness and death; the illness of someone close; not being able to meet the household's basic needs and having to ask for assistance to do so; and not being trusted in the community. Work-related difficulties were also identified as a reason for depression by several (male and female) caregivers; this included not being able to find a job or being turned down when applying for work, or experiencing difficulties at work. One female caregiver reported often feeling depressed because she had previously lost everything she owned to a fire.

I feel very sad because there are a lot of things I don't have. As I said, I don't even have soap. I feel affected because I assume that maybe I have become a menace to these people who help me... You know as we are in this house, I used to live in a proper house just like everyone else. But my house was burnt down by the fire in 2003. And in 2004 I lost my daughter and she was employed (female caregiver living with non-HIV-related illness, F15).

8.2 Types of support important for caregiver health

As indicated in Chapter 2, the main types of social support documented in the literature are emotional support (e.g. love, care and comfort), instrumental support (e.g.

material items or other forms of practical assistance), informational support (e.g. advice) and appraisal support (e.g. constructive feedback) (Heaney & Israel, 1997). Consistent with survey findings, there was overall consensus among respondents that social support positively affected their mental and physical health. Respondents reported receiving both emotional and instrumental support from significant others and family members, such as sisters and children, but also from friends and neighbours, church members and support groups. The large majority of respondents concurred that both emotional and instrumental support were important to them. Even when asked specifically about the relative importance of different types of support such as advice, encouragement, care and tangible help for their health, the dominant response was that these were all 'equal' and necessary. There were, however, a few isolated cases of respondents feeling that one type of support was more important than the others. For example, one caregiver felt that practical advice was the most useful type of support and a few other caregivers suggested emotional support was the most important. However, none of the respondents identified instrumental support in the form of material items (e.g. food or money) or practical assistance with chores as the most valuable type of assistance for them. This is noteworthy given the difficult socio-economic conditions experienced by many of the caregivers interviewed, and speaks to the value attributed to emotional support, such as advice, comfort and encouragement, in this community.

More specifically, HIV-positive and HIV-negative respondents agreed that both instrumental and emotional support were crucial in helping HIV-positive caregivers feel less anxious or depressed regarding their condition. Providing home-based care for a person with HIV-related illness was considered particularly important, especially during the advanced stage of the disease. However, respondents argued that the combination of various types of support for individuals living with HIV/AIDS was critical. For example, there was overall consensus that tangible help, even in the form of food or money, would have limited effects

on the mental and physical health of HIV-positive individuals in the absence of emotional and appraisal support such as love, care, empathy and encouragement. As explained by an HIV-positive female caregiver:

If you give them [HIV-positive individuals] hope, you have done everything, hope for them means “I will survive”. It is very important because I can give you money, you can do whatever but if you tell yourself that “I will survive”, you will survive ... because when you are taking that pill, you are taking it because “I want to get well.”(F2)

8.3 Positive relationship between more social support and better mental health

All caregivers perceived social support to have a positive effect on their mental health. No experiences or perceptions of negative effects of support were reported. Themes emerging from the data suggested three pathways through which social support could be positively influencing mental health among caregivers: 1) a direct positive effect of (emotional) social support on mental health; 2) an indirect positive effect of social support on mental health mediated by psychological resilience variables and coping processes; 3) an indirect positive effect of social support on mental health, as a result of social support reducing or eliminating the stressors causing anxiety or depression.

With regard to the indirect or mediated pathway (point 2 above), the main psychological mediating variables identified were hope, self-esteem and self-efficacy. The data also suggested that social support was leading to more adaptive coping, by encouraging active problem-solving coping and providing distraction from the mood and its causes, and

less maladaptive coping in the form of rumination, by preventing caregivers from thinking negatively and repeatedly about their mood and its causes.

These pathways and mediating factors are described in more detail below.

8.3.1 Direct relationship between more social support and better mental health

One of the dominant themes that emerged to explain the beneficial effects of social support on mental health was that of emotional ‘relief’ or a sense of emotional freedom, that followed on from sharing problems through dialogue with others, and subsequently receiving practical advice, comfort and reassurance. An idea frequently expressed was the feeling of emotional ‘release’ or unburdening that caregivers experienced after having spoken to someone about their concerns causing anxiety, and after having received advice and comfort. In some cases it was suggested that respondents could stop thinking and/or worrying about the problems once shared. This suggested a lessening of the emotional stress and anxiety ‘weighing down’ the caregiver. Where specific mediating factors were not indicated by caregivers (e.g. a conversation causing more optimism or hope), these explanations suggested a direct positive effect of social interaction and support on mental health.

The feeling of emotional release or unburdening was a theme taken up by both males and females, but mainly by female caregivers. For example, a healthy female caregiver told of how having someone listen to her problems and provide encouragement helped her feel less sad:

It is to be encouraged and not to keep things inside. That makes you feel better and all your problems end. I'm the kind of person who doesn't keep things inside, and when I

feel like that, I go to someone that I can speak to, because you can become thin [suggesting loss of appetite due to stress] if you can live my life. (F14)

Another healthy female respondent suggested that help received from her daughter and colleagues made her feel less anxious by allowing her to “release” this anxiety through talking about it and crying; afterwards she would stop constantly thinking about what was bothering her: “this is no longer on my mind”. The same respondent recounted that when she was depressed, both releasing this sadness by talking about it, and receiving advice, helped her feel less sad. She explained: “I have to talk about it if I want it to pass”. Another (healthy) female caregiver spoke about being “calmer” and “free in the heart” when receiving support. Other respondents also described a perceived sense of emotional ‘freedom’ or feeling ‘free inside’, suggesting calm or lack of emotional burden, derived from being supported:

Things have never been easy in life, but the main thing is to feel free emotionally or to be free emotionally, so when I get advice or support, that helps me - because things will never be easy, because every month there'll always be something that you are lacking. (Male caregiver with other (non-HIV-related) illness, M5).

The following excerpt from an interview with a healthy female caregiver suggests a perception of her sharing a burden with others when discussing her concerns, as if a weight is lifted off her shoulders and whatever was worrying or upsetting her will no longer consume her (“It won’t eat you up alone”). This caregiver explained how, when anxious or worried about something, she would seek support from her husband and sister:

I feel relieved – even if it would’ve worried me a lot, and it would have been a burden on my shoulders, but I feel relieved after telling one of them. (F5)

The suggestion that the emotional burden of one’s troubles may be shared with other people once they have been recounted alludes to the importance of personal interaction and a

strong social dimension of coping in this community.

Several respondents also spoke of feeling calmer after obtaining practical advice in relation to specific stressors. This comfort could derive from the caregiver being reassured that he/she was not alone in experiencing particular problems. For example, an HIV-positive female caregiver explained how the practical advice and care received from her sisters, when they visited, helped her feel less anxious:

Because when I tell her [my sister] about the children's treatment towards me she will tell me "you know, children are like that. What you should do is that you should get a grown up child to accompany you to the clinic," so that then I can feel better. After she has given me such advice I feel less anxious. (F8)

Lastly, a few respondents spoke about the comfort and peace of mind provided by the very knowledge that there was someone supporting them and/or that would be available to provide support should this be needed. This speaks to the importance of perceived support, regardless of whether needed or accessed. One HIV-positive female caregiver, for example, explained that, thanks to a supportive neighbour, she never felt anxious: "It is because the support is much closer to me and it is there for me all the time." Similarly, another (healthy) female respondent explained: "I feel better when there's someone who's able to help when I need something." In the same way, a male caregiver with a non-HIV-related health condition also spoke about feeling happier because of the knowledge that there would be people in his family or neighbourhood available to offer him support should he need it:

It is to know that we are united; not only in my home, but also with my neighbourhood, so I know that if there is something that I need to do, but not able to do it right away there are people who are going to help me to do that thing. (M5)

8.3.2 Indirect relationship between more social support and better mental health: psychological and behavioural mediating processes

Optimism and hope. A further dominant theme was that of social support leading to greater hope and optimism for the future, which would in turn help the caregiver feel less anxious or depressed. This was a theme raised by male and female, as well as ill and healthy, caregivers.

A male caregiver with a (non-HIV-related) health condition, for example, spoke about how the emotional support from his wife helped provide him with the hope that the challenges he was facing could be overcome and that the future would be better:

We [my wife and I] comfort each other-about our being unemployed, that someday we will find jobs, as we are living together...It [what makes me feel less depressed] is when we are able to talk and give each other ideas on how to raise our children, and when we are short of something, then my wife will go and ask for it and we know we will be able to patch things here and there. And the comfort, she will comfort me and tell me that everything will be ok. That I must not lose hope, I will be fine... She gives me both hope and encouragement that even if I failed but I should not lose strength but continue looking and I will end up doing that, with hope that maybe tomorrow I will succeed. So it's both the encouragement and hope. (M5)

An HIV-positive male caregiver, who had previously been in prison, told of how both life skills training received in jail and advice from his sister had helped him live a healthy life and continued to provide him with the hope and confidence to go on with his life.

I call her when I don't see things clearly or see life in a different way and she

supports me by saying life doesn't end here, even though she's married and lives in her own home. (M8)

Hope was in fact the most dominant theme that came up in response to the question of why social support was important for the wellbeing specifically of HIV-positive individuals. Both HIV-positive and HIV-negative respondents argued that it was crucial to instil, among caregivers living with HIV, the hope of survival, of living a relatively normal life, of being considered no different to healthy people or people with other illnesses, the hope of a better future. The excerpt below, taken from an interview with an HIV-positive female caregiver, emphasises how being provided with the hope of surviving and having a future may help prevent or reduce depressive symptoms related to illness:

I feel sad when I think about my illness. That is when they [my sisters] console me by saying there are lot of people who are sick but they are still alive. And I feel less worried to know that I'm not the only person who is sick... They encourage and give me hope... they advise me not to give up about life and I'm still going to live for a long time. They tell me a lot of things, that I am okay and that I should continue with life. (F6)

This HIV-positive female caregiver explained how providing a person living with HIV with the hope that life could go on, despite the disease, would make him/her feel less anxious:

To give advice to someone who is HIV [positive], that being HIV [positive] is not the end of the world, things like that. That has a good impact on the infected person... They feel less anxious and have hope when they get the support. (F6)

Yet another HIV-positive female caregiver told of how an HIV support group she was attending helped her feel less anxious, by providing her and the other group members with

hope, providing a forum to interact with other individuals facing similar problems, and advising members on how to deal with HIV-related stigma:

They give us hope, love and there is a lot that they provide us with. What can I say, it always feels good... We chat about the things we encounter in our daily lives like telling how my sister treats me at home by not using the glass of water I have been using... You know how people react when you are HIV positive, they avoid you. When you tell your story you will find that there is someone who shares your story or who is going through the same thing as you are. And they advise us to say no ... they advise us to tell our family members that because we are HIV positive it doesn't mean that we are going to infect them with the virus, you can't get the virus by sharing the bathroom with someone who is HIV positive. The support group is the platform where you let out all that makes you sad. (F12)

There was particular reference to the importance of providing caregivers with the hope that they would survive and live a normal life, so that they would want to live. It was even argued that without this hope and the desire to live, treatment would not be sufficient to ensure survival. As articulated by an HIV-positive female caregiver:

Hope. If you give them [HIV-positive individuals] hope, you have done everything, hope for them means I will survive... It is very important because I can give you money, you can do whatever, but if you tell yourself that I will survive, you will survive. .. Because when you are taking that pill, you are taking it because 'I want to get well' ... To tell an HIV positive person that this is not the end of your life, you still have a long life ahead of you. (M7)

The theme of hope in relation to the mental health of HIV-positive individuals was also echoed by HIV-negative caregivers interviewed. For example, a healthy male caregiver

spoke of the importance of both instrumental and emotional support in providing hope and the will to live. Being emotionally well was also linked to appetite and weight gain, which was directly linked to physical wellbeing.

It is the physical and emotional. They [HIV positive individuals] need to be cared for physically like being bathed, and emotional - by giving them hope and strength that everything will be fine, that as they take their treatment they will be fine. Just because they have the illness does not mean they will die... If they receive emotional and physical support, and not be discriminated against that can help them to feel much helped. And even gain weight if he/she has lost it...If I encourage them I give them hope and they will eat better, because things that make them to be sick is because they are nervous and worried. (M4)

Self-confidence and courage. A further, albeit less frequent, explanation given for the positive effect of social support on mental health was that it could boost self-confidence and courage. This suggests a positive effect of support on other traits associated with resilience, such as self-esteem and self-efficacy.

For example, it was suggested this support could change the way the caregiver saw his/herself, thus positively affecting self-esteem and creating a sense of belonging in the community. Or as articulated by one male HIV-positive caregiver, support could serve “to be able to see yourself exactly like other people who are HIV negative.”

A further theme raised was that of social support leading to respondents feeling more courageous or in control when confronting illness or other stressors. For example, one female caregiver explained that speaking about her problems helped her feel braver and less anxious:

It [support received] does have an effect [on anxiety] as it gives me courage because it is when I have shared what has been worrying me. (F12)

On being asked what it was about the support received from his wife, daughters and church members that helped him feel less anxious, a (healthy) male caregiver, who was a preacher, responded as follows:

It gives me power and to be brave, and when I am preaching, I don't have a problem knowing that we are united... It's always important, because of it I am able to do a lot of things, and I am able to help others. The support gives me the courage and strength to help others. (M4)

Less rumination. A further theme that was raised repeatedly to explain the effects of social support on mental health was that of support helping caregivers avoid constant negative thoughts and/or fixating on their problems. This theme was raised entirely by ill (and mainly HIV-positive) caregivers in relation to coping with their disease; moreover, it was raised predominantly by female caregivers. In particular, caregivers suggested that forms of emotional social support, such as companionship, dialogue and encouragement, could help HIV-positive individuals avoid repetitively thinking about the possible consequences of their illness, including imminent death. Conversely, the absence of human presence, interaction and support – being alone or feeling isolated – would risk leaving the HIV-positive caregiver to their negative thoughts about death. This repetitive negative thinking could be defined as ‘rumination’, a form of maladaptive emotion-focused coping, which can result in increased emotional distress (J. Smith & Alloy, 2009).

For example, the excerpt below illustrates how an HIV-positive female caregiver

perceived social support to be positively affecting her mental health and the mental health of other HIV-positive carers. She spoke about companionship and conversation that prevented her from frequently thinking about illness or death, and boosted her self-esteem and hope for the future (themes already discussed above):

Just like me as I'm HIV positive, I don't have to spend most of the time alone, because when you do that you may end up thinking about dying from this disease. It is better to have the company where you can spend time having a conversation instead of think about dying, and so you end up forgetting about it. And you need to tell yourself that you are still a human being and you can still live your life longer. (F4)

Similarly, two HIV-positive female caregivers spoke about how belonging to a support group helped them avoid fixating on thoughts of their disease and imminent death, as well as providing hope and assistance in dealing with stigma. The importance of caregivers realising that they were “not alone facing this epidemic” also surfaced once again, as the excerpts below illustrate.

It [the support group] makes you feel courageous, because when you are alone most of the times you think about what if you are dying now. All you think about is living with this virus. And that people always complain about you and they look at you as someone who is there to infect them with the virus. (F4)

By attending support groups, one gets to feel relieved, even mentally avoiding thoughts of imminent death, that now I'm HIV positive and I'm going to die. By attending these support groups you learn that you are not alone facing this epidemic ... When you are told that you are HIV positive you feel worried that you are about to die, you don't even think of buying something small because you are thinking that you are about to die. You don't think that you will die when the right time comes, the day

God set up for you. But if you become part of the support group, you are told that you won't die now, you will die on the day God has set up for you. (F12)

More distraction. A further theme that came up repeatedly during the interviews was that of caregivers 'forgetting' their concerns as a result of personal interaction and support. This suggests that social support could positively affect mental health by increasing distraction as an alternative emotion-focused coping strategy, defined as "focusing attention away from the mood and its causes onto pleasant or neutral stimuli that are engaging enough to present the mind from wandering back to the source of negative affect" (Rusting & Nolen-Hoeksema, 1998, p. 790). Distraction, unlike rumination, represents an adaptive coping strategy which would have the beneficial effect of reducing emotional distress (Rusting & Nolen-Hoeksema, 1998). In some cases the theme of distraction was linked to (less) rumination, suggesting that, at least to some extent, social interaction and support may be 'converting' rumination to distraction, that is, that it could be providing 'distraction from rumination' (Nolen-Hoeksema, Parker, & Larson, 1994).

The theme of distraction was raised entirely by HIV-positive caregivers, and mainly by female caregivers. It emerged in some of the quotations already included above to illustrate rumination, for example: "It is better to have the company where you can spend time having a conversation instead of think about dying, and so you end up forgetting about it". A further example is provided by the response of another HIV- positive female caregiver, when asked how she felt social support could affect anxiety among HIV-positive caregivers:

Yes, it [anxiety] will decrease, because if you have people around you, you tend to forget about your problems regardless of how bad the situation is. (F11)

Another HIV-positive female caregiver spoke of the connection and interdependency between her and her daughter, and how her daughter's support helped her forget about her difficult situation, which was instead a major source of anxiety when she was alone. Her responses also alluded to the importance of the presence of someone close to the respondent, versus simply a human presence:

Sometimes when I'm with her [my daughter] I end up forgetting that I'm in this kind of a situation. It only comes back again when I'm alone, but when she is next to me I forget all about that... It is about that connection because she sees it in me when I'm not well...(F9)

Moreover, a few responses suggested that, besides helping caregivers avoid repeated negative thinking, receiving (mainly emotional) support could also help replace negative thoughts with more positive ones, speaking once again to resilience factors such as hope and optimism, discussed above. As indicated by an HIV-positive caregiver, when asked whether the various types of support she reported receiving (including advice, encouragement and love) helped her with her work-related depression:

It [support] does [make me feel less sad], because with less stress, you are able to think positively, not on the negative things and all that - no, it does help. (F2)

More active problem-solving coping. Data also suggested that positive effects of social support on factors associated with resilience (such as self-efficacy and self-esteem) could lead caregivers to adopt a more active approach to coping with stressors, for example through problem-solving and/or tackling the problem more pro-actively. This was a less dominant theme than rumination and distraction, as it was raised by only a few caregivers. As one HIV-positive female caregiver explained, referring to support received from people in her social network:

It makes me feel good about myself and to have more confidence you know, not to run away from the problems but to solve them and continue with life. (F2)

It was also suggested that support could modify the caregiver's appraisal of the stressor faced, making it appear less daunting and more manageable. For example, a male caregiver spoke of how the support received from his wife in particular helped him deal with anxiety and depression, by providing him with courage and even making the problem appear more manageable. This suggests greater self-efficacy based in part on a change in his appraisal not only of his own ability, but also of the problem to be addressed:

With a lot of things, you see I don't have secrets as I share everything with my wife and if something is worrying me, we talk about it together, so there isn't a thing that will depress me and make me sad alone...Her support makes me brave, and she would tell me that this is what we need to do, so that we will conquer that situation we are facing together... I feel relieved and even the thing that was difficult would feel as if it were weakened. (M4)

8.3.3 Indirect effects of social support on mental health by reducing stress/stressors

A less frequently raised theme that emerged from the data was that of instrumental support helping reduce anxiety caused by the absence of specific items. An example would be tangible support with money or food items helping to address household food insecurity, where the caregiver was not able to meet this basic household need. This of course implied a 'match' between the items (or absence thereof) causing the caregiver's stress and anxiety, and the items provided by members of the caregiver's social network (i.e. a match between the

support needs and the type of support provided).

Rather than a process explaining the main or stress-buffering effects of social support on health, this theme appears to be speaking to the direct effects which social support may have on specific stressors negatively influencing mental health; that is, social support would be reducing or eliminating the stressor (e.g. food insecurity; absence of adequate shelter) thus in turn reducing or eliminating its negative effects on caregiver mental health.

For example, when asked whether the money and food received from others helped them feel less anxious, two female caregivers responded as follows:

It helps. You get worried when you don't have something to cook, but you become fine when you've found it. You cook, eat and sleep. (Healthy female, F14).

It helps a lot especially when I'm faced with a particular problem; like worrying about what to eat today, and so I will become happy if the children receive something to eat. (Female with other illness, F15).

8.4 Negative effects of support seeking on mental health

While none of the respondents interviewed had experienced or could relate to negative effects of social support on mental health, it should be noted that three caregivers (2 male and 1 female) spoke of the negative mental health effects of seeking support. Having to actively seek assistance from neighbours or other community members reportedly made caregivers feel dependent or a burden on others which, in turn, could negatively affect their self-esteem. As described by a healthy male caregiver:

Being affected is what I was telling you about, it's when you are always depending on

other people and not working while you are alive and capable. That is hurting so much, that always leaves a mark on you ... When they help me I feel better. But I will be complaining inside, and hurting emotionally that every time I need to go out and ask for help, so it's much better to bother your wife or your siblings [intending close family members as opposed to neighbours or friends]. (M1)

As indicated in the above quotation, *receiving* the support required was considered to have a positive impact on recipients' psychological state. However, this (healthy) male caregiver suggested that even the positive effects of receiving tangible support (e.g. food) on mental health could, to some extent, be counteracted by the emotional burden of having to ask for help, or *seek* this support. The data suggests this could be especially true for males in this community, particularly males without a health condition, who were generally expected to be able to provide for their family.

I feel healthier, but not that much, especially if you are a man and your family is always provided for by other people while you are still capable, when you are not disabled physically or mentally in any way. That does not feel good. It's one thing if you are supported by government, that is understandable, but not your neighbours (M1).

Similarly, a female caregiver suffering from a non-HIV-related health condition explained how going to seek support from the pastor at her church made her feel like “a menace”:

I feel sad because now I feel like I am a menace – and also, that out of the whole congregation, why am I the only one who seems to be in such a struggle? Although he [the pastor] will say that I should just say whenever I need bread or something. But now I have decided not to go there regularly. (F15)

The same female caregiver explained how she felt happy when receiving support. However, unsuccessfully seeking support could also cause her sadness or anxiety, for example, when the caregiver could not find the desired provider and/or felt there was no-one to turn to for support:

I sometimes feel happy when I receive support, but it is the opposite when I go to the pastor's place only to find he is not there. So I become sadder because that means I will not find anyone who will help me. (F15)

8.5 Pathways between social support and physical health

With the exception of one (healthy) female respondent, all caregiver participants perceived the social support they received to have a positive effect on their physical health. When asked how they perceived social support to be affecting physical health, the explanation most frequently given or alluded to was that of psychological health resulting in better physical wellbeing (this was a theme raised by 20 of the 24 study participants). However, additional explanations for the support – physical health relationship also emerged, particularly on probing further; for example, caregivers spoke of the effects of social support on health-related behaviours and better access to health-related items or facilities (for example, the provision of food or medicines, or transport to clinics). These themes are described in detail below:

8.5.1 Positive effects of social support on physical health through better mental health.

The data clearly illustrate the perception among (both ill and healthy) respondents that

mental and physical health were closely related; in some cases these constructs were even referred to as if they were one in the same. This perceived interconnection was highlighted by caregivers associating terms with physical health that would usually be associated with mental health, or vice versa, e.g. feeling 'physically relieved'. Also, on various occasions respondents answered questions about physical health status by directly referring to mental health status, for example: support positively affecting physical health by relieving one of a sense of burden (helping to feel 'emotionally free'), helping with depression and helping avoid negative thoughts. This is illustrated by the excerpt below:

Why I would say yes [referring to whether support positively affects her physical health]. Because my health and my wellbeing, I'm fine even though I'm gaining more weight though. It's like I'm relaxed. All the burden and everything is off my shoulders... (HIV-positive female, F2).

As indicated by the above quote, better mental health was also repeatedly linked to physical health symptoms such as better appetite and weight gain, and, conversely, worse mental health was associated with loss of appetite and weight loss. Appetite and weight gain/loss were the physiological processes most frequently raised (by 7 caregivers). The implication was that being stressed and not eating properly would negatively affect physical wellbeing and, vice versa, feeling happier and less stressed, as a result of support, would improve one's appetite and physical health. The excerpts below illustrate this perception:

It [support] helps [with how I feel physically] because I had lost a lot of weight but my weight has come back... It's the advice and feeling free. (Healthy female, F5).

Similarly, an HIV-positive female caregiver spoke about how the help she received from her employer, which led to her extending her house and improving her living conditions, had helped her regain her appetite. She implied that it had relieved the stress related to not being able to meet basic household needs, as well as provided her with hope:

In my body - I was losing weight, because I was not eating well, but now I am gaining and I can see that I am getting back to my normal weight ... I had lost hope before, but now I am hopeful, and I am better and have gained weight, and I always have a positive attitude. I am now also a person who can give advice to others (F11).

When asked how she felt on receiving support, the same caregiver explained:

I feel better because I don't eat when I'm depressed. But my appetite comes back when they encourage and advise me. So my life gets affected, and I get better. (F11)

Better mental health was also linked to other physiological processes or symptoms, such as blood pressure and fatigue. For example, an HIV-negative female suffering from high blood pressure spoke of how the tangible help she received from her daughter (e.g. assistance with food or chores) led her to feel calmer and less worried, thus improving her blood pressure. She spoke of her worry being “lifted up” as if this support was perceived to relieve her of a physical and emotional burden weighing down her body, and explained: “... when I'm frightened my BP goes high.”

Several respondents (3) also spoke about how they experienced less physical fatigue when their emotional wellbeing improved as a result of support received. For example, a healthy male respondent spoke of how support positively affected his physical health by preventing him from feeling depressed or anxious and making him feel strong. Being worried or depressed was, in turn, related to fatigue, as this excerpt illustrates:

It [support received] makes me very strong and I feel healthy and I don't feel depressed, because there is nothing that worries me emotionally... When I am worried, I feel tired and I just need to rest, but after that [support] I feel much better (M4).

Similarly, an HIV-positive female caregiver spoke of how stress caused her tiredness, and how conversing with those close to her helped her feel less worried and physically better:

I would say I'm not prone to having worries all the time because when you have stress that causes tiredness... When I'm having a conversation either with my mother or friend, that makes me feel well emotionally and physically, so I feel well. (F12)

An elderly female caregiver suffering from diabetes spoke of how emotional support, in the form of dialogue, care and advice from her sister, made her feel emotionally and physically stronger, albeit temporarily. She explained how this emotional support would help her forget about her illness and even experience less pain, despite the fact that she did not receive any of the practical assistance necessary from her family to treat the illness (e.g. medicine or good food).

It happens that I feel physically better due to feeling better emotionally, especially as someone who is always alone not talking to anybody. By not talking to anybody, I end up sleeping all the time every day... When I'm feeling that way sometimes I forget that I'm sick, even though I can't walk or see but it feels good, like I'm not sick at all. (F8)

Similarly, an HIV-positive female caregiver also spoke of how receiving advice and reassurance from members of her church made her feel less stressed and physically stronger, suggesting that she felt less pain or was able to better deal with the pain. Feeling stressed, on the other hand, was related to fatigue, and experiencing more pain and headaches.

No matter how stressed I was feeling, I feel better [after receiving support from church members] ... I feel better, I don't feel the pain. Sometimes I really feel sick but I feel better after speaking with them. I feel better and tell myself that I'm going to get help. (F16)

When asked how she felt when she was stressed, the same caregiver responded:

I feel sick and my body doesn't feel okay. I feel tired and suffer from headaches because of the way I think. (F16)

A male respondent, with a kidney condition that required regular dialysis, spoke of the importance to him of the regular support he received from his family and friends. Besides the tangible help they provided him with (e.g. transport to the clinic), they also gave him hope and encouragement. He believed this emotional support had been central in helping him remain physically strong, and not giving up on life:

It [support] helps me a lot, because I always have this hope that one day I'll be better, because I have people next to me who are always pushing me, giving me support... encouraging me all the time, and I think if I didn't have people encouraging me then maybe I wouldn't be here today. (M7)

8.5.2 Positive effects of social support on physical health through more positive health behaviours

The majority of respondents (17) also spoke of how support provided, mainly by people close to them, led them to adopt more positive health behaviours. This was a theme taken up by both male and female caregivers, and both (HIV- or other-) ill and healthy caregivers. This support mainly took the form of advice and encouragement, but in some cases included tangible assistance, such as buying or cooking healthy foods, and facilitating access to health facilities or items (e.g. medicines).

For example, several male caregivers spoke of practical advice, provided mainly by their wives and others close to them. They reported having acquired more positive health

behaviours (e.g. improved diet) and perceived positive effects on their physical health as a result of this. The excerpts below, from interviews with two male caregivers, illustrate some of these themes:

You know you get advice from there, that when you eat you should not just eat (greedily), that you need to think about kids and think about tomorrow, and not to eat everything at once, because of the situation that we are facing... that to be healthy, I must not be emotionally upset all the time, and that I shouldn't eat a lot. (Healthy male, M1).

Sometimes she [my wife] will bring things that I would not have expected, things that I would be seeing for the first time and they are also healthy things... different kinds of vegetables and fruits stuff, like that... I definitely praise it, because it makes me strong. As you can see me, it's been a while since I last visited a doctor because of sickness. I feel healthy. (Male caregiver with other illness, M5).

An HIV-positive male caregiver spoke of how the advice and disapproval from his wife had helped him live a healthier life by quitting smoking and drinking, suggesting a form of positive social control.

You see, I was drinking alcohol and smoking cigarettes before, but now an alcoholic or a smoker doesn't come and stay in my house because I am not part of that lifestyle anymore ... like sometime when I would be alone at home smoking and say maybe after two hours my wife arrives, and she will tell me that I was smoking and then I realized that what I was doing was wrong. (M6)

The same respondent spoke of the support of a nurse at the clinic, who reminded and encouraged him to fetch his HIV medication and take it regularly. Similarly a female caregiver, suffering from an unidentified illness, spoke of how the advice and encouragement

of close family members had led her to start taking her medication.

Several male and female caregivers also talked about the importance of instrumental support in improving their physical health, by facilitating access to health care or health-related items. Types of support included providing or fetching medication, assisting with transport to health facilities and providing food. For example, one (healthy male) respondent, who was also a pastor, told of how church members gave him money to buy pills or protein tablets, so that his body could 'feel healthier'. An HIV-positive female caregiver spoke of how her neighbour (her sole support provider) helped her with money for transport, so that she could collect her ARVS:

When I'm supposed to go pick up my ARVs from the clinic, she helps me with the bus fare to get there or anything that I might need from the hospital - she is there for me.
(F4)

Similarly, another HIV-positive female caregiver described how her daughter helped her live a healthier life, by ensuring that she was taking the necessary medicines and by collecting these medicines herself:

When it is my due date to fetch my medication she [my daughter] asks when was the last time I went for my medication, and when I have found my clinic card she will wake up early in the morning to go pick up my medication (F9).

Another female caregiver spoke of the reciprocity between herself and a very close neighbour and friend, which positively contributed to her nutrition and physical wellbeing. This included exchanging vegetables from their community gardens and helping each other with medicines:

We help each other with many things, because as I'm growing vegetables like

cabbages, beetroot and carrot. When it's time to harvest my vegetables, I give some to her and she does the same. We help each other and we are one... But also when I've run out of pills, I just go to her house and I ask her to give me some. (Female with other illness, F13).

The young male caregiver with kidney disease highlighted the importance of his friends' and family's instrumental support, as they took turns in accompanying him to the hospital multiple times every week for kidney dialysis. When asked whether this support affected his physical health, he responded:

Yes very much. They are contributing very much, because I am dialyzing three times a week: Monday, Wednesday and Friday. You can see that I have this catheter in my leg, so I can't use public transport. I have to call one of my friends to take me to the hospital, say around ten in the morning, he will do that for free and I will come back at noon around six and I will phone another friend, they will come and drive me home... I can't drive anymore now, it's been two months now that I don't drive. They are always coming three times a week to drive me to hospital and they do this for free. With open hearts. (M7)

8.6 The importance of support for health beyond coping with specific stressors

When asked to explain how they perceived social support to be affecting their mental and physical health, caregivers tended to refer to the role of support in relation to particular stressors experienced (e.g., sources of anxiety and depression, or specific health conditions faced), as is evident by the findings presented above. However, when asked specifically

whether they felt that social support was important for their health more broadly, beyond coping with specific stressors and stressful situations – even when ‘things were going well’ - the large majority of participants (all but one female caregiver) responded affirmatively. Reasons given included some of the themes already discussed, in relation to social support and health more broadly (e.g. psychological variables associated with resilience and positive social regulation), as well as ‘new’ or more nuanced themes, such as maintaining relationships to secure support during difficult times, comfort in the knowledge that support would be available, and personal development and knowledge gain. These are described in more detail below:

8.6.1 Comfort and greater psychological resilience through regular interaction

Some of the reasons given to explain the value of social support as a general health resource, beyond coping with specific stressors, echoed themes already discussed above. These included the mental health benefits of regular conversation, encouragement and exchange of ideas. This personal interaction and support was seen as contributing to a feeling of being ‘loved’ and cared for, as well as boosting self-esteem and courage. Some of these themes are illustrated by the quotes below:

No, it's not about going through difficult times and all that, but in life you do need a person that you can talk to, and where you trust, you know that I'm being loved here... I can express my feelings and all that. (HIV-positive female, F2).

It's always important [referring to support received from respondent's wife and daughters, and church members]. Because of it I am able to do a lot of things, and I

am able to help others. Their support gives me the strength and courage to be able to help others... It's the love, because it encourages you and makes you strong, so that you persevere. (Healthy male, M4).

8.6.2 Positive influence on social and health behaviour

There were also suggestions that regular personal interaction and support could give rise to a form of on-going positive social control or regulation that encouraged more positive behaviour, as well as boosting an individual's self-confidence to follow through with this behaviour (a theme already addressed above). The positive influence of support on behaviour was a theme that came up in relation to the importance of social support on physical health more generally. However, when discussed in relation to the importance of support beyond coping with specific stressors, responses tended to refer to positive health and social behaviours more broadly (versus simply positive health behaviours). This could include encouragement to be more proactive, and achieve specific goals. For example, when asked why she felt it was important to receive support and have people around her even when things were going well, an HIV-positive female caregiver responded:

It's because they [my husband and children] tell me not to be always indoors. My husband and my children emphasise that I need to go out to do driving lessons because I'll have a car one day. I tell them that I can't do lessons at my age. And they tell me that I'm still young I can do anything that I want and life goes on. (F6)

Similarly, two male caregivers spoke of people in their social network helping to identify and control their bad behaviour and/or encourage them to engage in more positive or

productive activities:

Sometimes you can be so excited when things are good, and end up behaving in the wrong way, but when you have people around who support you, they can control you and tell you when you are misbehaving. They tell you to calm you down and remind you what kind of a person you are and what you are suffering from, so for you to behave this way is not good. (Male with other illness, M7).

I have a good relationship with these people [people belonging to his social network], because they made me to see that I need to go to work and do good things, and not bad things you see. (HIV-positive male, M6).

8.6.3 Maintaining relationships to secure support for difficult times

A 'new' theme that emerged specifically in relation to social support as a general health resource was the suggestion that maintaining healthy supportive relationships was important, even when things were going well, so that support would be available when it was needed. This perspective alludes to the functional aspect of personal relationships, but, it could be argued, it envisages personal interaction and reciprocal support as a form of 'investment' or 'insurance' that could ensure the availability of required assistance when stressors arise. As put by an HIV-positive male caregiver:

Sometimes you can be in a good space, but as with a bad situation, it cannot last forever, so it's always with the thinking that there'll be difficult times ahead. (M6)

Similarly, a female caregiver spoke of the importance of socialising and maintaining

relationships so that there would be people around her when she needed support, perhaps even watching out for her to identify your support needs:

When you are a human being, it is very important to socialize with other people so that they can know what kind of a person you are or how you live. That is why I'm close to someone who cares for me, who is there when things are good or bad. I once got sick and this friend of mine was there for me, all the time checking on me, so I appreciate her support. (Female with other illness, F13).

8.6.4 Comfort in the knowledge that support would be available

A further - related but slightly different - explanation that emerged from the data suggested a positive psychological effect deriving from the knowledge that there would be people available to provide support if needed. This speaks to the importance of perceived support availability, the assessment of which would be based on actual regular supportive relationships. As articulated by two caregivers, when asked why they thought support was important even when not dealing with specific stressors:

It's because you see that you are not alone, there are people who support you and comfort you... (Healthy male, M1).

What can I say? It is just knowing that there is someone you can talk to, giving each other advice and to tell him/her about the life you are living. (HIV-positive female, F12).

8.6.5 Personal development and knowledge gain through support

Lastly, there was also reference to regular social interaction and support leading to personal development and knowledge gain for the support recipient. This could occur, for example, through the provision of regular information or advice which could be useful more generally and/or specifically when a problem arose. Similarly to the notion of developing regular supportive relationships as an 'investment' for difficult times, this theme highlights the potential value of supportive relationships in developing the support recipient's skills and knowledge, as a resource which he/she may draw on difficult times. As explained by one HIV-positive female caregiver:

It [being supported] is helpful in life and it opens your eyes, because it can happen that there are things that you don't know about, but there is someone who has experienced that, so that person can advise you and help you to be able to know about that... It's important for a person to have a support in life, and it's helpful to have knowledge. Because in things that you come across in life you can have answers, because even when something happens, you already have knowledge about that thing...Yes, it [support received] does make me strong, and I can feel that I have grown (F11).

8.7 Importance of specific support providers

A theme that emerged spontaneously during the interviews, when discussing the effects of social support on health, was the importance of the support provider. This was a

theme taken up by both male and female caregivers, but predominantly by females. It was suggested that support could be especially beneficial for health if provided by individuals who were close to the person receiving support, or who had specific experiences or characteristics in relation to the stressors faced by the recipient.

The data suggest that the identity and characteristics of the support provider were especially important for HIV-positive support recipients. For example, one HIV-positive female caregiver spoke of how advice and encouragement could be especially effective in providing HIV-positive individuals with hope, if received from someone who had experienced the illness themselves and succeeded in regaining health:

When someone advises you with something that she/he experienced, and you see that she/he is doing well... for example she might be telling you that her family died in a car accident and then you see that she/he has accepted and moved on with life. And you will also have hope that you will also get past that situation that you are facing right now. Maybe she will tell you that she was facing the same situation that I am facing, and you can see that she is strong and healthy. So you have faith that you will also feel strong. (F11)

Similarly, another HIV-positive female respondent referred to the various types of instrumental and emotional support provided by home-based caregivers (HBCs) in the community and how their support contributed to the wellbeing of ill individuals visited. She also highlighted that an HIV-positive HBC could serve as a role model and example of hope, by representing someone who had succeeded in managing the disease.

They help because you find someone who is very sick, who is not taken care of by his family. They [HBCs] go there to bathe that person if he/she is bed-ridden, prepare food for him/her and go to the clinic to collect his/her medication.... Yes, they also

give advice.... They are able to talk to you and put you in the right direction. That now that you have this disease, they then tell you that you are going to live a long life, take care of you then you become okay... They [HIV-positive individuals] can get helped by this support, which can help them accept their status, because they can see that the other person was also helped by these people. So he gets hope that everything is going to be alright. (F16)

Another female caregiver spoke about the particularly comforting effect of receiving advice from elders in the community, as their age and wisdom were considered important characteristics that made their advice all the more credible:

It [feeling less anxious] is to let what is bothering you to pass and to listen to the advice of older people. We grew poor and very respectful. This is the first time we are experiencing disrespect-with these children. (Healthy female, F14).

An additional important support provider characteristic identified was that of empathy and a positive attitude towards the support recipient, as opposed to someone who would judge and discriminate. For example, an HIV-positive female caregiver argued that support could play an important role in helping HIV-positive/AIDS-ill caregivers with depression and anxiety, through conversation and encouragement, if provided by someone who was empathetic and did not discriminate against people with the disease:

The more you talk the less you feel, you are not depressed. At least I do have a person I can talk to. Not a person who is going to discriminate against and laugh at me. A person who is going to understand me you know.... Because mostly they [people living with HIV] were being discriminated against, not being loved. (F2)

There were also references to the importance of providers who were close to and/or trusted by the support recipient. For example, a male respondent with a non-HIV-related

health condition spoke of the importance of emotional support for AIDS-ill individuals, such as comfort and care, provided specifically by someone close, who was loved and trusted:

They [people living with HIV] do receive support from the clinics and hospitals, but they also need the support from people that are close to them - like giving them advice and love. I think that is the most important thing... Yes, to take the treatment is not enough, the support from the family is also important... That is why I am saying they need support from their families, and I know they have counsellors at the clinic and in hospitals that counsel them, but to have someone who you live with, someone that you grew up with, to know that they are there for you, that makes you feel very comfortable. It's not the same to listen to a stranger than to listen to your close friend or relative. (M7)

This theme was reinforced by an HIV-positive female caregiver's reference to her very close relationship with her neighbour, who helped her with food when able to. The special connection and regular conversation with this person assisted this caregiver in dealing with depression:

It [support received from my neighbour] makes me feel less depressed because sometimes I do talk to her about everything that makes me feel depressed and after talking to her I feel less depressed. Because when I talk to her it feels as if I'm talking to my parent, because even my biological mother has never given me such advice as my neighbour, Z¹⁸, does. (F4)

Also, the data suggest that the identity and/or characteristics of support providers were considered particularly important with regard to social support as a general health resource. For example, the same HIV-positive female caregiver spoke of the comfort and

¹⁸ Full name deleted for the purpose of confidentiality.

strength she derived from the strong relationship she had with a friend and neighbour, in that they were always ‘connected’, communicating regularly, regularly checking on each other and their respective families and checking whether the other needed help.

I feel relieved and strong, especially when I see her in the morning, I feel free in the spirit. (F4)

Another respondent suggested that the connection with those close to her, who genuinely cared and could understand what she was going through (such as her mother and sister), helped her feel more relaxed, even when she was not dealing with particular problems:

It [my life] changes and I really feel okay. Because it is nice to talk to someone who feels what you are going through. Not to have someone who pretends as if she has emotions for you but ends up gossiping about you... I feel loosened up... (Healthy female, F14).

Similarly, an HIV-positive female caregiver spoke of the special connection between herself and her daughter, and suggested that her daughter’s mere presence could improve her psychological wellbeing:

When she [my daughter] is around me I don’t experience anxiety... It is about that connection because she sees it in me when I’m not well... (F9)

8.8 Discussion of qualitative findings

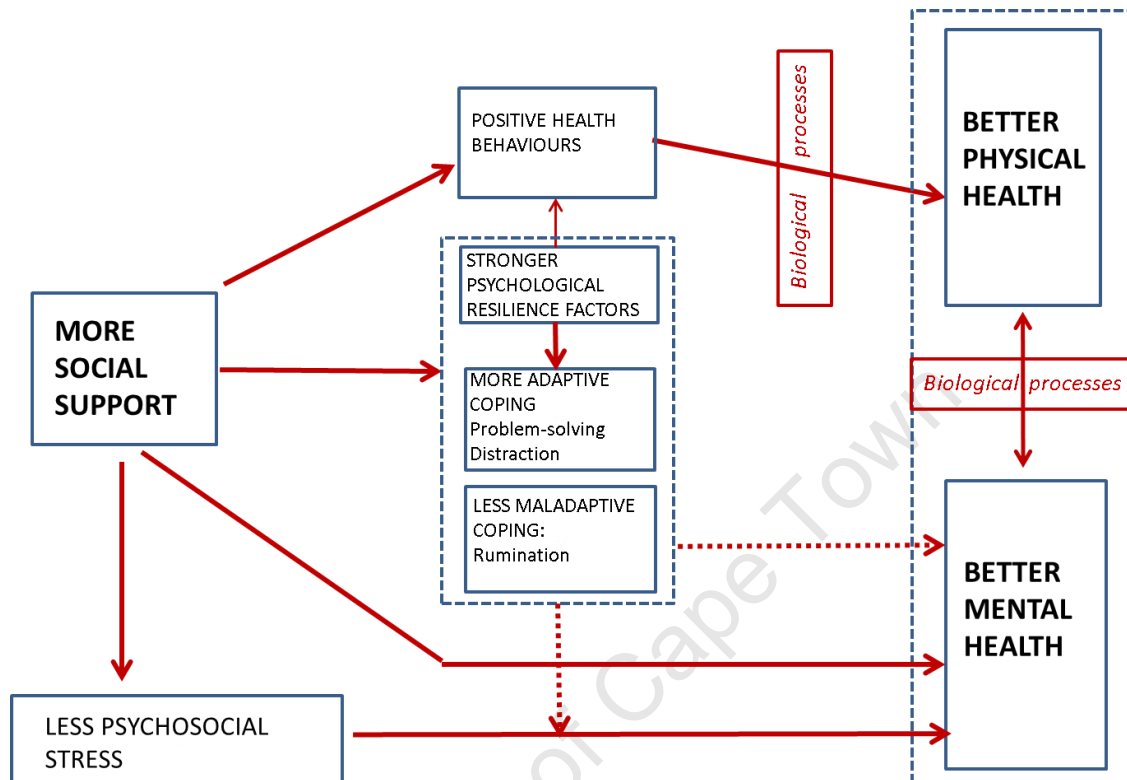
8.8.1 Synthesis and diagrammatic representation of pathways explaining the support-health relationship

The primary objective of this qualitative work was to identify the pathways and mediating processes through which caregivers perceived social support to be influencing their health (House, Umberson, et al., 1988). As indicated above, there was overall consensus among caregivers that (instrumental and emotional) social support had a positive impact on their mental and physical health; this was the case for ill and healthy caregivers¹⁹.

These positive health effects were perceived to occur through multiple, potentially co-existing, pathways and mediating factors, which have been described in detail above. The mediating processes identified were mainly psychological and behavioural, though there was some reference to physiological processes. More specifically, the data point to three key pathways explaining the positive relationship between more social support and better mental health, and to two pathways explaining the positive relationship between more social support and better physical health. These are illustrated diagrammatically in Figure 8.1 below, which was developed based on the House et al (1988) theoretical framework.

¹⁹ As indicated in the presentation of findings, there were a few references to negative psychological effects of support seeking, related to the need for support. This is, however, distinct from support available or actually received, which are the constructs of interest for this research and were always associated with positive health effects in the data.

Figure 8.1. Diagrammatic representation of perceived pathways and mediating factors explaining positive effects of social support on health



The first pathway between social support and mental health is a direct one, representing, for example, the way talking about problems, and receiving advice and encouragement, may directly diminish anxiety or depressive symptoms. This pathway is illustrated in Figure 8.1 by the arrow directly linking *social support* to *mental health*. The second pathway is an indirect one, which occurs through social support alleviating or eliminating the source(s) of psychosocial stress (e.g. food insecurity, lack of financial resources), which would in turn reduce or eliminate the effect of stress/stressors on mental health. This pathway is represented in Figure 8.1 by the arrows linking *social support* to *psychosocial stress* and *psychosocial stress* to *mental health*.

The third identified pathway linking social support to mental health is also an indirect one, occurring through psychological and behavioural mediating processes. The data indicate that various types of - mainly emotional - support may be positively affecting mental health by both strengthening psychological factors associated with resilience and leading to coping styles that are more beneficial for mental health. With regard to coping, the data suggest that social support is encouraging adaptive forms of coping, such as more active problem-solving coping and distraction, and reducing rumination, as a form of maladaptive emotion-focused coping. Based on caregivers' recounts, the effects of social support on active coping are likely (at least in part) mediated by psychological resilience variables, such as self-esteem and self-efficacy, whereas the effects on rumination and distraction coping are likely a direct result of support and social interaction. This pathway is represented in Figure 8.1 by the arrow linking *social support* to the boxes representing *psychological resilience factors*, *adaptive coping* and *maladaptive coping* styles, and linking these boxes to mental health. The arrows showing potential stress-buffering or main effects of social support on mental health through these mediating processes are dashed, to indicate that it is not possible, through the qualitative data, to determine the extent to which these processes are mediating direct versus stress-buffering effects of support on mental health.

The data also highlight two pathways perceived to be linking more social support to better physical health. The first is through its positive effects on better mental health, which, in turn, were perceived to lead to better physical health. This is represented in Figure 8.1 by the bidirectional arrow linking *mental health* to *physical health*, indicating the strong perceived relationship between physical and mental health. The second pathway represents the mediated effects of social support on physical health through more positive health behaviours (or positive social regulation), for example eating healthier food or accessing medicines and health care. This is illustrated in the diagram by the arrows linking *social*

support to positive health behaviours, and positive health behaviours to physical health. There were also a few isolated references to positive health behaviours being influenced indirectly by social support, through its positive effects on psychological resilience factors such as hope or self-esteem. This link is rather weak however, given the little data supporting it, and would require further investigation; as a result a thinner arrow was included in Figure 8.1 to link *psychological resilience factors to positive health behaviours.*

There were relatively few references in the data to biological, versus psychological and behavioural, processes explaining health effects of social support. Yet, as highlighted by various authors (House, Umberson, et al., 1988; Uchino, et al., 2012), effects of support on physical health status will at some point need to involve biological processes. The red boxes in Figure 8.1 serve to illustrate that these biological processes would have to occur in at least two points: between positive health behaviours and physical health outcomes, and between mental health and physical health outcomes. The qualitative data does contain several references to physiological processes, aimed at explaining link between mental and physical wellbeing. The symptom most frequently associated with worse mental health was weight loss due to loss of appetite; others included fatigue, headaches and higher blood pressure. While links between more positive health behaviours and physical health outcomes were not discussed by respondents, these are easily supported by existing literature on risk and protective behaviours for health (e.g. on the health risks of behaviours such as smoking or bad diet; on links better treatment adherence and better physical health outcomes) (Critchley & Capewell, 2003; Holman, English, Milne, & Winter, 1996; Holt-Lanstad, et al., 2010; Katzmarzyk, Janssen, & Ardern, 2003; Prince et al., 2007).

Moreover, while the qualitative data does not allow us to draw conclusions about which effects of social support on mental health (i.e. stress-buffering versus main effects) are mediated by the psychological and behavioural processes described above, it is likely that, to

some extent, these processes are mediating both main and stress-buffering effects. When asked generic questions about how they perceived social support to be affecting their mental health, most caregivers referred to its importance in coping with specific stressors (e.g. child behavioural problems, financial problems, illness) that led to anxiety or depression. There was, however, also general consensus that social support had broader positive health effects even in the absence of specific stressors, which could suggest main effects of support. These broader positive health effects were perceived to occur as a result of regular social interaction with specific support providers, and through various psychological and behavioural pathways illustrated in Figure 8.1; these include psychological resilience variables, more positive social and health behaviours, greater perceived social support and transfer of knowledge and skills that could strengthen the recipient's ability to cope with stressors. As specified above, the dashed arrows linking psychological and behavioural mediating processes to mental health outcomes in Figure 8.1 indicate that these processes could potentially be explaining stress-buffering or main effects – and most likely, to some extent, both. In order to conclusively link effects to processes it would, however, be necessary to conduct quantitative analysis testing these effects and their potential mediators.

Lastly, although not among the key foci of this research, the identity and characteristics of support provider(s) emerged as central factors perceived to be influencing the effectiveness of social support on health. The provider's relationship with the caregiver was considered particularly important with regard to the broader health effects of support, while provider experience and characteristics were considered especially useful in helping the caregiver deal with specific stressors that the provider may have already faced or be facing (such as HIV or other illness).

8.8.2 Differences between caregiver sub-groups

Overall there was a high level of consensus among participant responses for most of the themes that emerged although, as indicated above, some themes were taken up more frequently than others. There were also no clearly conflicting or opposing views emerging for any one particular theme, within or across sub-groups of (male and female; ill and healthy) caregivers.

Most themes were taken up by both male and female, and (HIV- or other-) ill and healthy caregivers, with a few exceptions. For example, the theme of hope and optimism, discussed to explain the positive effects of social support on mental health, was raised by all groups of caregivers, but discussed most frequently in relation to the mental health of HIV-positive caregivers. This suggests that hope, deriving mainly from emotional support provided, could represent a particularly important psychological mediator between more social support and better mental health for individuals living with HIV. As discussed above, this embraces the hope of survival, of living a “normal” healthy life, of being accepted by the community and seen “like other people who are HIV negative,” and of a better future. Rumination and distraction were themes raised only by ill caregivers, and predominantly by HIV-positive caregivers (all but one of the ten caregivers who raised these themes were HIV-positive). They were also raised mainly by female caregivers. This suggests that less maladaptive coping in the form of rumination, and more adaptive coping in the form of distraction, may be especially important mediating processes explaining the support-mental health relationship for HIV-positive caregivers, particularly for female caregivers living with HIV.

Lastly, references to the importance of support provider characteristics were discussed

mainly by female caregivers (7 of the 8 caregivers who referred to this theme were female), suggesting that the relationship with or characteristics of the individual(s) providing support may be more important to females than to males. The various references to the importance of support provider characteristics for HIV-positive individuals also suggest that individuals who may themselves be living a healthy life with the disease, individuals with an empathetic and positive attitude towards people living with HIV and/or individuals who are close to and trusted by the caregiver, may be the most effective support providers for HIV-positive caregivers.

8.8.3 Discussion of qualitative findings in relation to the literature on social support and health

While the model illustrated in Figure 8.1 has been constructed based on qualitative data collected from a relatively small group of caregivers (24), it should be noted that it reflects many of the factors and associations found by previous quantitative studies conducted with HIV-positive and broader adult populations. First, it suggests both direct and mediated pathways between social support and health outcomes (House, Umberson, et al., 1988). Second, the mediating factors emerging from the qualitative data to explain the support-health links are, to a large extent, consistent with those highlighted in the empirical and theoretical literature on social support and health (Burns, et al., 2008; House, Umberson, et al., 1988; Shaw, et al., 2004; Thoits, 2011; Uchino, et al., 2012) and, more specifically, with findings of previous quantitative studies conducted with HIV-positive individuals (mainly in North America).

Mediating factors explaining the support – health relationship: As described in Chapter 4, empirical quantitative studies investigating the relationship between social support and health with PLWHIV have tested for and found evidence of mediators including more active coping and less avoidance coping (Schmitz & Crystal, 2000) and psychological factors such as self-esteem, mastery and hope (Simoni, et al., 2005; Yadav, 2010). They also provide some evidence of mental-physical health links (Jia, et al., 2004) and positive effects of support on health behaviours (including antiretroviral treatment adherence (Burgoyne, 2005)) explaining effects of social support on physical health. The findings of this qualitative work are also coherent with the broader health literature highlighting the strong relationship between mental and physical health (Prince et al, 2007, for example, argue that ‘there is no health without mental health’) and the literature showing associations between ‘good’ health behaviours and better physical health outcomes (Critchley & Capewell, 2003; Holman, et al., 1996; Holt-Lanstad, et al., 2010; Katzmarzyk, et al., 2003; Prince, et al., 2007).

Moreover, these qualitative findings add further depth to the existing evidence on support-health mediating processes for this specific population of caregivers of children, and in particular for HIV-positive caregivers. For example, they emphasise the particular importance of hope as a psychological mediating factor for HIV-positive caregivers. This resonates with Yadav’s (2010) research with HIV-positive adult recipients of NGO support, which showed that the observed positive effects of social support on physical and psychological wellbeing were mediated mainly through hope (Yadav, 2010).

Findings of this qualitative study also highlight the effects of support on various types of adaptive and maladaptive coping strategies, which merit further consideration, based on the theoretical and empirical literature on coping. As explained in Chapter 2, coping responses are defined as constantly changing cognitive and behavioural efforts (thoughts and acts) employed by individuals to manage stressful events, which include an appraisal of the

importance of the stressor for their wellbeing, and their options for coping (Folkman, et al., 1986; Lazarus & Folkman, 1984). They therefore represent both behavioural and psychological processes mediating the support-health relationship. Moreover, coping strategies are often categorised as problem-focused and emotion-focused (Burns, et al., 2008; Folkman & Moskowitz, 2004). While active problem-focused coping strategies are often associated with more social support and positive mental health outcomes, and emotion-focused coping with less social support and worse health outcomes (Folkman & Moskowitz, 2004; Patterson, et al., 1993; Wolf, et al., 1991), there may be situations where the opposite is true, that is where forms of emotion-focused coping, such as distancing and distraction, are associated with better mental health outcomes (Folkman & Lazarus, 1985; Folkman & Moskowitz, 2004). In fact, this qualitative data indicate that, besides increasing active problem-solving coping as an adaptive form of coping, social support may also be increasing distraction, which in this case would be considered a form of adaptive emotion-focused coping, leading to better psychological health. It also suggests that social support may be reducing rumination, which could be considered a form of maladaptive emotion-focused coping, leading to more depression or anxiety.

Rumination and distraction appear to represent key behavioural and psychological mediators for HIV-positive individuals in our sample, and especially for females living with HIV. The literature indicates that both (self-focused) rumination and distraction may be considered mood regulation strategies, described as “thoughts and behaviours intended to eliminate, maintain or change emotional states” (Rusting & Nolen-Hoeksema, 1998, p. 790). Rumination, defined as “repetitively thinking about the causes, consequences and symptoms of one’s negative affect” (Nolen-Hoeksema, 1991; J. Smith & Alloy, 2009), has emerged, over the past few decades, as a key construct in understanding the development and persistence of depressed mood (J. Smith & Alloy, 2009). As indicated by Smith and Alloy

(2009; p. 14) it “may be triggered by both the realization that one is not where one desires, and the negative affect that is likely to accompany that realization.” Rumination is considered to be best categorised as an avoidant emotion-focused coping strategy, linked to less motivation and less confidence with problem-solving, and likely to worsen and lengthen negative mood (J. Smith & Alloy, 2009), through pessimistic, maladaptive thinking (Nolen-Hoeksema, et al., 1994). It has also been linked to increased alcohol abuse (Nolen-Hoeksema & Harrell, 2002) and avoidance of social situations (Mellings & Alden, 2000; J. Smith & Alloy, 2009).

While rumination has been most commonly associated with depression, several studies have shown relationships between rumination and other mental health conditions and/or symptomology, such as anxiety, trauma symptoms and panic disorder (J. Smith & Alloy, 2009). There is also a gender dimension, since women have been found to be more prone to rumination, which may contribute to higher rates of depression among women; in fact, some studies have found the gender difference in depression may be entirely mediated by the gender difference in rumination (Butler & Nolen-Hoeksema, 1994; Nolen-Hoeksema, et al., 1994).

High quality social support, on the other hand, has been found to reduce the tendency to ruminate (Nolen-Hoeksema, 1991), and (consistent with findings of this study) ruminative coping has been found to mediate the relationship between social support and depression (Nolen-Hoeksema, et al., 1994). In particular, it is argued that bereaved people who are socially isolated will be more inclined to ruminate because of the absence of people to provide distraction from rumination (Nolen-Hoeksema, et al., 1994). It is also argued that in the absence of good quality social support, an individual’s ruminative thoughts will go unchallenged, there will be no-one to encourage engagement in active coping strategies, the

individual may not receive affirmation or emotional support and the social network itself may provide stressors to ruminate about (Nolen-Hoeksema, et al., 1994).

Whereas rumination has been found to maintain depressed mood, distracting external stimuli may have the opposite effect, leading to relief from depressed mood (Nolen-Hoeksema, et al., 1994). Distraction may be considered an alternative emotion-focused coping strategy described as “focusing attention away from the mood and its causes onto pleasant or neutral stimuli that are engaging enough to prevent the mind from wandering back to the source of negative affect” (Rusting & Nolen-Hoeksema, 1998, p. 790). It therefore involves diverting attention away from problem or stressors causing anxiety or distress, by thinking about other things or engaging in specific activities. Laboratory studies have found distraction to temporarily lift depressed mood and reduce feelings of anger, and other research has found active distracting strategies (e.g. leisure and social activities such as exercise or music) to reduce negative mood, stress and anxiety (see for example: Rusting & Nolen-Hoeksema, 1998; Shimazu & Shaufeli, 2007; Stone, Kennedy-Moore, & Neale, 1995; Thayer, Newman, & McClain, 1994). Distraction has also been found to be associated with greater pain tolerance and lower pain intensity, indicating its effectiveness as a strategy for coping with pain (Kohl & Rief, 2013; T. Thompson, Keogh, Chen, & French, 2012).

In terms of the gender dimension, while research shows that rumination is more common among women, the evidence is less conclusive regarding gender differences for distraction: some studies have shown men to be more likely to use distraction-oriented strategies when dealing with depression or anxiety (Butler & Nolen-Hoeksema, 1991; Thayer, et al., 1994), while others have shown women to be more likely to distract themselves from an angry mood (Rusting & Nolen-Hoeksema, 1998). It has also been argued that distraction may be a more effective strategy for “low-activation” emotion such as sadness as opposed to “high activation” emotions such as anger (Rusting & Nolen-

Hoeksema, 1998), suggesting it may be a particularly effective coping strategy for depressive symptoms, as is the case for rumination. It should, however, be noted that, while distraction has been found to improve mood in the short run, its long term effects are still unclear (Stone, et al., 1995).

The qualitative data also highlight the existence of multiple ‘levels’ of mediating variables constituting mediated pathways, thus illustrating the complexity of the dynamics explaining support-health links. An example would be provided by effects of support on psychosocial variables (e.g. hope or self-esteem), that may influence coping responses and in turn health outcomes. This suggests the co-existence of several causal pathways involving multiple psychological and behavioural variables, represented by the box labelled ‘biopsychosocial processes’ in the House et al model (see figure 1.1 in Chapter 1). These findings reinforce the importance of simultaneously measuring and exploring multiple mediating variables (House, Umberson, et al., 1988), as well as the pathways linking them to each other, and to the social support and health outcome variables of interest.

Effects explained by mediating processes. While it is not possible to derive conclusive findings from this data regarding the presence of main versus stress-buffering effects, or the mediating factors explaining these effects, the data suggest that some of the mediating processes identified above may be relevant for both main and stress-buffering effects of social support on mental health. This resonates with House et al.’s (1988) and Thoits’ (2011) arguments that main and stress-buffering effects may be explained by the same mechanisms that operate more intensively or differently in the presence of stressful situations (House, Umberson, et al., 1988; Thoits, 2011). Our data in fact highlight some of the psychological mediating mechanisms identified by Thoits (2011) as key to explaining

both main and stress-buffering effects of social support (and of social relations more broadly): these include social influence and control, self-esteem, a greater sense of control over life and specific stressors, and companionship. Explanations given by caregivers for the importance of support even in the absence of specific stressors recall Thoits' (2011) theory that everyday supportive actions (e.g. caring, love, information exchanges, discussion of potential problems) may improve psychological and physical health through some of the psychological mechanisms listed above; and, when major stressors occur, by assisting the individual to cope with these.

References in the data to the value of maintaining social relations in good times, in order to secure social support and accumulate human resources (skills and knowledge) to better cope during stressful times, would appear to resonate with Thoits' (2011) theory and with what Aspinwall and Taylor (1997) describe as 'future-oriented proactive coping' (Aspinwall & Taylor, 1997; Folkman & Moskowitz, 2004). Proactive coping refers to coping in advance to prevent or attenuate the impact of potential stressors, and includes "the importance of building a reserve of resources (including temporal, financial and social resources) that can be used to prevent or offset future net losses" (Folkman & Moskowitz, 2004, p. 757). Resources are accumulated in order to allow the individual to move toward positive and challenging goals associated with personal growth. Proactive coping is considered a relatively new development in coping that merits further attention, and may have particular value for psycho-educational and cognitive-behavioural interventions (Folkman & Moskowitz, 2004).

Direct effects of social support on stress and mental health. As previously indicated, the qualitative data show that social support is perceived to have a positive impact

on mental health through additional (direct) pathways, over and above those mediated by the biopsychosocial processes described above. For example, the data suggest that more social support may be directly leading to better mental health, mainly as a result of the calming effect of communicating one's problems and receiving comfort, advice and encouragement. The mental health benefits of talking or writing about experiences, problems and concerns have been documented in the literature by various authors, and there is also some evidence pointing to positive neurological and other physical health effects (Kaplan-Solms & Solms, 2000; Launer, 2005; Pennebaker, 1993). Launer (2013, p. 466) argues that most psychoanalysts believe that talking works because "... it provides people with a means of creating a coherent narrative from disconnected symptoms, events, memories and thoughts in the context of a relationship with someone compassionate and attentive." Talking to others has also been identified as a coping strategy for grandparent caregivers of children (Waldrop & Weber, 2001) and as self-care behaviour for depressive symptoms among people living with HIV (Eller et al., 2010).

The data also indicate that social support may be positively affecting mental health (particularly anxiety) by reducing specific stressors that may be causing anxiety or depression, through tangible support received (e.g. food, money or shelter). This indirect pathway between social support and mental health would appear to speak to the stress prevention model discussed by authors such as Dignam and Barrera (Barrera, 1986; Dignam, Barrera, & West, 1986). Barrera (1986) explains how this model represents one of the diverse hypothesised connections between social support, stress and distress. It hypothesises social support to be indirectly associated with distress through two mechanisms: 1) social support (usually in the form of enacted support/ support received) may prevent stressful events from occurring, which would in turn reduce or prevent distress; 2) social support may reduce the perceived threat of events that have already occurred (Barrera, 1986). The data from this

qualitative study suggest a relationship between more social support and less stress via the first mechanism, that is, through tangible help that prevents the occurrence of stressful conditions (e.g. food or money preventing household food insecurity or inability to meet other basic needs).

Support providers. Lastly, the qualitative findings draw attention to the importance of support providers. They suggest that broader everyday social support may be most effective if provided by someone who has a good relationship with the caregiver, someone who is trusted and/or who cares about his/her wellbeing. This resonates with Lakey and Orehek's (2011) theory that relationships with specific support providers may be key to explaining the role of social support as a general resource for health, since people regulate their affect, thought and action through regular ordinary conversations and shared activities with specific providers in both stressful and non-stressful situations (Lakey & Orehek, 2011).

However, the data also suggest that the nature and characteristics of specific support providers may be important in ensuring positive health effects in the case of specific stressors (e.g. the importance of a person with empathy and/or similar experiences in supporting caregivers with HIV). Thoits (2011) in fact distinguishes between providers who are "primary group members" and providers who are "secondary group members," in order to theorise on the usefulness of different types of support providers in performing support functions for a given individual. Primary group members are defined as "significant others" or people to whom the support recipient is emotionally tied and views as important in their lives, such as family members, relatives and friends (Thoits, 2011, p. 146). Secondary group members are described as people with whom the individual has more formal interaction, where knowledge about the other person is less personal and interaction may have short or extended duration (e.g. work colleagues, members of religious organisations). Thoits (2011)

argues that these two types of social network members may perform quite different – albeit both useful – functions in the presence of specific stressors. Significant others will likely be most valuable in providing emotional sustenance, which would reduce psychological stress and physiological arousal (through some of the psychological mechanisms previously discussed); they may also provide coping assistance, though they may themselves be too close to the problems and/or have little direct experience with the person’s specific stressor(s). Secondary group members or ‘similar others’ may, instead, be particularly effective at providing active coping assistance because of their previous experience with specific problems and knowledge of how to address these; they may also serve as role models who can be “observed and emulated” (Thoits, 2011, p. 154). In sum, Thoits (2011) argues that the effectiveness of the support provided and the social psychological mechanisms involved should depend on the type of support supplied and on whether it is provided by “experientially dissimilar” versus “similar others”.

8.9 Synthesis of qualitative findings

Results of the qualitative component of this research highlight multiple – direct and indirect - pathways and mediating variables perceived to be linking social support to health outcomes, and possibly explaining positive associations between more social support and better caregiver health observed through the quantitative analysis. Psychological and behavioural mediating processes identified included psychological factors associated with resilience, coping processes and positive social control leading to more beneficial health behaviours. When explaining the importance of social support as a general health resource, beyond coping with stressors, caregivers also spoke of the importance of maintaining relationships in “good times” in order to secure knowledge and support for difficult times.

Moreover, the data also suggest that specific mediating processes may be more important for particular sub-groups of caregivers; these include rumination and distraction for female and HIV-positive caregivers, and hope for HIV-positive caregivers. Finally, the importance of support provider characteristics for the support-health relationship emerged inductively from the qualitative data, and was discussed primarily in relation to HIV-positive caregivers and to the value of social support as a general health resource.

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CHAPTER 9: CONCLUSION

This final thesis chapter aims to bring together the quantitative and qualitative findings emerging from this mixed methods study, to relate them to the research questions and (House et al) theoretical framework guiding this work, and to discuss their implications in relation to theory, existing empirical research and practice. The first section of this chapter synthesises respective quantitative and qualitative findings, as they address the four general research questions. It illustrates potential links between findings from these two separate components by positioning them within the same theoretical framework. Based on a critical reflection of both the research process and findings, it also discusses implications of this research with regard to the conceptualisation and measurement of social support among similar caregiver populations. The second section of this chapter discusses the research findings in relation to the existing literature, and identifies gaps for future research to potentially address. The third section considers the implications of findings for practice, and includes a review of past and current interventions that aim to incorporate social support as a resource for health. The fourth section of this chapter discusses conceptual and methodological limitations of both the quantitative and qualitative research components. Finally, the chapter and thesis conclude with overall reflections on findings emerging from this mixed methods research.

9.1 Summary of findings in relation to the research questions and theoretical framework

The overall purpose of this research was to investigate the relationship between social support and health status among primary caregivers of children living in HIV-endemic South African communities, with a particular focus on HIV-positive caregivers. Mixed methods research, consisting of both a quantitative and qualitative research component, was employed in order to achieve this purpose. Specifically, this study sought to address four general research questions. These questions, and the main methodology used to address each of these, were illustrated in table 1.1 in Chapter 1. They are once again illustrated below in table 9.1, which also outlines the key findings of this research that are relevant to each general research question. The quantitative and qualitative findings of this research have been reported and discussed separately in previous chapters of this thesis (Chapters 6 and 8). They will be briefly summarised below once again, then discussed in relation to the theoretical framework and literature guiding this study.

Table 9.1. General research questions, methodologies and key findings

1) Is living with HIV/AIDS a risk factor for depression and anxiety among caregivers of children, and how does this compare to living with other chronic illness?

- Methods: hierarchical logistic regression analysis of quantitative data
- **Overall findings: Both living with HIV/AIDS and other illness are predictors of depression and anxiety, but HIV/AIDS is the stronger predictor**

2) Does social support have a main effect on caregiver depression and anxiety or buffer against the effects of HIV/AIDS- and other illness- related stressors on depression and anxiety?

- Methods: hierarchical logistic regression analysis of quantitative data, with interaction terms
- **Overall findings: Social support has a main effect on caregiver anxiety, and may buffer against effects of other illness-related stressors on depression.**

3) Is more social support associated with better self-reported general health and functioning among HIV-positive, other ill and healthy caregivers?

- Methods: linear regression analysis of quantitative data
- **Overall findings: Social support is directly associated with better self-reported mental health for all caregivers. It is also associated with better self-reported physical health, but only for caregivers without an existing health condition.**

4) What are the perceived mediating pathways and processes explaining the relationship between social support and caregiver health?

- Methods: thematic analysis of qualitative data
- **Overall findings: social support is perceived to be positively affecting mental and physical health through multiple pathways and mediating processes. Mediating mechanisms include psychological variables associated with resilience, coping processes and positive health behaviours.**

9.1.1. Summary of quantitative findings addressing research questions 1 – 3

Results of the quantitative component of this study were presented and discussed in Chapter 6 of this thesis. They indicate that caregiver HIV/AIDS and other illness are significant stressors associated with worse mental health for caregivers in this sample, and that HIV/AIDS represents a greater risk factor for poor mental health than other chronic illness.

They also provide evidence of a positive relationship between more social support and better caregiver health, though findings were not consistent for all health outcomes and comparison groups of caregivers. Direct relationships were found between more social support and less anxiety. These point to main effects of social support on mental health. There was also some evidence of social support buffering against stressors linked to (non-HIV-related) illness on depression. The positive relationship between greater support availability and better mental health was reinforced by evidence of positive significant associations between higher social support and better self-reported mental health for HIV-positive, other ill and healthy caregivers in the sample (as per mental health dimensions of the SF-12 general health and functioning tool).

Quantitative findings with regard to the relationship between social support and physical health showed a positive direct association between more social support and better self-reported physical health (as per the physical health dimensions of the SF-12 tool); however this was only the case for 'healthy' caregivers, and not for caregivers living with HIV/AIDS or other illness.

9.1.2 Summary of qualitative findings addressing research question 4

Results of the qualitative component of this research were described and discussed in the previous chapter (Chapter 8). They suggest that multiple pathways and mediating variables may be explaining the overall positive relationship between more social support and better caregiver health, observed through the quantitative analysis. Qualitative findings showed that caregivers perceived social support to be positively influencing their mental health through various direct and indirect pathways. The direct pathway between social support and mental health was explained mainly by the beneficial mental health effects of talking about problems, and receiving encouragement and advice. Mediating processes identified to explain indirect effects on mental health included psychosocial variables (comprising psychological factors associated with resilience, such as hope, self-esteem and self-efficacy) as well as more adaptive and less maladaptive approaches to coping with stressors (namely: more active problem-solving coping and distraction, and less rumination). Moreover, the qualitative data suggest a further indirect pathway between social support and mental health, as a result of (instrumental) social support reducing or eliminating certain stressors that negatively impact mental health. Social support was also perceived to be positively affecting caregiver physical health, through better mental health and more positive health behaviours. These pathways and mediating factors emerging from the qualitative data were illustrated diagrammatically in Figure 8.1 in the previous chapter.

Overall, the qualitative findings showed a high level of consensus among caregivers. There were no conflicting positions within themes, and most themes were taken up by male and female, as well as ill and healthy caregivers. There were a few exceptions, however. For example, the themes of rumination and distraction were raised mainly by female and HIV-

positive caregivers, and the theme of direct positive effects of social support through talking about problems was raised mainly by females. Also, the theme of hope, as a key resilience variable leading to better mental health, was discussed mainly in relation to HIV-positive caregivers. Finally, the importance of the support provider for the support-health relationship was discussed primarily in relation to dealing with HIV as a stressor and to the value of social support as a general health resource.

9.1.3 Discussion of quantitative and qualitative findings in relation to the theoretical framework

Figure 9.1 below is an adapted version of a section of the House et al (1988) model, illustrating findings of both the quantitative and qualitative analysis of this study, on effects and processes explaining the relationship between social support and caregiver health (addressing research questions 1 – 4).

The green arrows represent pathways supported by the quantitative analysis. These are: significant associations between the presence of caregiver HIV/AIDS and other illness and worse mental health (represented by the green arrow linking the *chronic/acute psychosocial stress* box to *mental health*); direct main effects of social support on mental health (*e2 pathway*) and on physical health (specifically for caregivers without a health condition) (*e1 pathway*); and direct stress-buffering effects (specifically for depression) (*a pathway*).

The red arrows illustrate pathways emerging from findings of the qualitative data. The red arrow linking *social support* to the *mental health* box represents qualitative evidence of

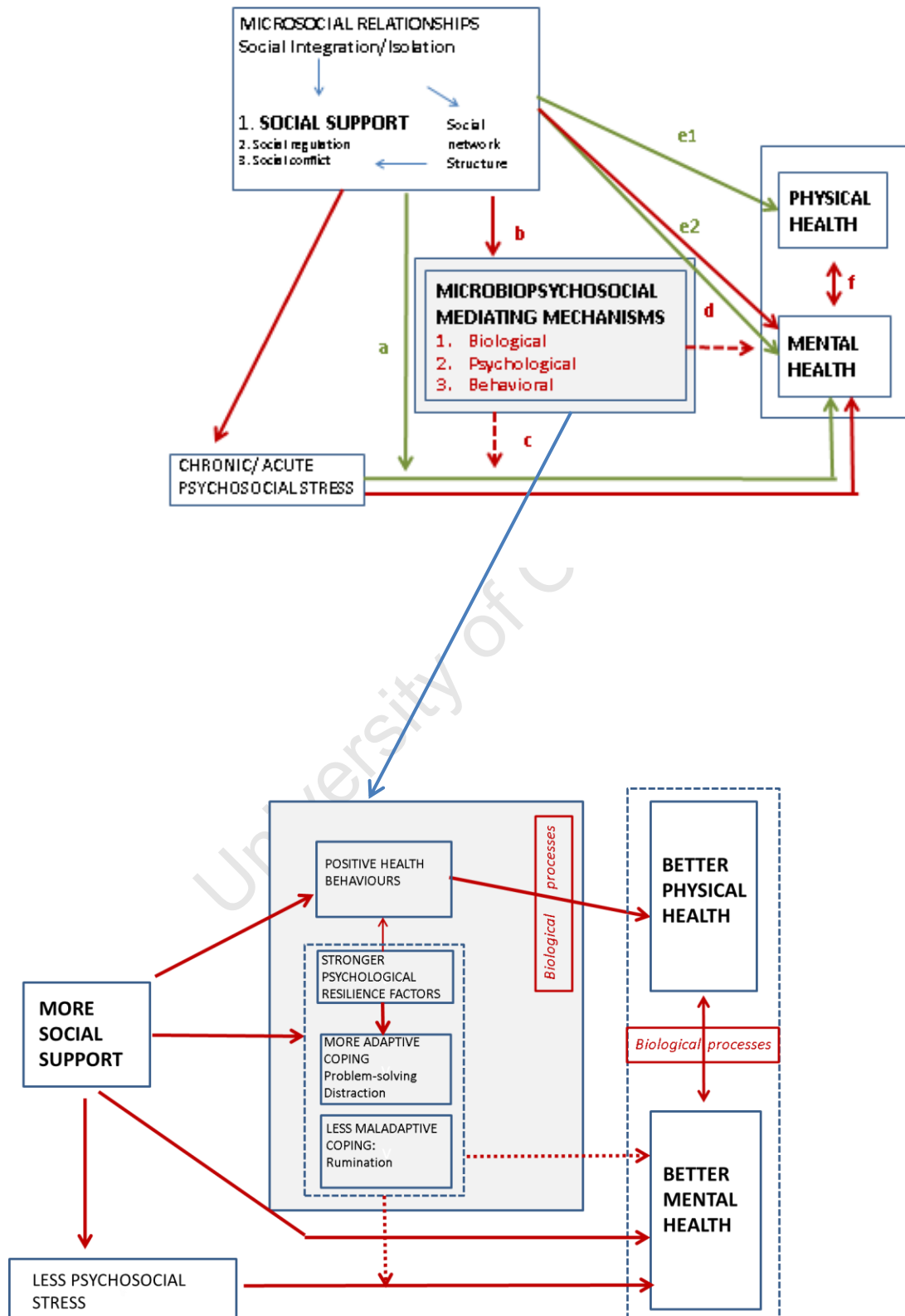
direct effects of social support on mental health. The red arrows linking *social support* to the *microbiopsychosocial mediating mechanisms* box and, in turn, these mechanisms to mental and physical health, represent the perceived positive effects of social support on health mediated by various psychological, behavioural and physiological processes. These multiple mediating factors, illustrated in Figure 8.1 in the previous chapter (and included again in Figure 9.1), could be considered an elaboration of the *microbiopsychosocial mediating mechanisms* box included in the House et al model, as indicated in Figure 9.1 below. Moreover, the red arrows linking social support (as an element of *microsocial relations*) to the *chronic/acute psychosocial stress* box and *chronic/acute psychosocial stress* to *mental health* represent qualitative evidence suggesting that social support may be improving mental health outcomes by reducing the presence of stress or occurrence of specific stressors that negatively influence mental health.

Figure 9.1 allows for a more immediate visual representation of what both the qualitative and quantitative indicate regarding support effects and mediating processes, as well as potential linkages between these effects and processes. The illustration of quantitative and qualitative findings in one diagram is also useful to highlight effects or processes supported by both types of data. Moreover, it draws attention to pathways that may not have been supported by this study's data and/or that require further investigation. These are in part linked to the limitations of this research. First, it is not possible to ascertain from the qualitative work whether the mediating mechanisms identified by caregivers could be mediating main (*b/d* pathway) or stress-buffering effects (*b/c* pathway) of social support on mental health, or both. As a result, the *c* and *d* pathways in Figure 9.1 are represented by arrows with dashed lines. Second, without being able to test these mediators quantitatively, it is not possible to ascertain to what extent direct associations found in the quantitative analysis (represented by the green *a*, *e1* and *e2* arrows) are in fact partially or entirely mediated by one

or more of the processes described in the qualitative work, and therefore best represented by the *b/c* and *b/d* mediated (versus direct) pathways in the diagram. Third, the qualitative evidence was unable to provide explanations for the *e1* pathway, that is: the direct relationship between social support and physical health. This is, however, not surprising, as this pathway would require greater knowledge of physiological processes best explored through research with a biomedical component.

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Figure 9.1. Diagrammatic illustration of quantitative and qualitative research findings in relation to the House et al theoretical framework



9.1.4 Reflections on the conceptualisation and measurement of social support in this sample

Both the quantitative and qualitative data provide some insight on how caregivers in this community conceptualise and experience social support. This has implications for the measurement of social support and the approach to future research with this population. The main points emerging from this study are indicated below; they are based on a reflection of both the quantitative and qualitative research processes and findings.

Importance of the support context. It was clear from the qualitative component preparatory work (with isiZulu bilingual research assistants) and the qualitative data collection, that a composite construct of ‘social support’ would have been impossible to effectively translate into a few isiZulu words, and would have been too abstract a concept for respondents to be able to relate to. It became apparent that it was important to refer to examples of specific types of support (e.g. help with money or food, providing love and care) and, in particular, to the experiences of support received by individual caregivers from specific providers, in order to convey an understanding of what was meant by social support and to contextualise the interview questions on social support and health. This realisation informed the design of the qualitative instrument, which included a description of different possible types of social support, as well as questions on caregivers’ most important support providers and the types of support they received.

Social support considered a positive resource for health. It was also clear from the qualitative data that participants considered social support a positive resource for health. None of the caregivers interviewed in the qualitative study had experienced or could even hypothesise negative effects of support. While there were some references to the negative psychological effects of having to seek support in difficult times, the receipt of this support was always considered a positive phenomenon. This reinforces quantitative findings of positive associations between more social support and better health outcomes. It should be noted, however, that these findings do not exclude the existence of possible negative effects of social relations more broadly (e.g. through social conflict, stigma or social control), the measurement of which may be of value with similar populations. It simply suggests that social support, as one (functional) element of social relations, is associated with positive health effects in this community.

High correlation between types of support. Both the quantitative and the qualitative data indicate that the perceived availability of emotional and instrumental social support were closely related in this sample. While the original authors of the MOS-SSS scale (Sherbourne & Stewart, 1991) found that it measured four specific types of social support (emotional and informational support, tangible, positive social interaction and affection) in their work with populations in the developed world, factor analysis from this study suggests that the MOS-SSS scale was measuring only one 'perceived social support' construct in this particular sample. All MOS-SSS sub-scales – measuring tangible and emotional support – were highly correlated in this sample. This indicates that the perceived availability of various types of emotional support among caregivers in this study population was highly correlated with the perceived availability of tangible support, and that it would not have been possible to

investigate the relationship between individual types of support and health using MOS-SSS subscales. It should be noted that, on using the MOS-SSS with a sample of 263 Black South African adults with diabetes, Westaway et al (2005) identified two factors, respectively indicating sub-constructs of socio-emotional and tangible support (as opposed to the four subscales identified by the original authors in their work with chronically ill adults in the USA). The high correlation coefficients between subscales with this particular sample instead indicate that the MOS-SSS is measuring only one construct of social support, including both socio-emotional and tangible support. Qualitative findings appear to reinforce the close relationship between types of tangible and socio-emotional support: caregivers felt that they were equally important for health, often spoke about different types of support in conjunction, and had difficulty conceptualising positive health effects of tangible support in the absence of emotional support.

Importance of support providers. Lastly, the many spontaneous references in the qualitative data to the importance of *who* was providing support, suggest that the effectiveness of support is often perceived to be influenced by the identity and/or characteristics of the individual(s) providing it. This has various possible implications with regard to the conceptualisation and experience of support in this community. For example, given the perceived importance of instrumental and emotional support provided in conjunction, it is possible that respondents received or expected to receive various types of support from the same support provider(s). In this community it may therefore be perceived to more important to have one or more supportive members in one's close social network – that is to 'have support' - rather than to be receiving one specific type of support versus another.

9.2 Discussion of quantitative and qualitative findings in relation to the existing literature

9.2.1 Social support as a protective factor for caregiver mental health

Overall, the quantitative and qualitative findings of this thesis reinforce the importance of social support as a protective factor for caregiver health. The quantitative results provide evidence predominantly of main effects of support on mental health, suggesting that social support is a general (mental) health resource for all caregivers, whether or not living with (HIV or other) physical illness. These findings are in line with the large body of existing theoretical and empirical literature, presented in Chapters 2, 3 and 4 of this thesis, that show a positive relationship between more social support and better mental health, more frequently observed through main effects (House, Umberson, et al., 1988).

The qualitative data suggest that the positive relationship between more social support and better mental health may be explained by the existence of multiple pathways and mediating variables, described in Chapter 8 and illustrated in Figures 8.1 and 9.1. These include many of the psychological and behavioural processes identified in the theoretical literature (House, Umberson, et al., 1988; Thoits, 2011) and in previous empirical work with HIV-positive and broader adult populations; they comprise psychological variables associated with resilience and more beneficial coping responses for mental health (Schmitz & Crystal, 2000; Simoni, et al., 2005; Yadav, 2010).

Moreover, the qualitative findings of this research suggest that specific mediating mechanisms could be more important in explaining positive effects of social support on the

mental health of certain sub-groups of caregivers. For example, greater hope as a resilience variable, and more distraction and less ruminative thinking as coping responses, emerged as key factors perceived to be mediating the relationship between more social support and better mental health for HIV-positive caregivers in particular. These findings recall Yadav's (2010) work with HIV-positive individuals in Nepal, showing positive effects of social support on physical and psychological dimensions of quality of life to be mediated mainly through hope. They are also to some extent consistent with previous studies showing more problem-focused and less emotion-focused coping to be mediators of the positive support-health relationship (Burns, et al., 2008; Schmitz & Crystal, 2000); however, this study also shows how some forms of emotion-focused coping (i.e. distraction) may also be protective of health.

Instead, the mental health benefits of emotional 'unburdening' through talking about problems, as well as rumination and distraction as coping strategies, were all themes raised predominantly by female caregivers. There is, in fact, evidence of differences in the way male and female caregivers seek or utilise support to deal with stress and distress. For example, a 2002 meta-analytic review examining sex differences in coping, found that women were more likely than men to seek both instrumental support and emotional support, through verbal expressions to others, in order to deal with stressors (Tamres, Janicki & Helgeson, 2002). Also, rumination has been associated mainly with (more intense and persistent) depression as an outcome, and studies have found women to be more likely to engage in ruminative thinking (J. Smith & Alloy, 2009). In fact, as indicated in the previous chapter, some studies have found the gender difference in depression to be entirely mediated by the gender difference in rumination (Butler & Nolen-Hoeksema, 1994; Nolen-Hoeksema, et al., 1994). It should, however, be noted that conclusions regarding mechanisms explaining protective effects of support on depression versus anxiety cannot be confidently drawn from

the qualitative data deriving from this study, and would require further quantitative investigation.

Lastly, it is interesting that social support appears to be buffering effects of stressors deriving from non-HIV-related illness on depression, but not stressors deriving from HIV/AIDS. As argued by previous authors, it is possible that resources such as social support may be insufficient to protect individuals caring for children from the particular effects of HIV, especially when living in difficult social conditions (Mellins, et al., 2000). There could also be social factors related to HIV, such as stigma, hindering the ability of social networks and social support to buffer against HIV-related stressors, as they may do for other illness. If this is the case, it could indicate that measures to address or eliminate stigma could ‘activate’ the ability of social support to buffer against the negative mental health effects of HIV. These are simply hypotheses however, and would also require further investigation.

9.2.2 Social support as a protective factor for caregiver physical health

Findings of this thesis that speak to the relationship between social support and caregiver physical health are less conclusive than those regarding the relationship between social support and mental health, likely in part because of the limited instruments available to quantitatively measure physical health outcomes. Quantitative findings show social support to be positively associated with better self-reported physical health (as measured by the physical health component of the SF-12 general health and functioning scale) for caregivers without a health condition, but not for caregivers living with HIV or other illness. This may be explained by the physical health impacts deriving from an existing chronic health condition, whether HIV/AIDS or other illness, which may once again be too large or long-term to observe protective effects of support. It should be noted that these findings of the

absence of a relationship between social support and physical health for sub-groups of HIV-positive and/or ill caregivers do not support evidence of several previous studies showing social support to be associated with slower disease progression and better health outcomes among HIV-positive individuals (Leserman, 2003; Pakenham, et al., 1994). They are also surprising in light of evidence on the strong links between better adult mental and physical health (Prince, et al., 2007) and the qualitative data from this study, showing that (ill and healthy) caregivers perceived social support to be positively impacting their physical health, through better mental health and more positive health behaviours.

One possible explanation for these apparent contradictions between the quantitative and qualitative findings, on the relationship between social support and physical health for ill caregivers, is that individual perceptions of better physical health may not always be a true reflection of actual physical indicators. Both the quantitative and the qualitative results were based on caregiver perceptions. The quantitative study, however, was based on data collected from 2477 caregivers, whereas the qualitative study was based on data collected from a small group of (24) caregivers, that therefore cannot be generalised to all caregivers in this community. Also, as indicated previously, there were limitations of the physical health indicator used in the quantitative analysis of this study: only one tool was available in the survey to measure general physical health status (the SF-12 and its subscales), as opposed to the multiple scales available to measure self-reported and symptomatic mental health outcomes, and national normative data was not available to weight the SF-12 subscales. Moreover, since biological data was not collected in this study, the self-report physical health SF-12 measure could not be cross-checked with biological indicators. Lastly, it is possible that the lack of significant associations between more social support and better physical health, found in the cross-sectional quantitative analysis for (HIV- and other-) ill subsamples, may be indicating a circular form of causation (Turner, 1981) working in the

opposite direction: in other words, it is possible that ill caregivers are receiving *more* support *as a result* of their illness, from what the qualitative data suggests is an overall supportive community, which could be obscuring positive effects of more social support on better health. These dynamics should best be explored through longitudinal research, as discussed in greater detail below.

9.3 Implications of findings for future research

9.3.1 Further research on effects of social support on physical health.

Results of this study point to several key areas for further research. One area would comprise further investigation on the support – physical health relationship, with both HIV-positive and HIV-negative caregivers. As discussed above, whereas quantitative and qualitative findings of this work overall highlight a positive relationship between more social support and better mental health, findings in relation to physical health effects of social support are less conclusive, and in part inconsistent. There is clearly scope for further quantitative investigation on the relationship between social support and physical health outcomes with similar populations, which ideally should include both self-report and biological indicators of overall physical health, and, for ill caregivers, indicators of length of illness and disease progression. Moreover, longitudinal studies would be particularly valuable to provide insight on the causal directionality of observed relationships, in order to confirm that social support is in fact influencing physical health outcomes (as opposed to physical health influencing social support availability).

9.3.2 Further research on mediating processes explaining the support-health relationship

There is also much scope for further research on the mediating mechanisms explaining the support – health links within similar populations. The qualitative findings of this thesis point to multiple potential pathways and variables mediating the relationship between social support and (physical and mental) health among this sample of caregivers. They highlight the complexity of the intervening mechanisms explaining the support-mental health links, and reinforce the importance of simultaneously measuring and exploring multiple mediating variables, as well as their relationship to each other (House, Umberson, et al., 1988). While the exploratory model developed from this qualitative work (see Figure 8.1) could be useful to serve as a basis for future work, the biopsychosocial processes emerging from this analysis should best be tested through focused social support survey tools, and quantitative pathway analysis with representative caregiver samples. This would also allow for a greater understanding of the mediating processes explaining stress-buffering versus main effects, and/or whether similar processes can explain both types of effects (Thoits, 2011).

Findings also draw attention to specific pathways and mediators that require particular attention. Some of these are relevant to specific sub-groups of caregivers or specific health outcomes. For example, based on the qualitative findings of this thesis, it may be useful for future research to quantitatively investigate coping processes such as rumination and distraction, as well as the benefits of talking to others about one's problems, for male and female caregivers separately. Similarly, the above-mentioned coping processes, and certain

psychological resilience variables (e.g. hope) could be investigated with comparison groups of ill and healthy, or HIV-positive and HIV-negative, caregivers.

It would also be useful to better understand why social support may be buffering effects of stressors deriving from non-HIV-related chronic illness on depression, but not stressors deriving from HIV/AIDS. Research should further investigate what it is about living with HIV/AIDS that makes it a greater risk factor for mental health than other chronic illness and prevents the ability of social support to buffer its effects on depression, as it may do for other chronic illness. Perhaps further focus should be afforded to the role of social factors, such as stigma, that may be hindering potential stress-buffering effects of support among caregivers living with HIV.

The exploratory model developed from the qualitative data also draws attention to several pathways and mediators that deserve greater attention. An example is the direct pathway between social support and physical health and, more generally, the physiological processes explaining (direct or mediated) effects of support on physical health outcomes. Though there were various (spontaneous) references in the data to certain physiological processes (e.g. appetite, blood pressure, fatigue), these were raised to explain the link between better mental and physical health, as opposed to the direct pathway between social support and physical health outcomes. Much still remains to be uncovered around these processes, both with this sample of caregivers and more broadly. This would likely be best achieved through further studies that link behavioural and biomedical data.

Moreover, while there was some allusion in the qualitative data to positive health behaviours being in part indirectly influenced by social support through psychosocial factors such as hope or self-esteem, the link is rather weak. This would be another area to further explore, in order to better understand the relationship between variables mediating the social support and physical health relationship.

9.3.3 Further research on sources of support and support networks

Given findings related to the MOS-SSS scale and qualitative data showing strong links between instrumental and emotional support, it would appear that investigating the health effects of specific types of support may be of limited use in this population. These findings, as well as those on the importance of support providers, suggest it may be more useful for future research with similar populations to employ social support tools with subscales that measure specific sources of support. It may also be worthwhile for research to better understand the importance of specific support providers for the protective effects of support on health. This would include addressing questions around whether some providers are associated with greater health benefits of support and whether specific providers/provider characteristics are of particular value in dealing with specific stressors (Lakey & Orehek, 2011; Thoits, 2011).

There is also considerable scope for future research to explore the relationship between structural (network) and functional dimensions of support with similar populations. While support types, providers and processes are three distinct dimensions of support, it is important to achieve a better understanding of their linkages in relation to health among specific populations; for example, to determine whether the types of support most important for health may derive from specific providers and influence health through specific pathways.

9.3.4 Intervention research

Lastly, for this research to be of practical relevance for the wellbeing of caregiver populations in Southern Africa, there should also be a greater focus on the design and evaluation of social support components for interventions to be implemented with similar populations. In this respect it would be particularly useful to better understand which dimensions of social support (e.g. providers, types of support) are most important for mental health, as well as the different ways in which this support may be affecting mental health (House, Umberson, et al., 1988; Uchino, et al., 2012). A further key question, that future research (and interventions) should pay greater attention to, is the extent to which these dimensions of existing informal social networks can be successfully replicated and/or included in formal programmes. The evidence of a positive relationship between more social support and better health outcomes, provided by this and many other studies, is based on support deriving from naturally occurring relationships, versus experimental situations or intervention components. It would be important to better understand whether and how benefits deriving from these naturally occurring (generally longer-term) relationships can be successfully applied to (often shorter-term) interventions (Ertel, Glymour, & Berkman, 2010; Holt-Lanstad, et al., 2010). This point will be further considered below, in the next section (9.4), which considers the relevance of these findings for policy and practice.

9.4 Relevance for policy and practice

In order for evidence showing the importance of social support to have a positive impact on the wellbeing of caregivers living in HIV-endemic communities, it would need to effectively inform policy and interventions aimed at protecting the health of these caregivers. This section discusses implications of this study's findings for policy and practice, and describes some of the social support interventions that have been implemented and documented in the international published literature.

9.4.1 Implications of this study's findings for policy and practice

This study's findings of an overall positive relationship between social support and mental health have important implications for policy and interventions aimed at safeguarding the health of caregiver and child populations in similar Southern African communities. This is not only because of high levels of mental health conditions (Patel, 2007) and the mental health risks of HIV, but also because worse mental health has been linked to disease progression and mortality (Antelman, et al., 2007; Ickovics, et al., 2001; Sherr, et al., 2011), as well as worse parenting and child health outcomes (Reading, 2005; Stein, et al., 2008). These mental health risks and potential protective effects of social support have particular relevance for female caregivers and the children they care for, given that women in the region are taking on the majority of caregiving responsibilities for children and are disproportionately affected by HIV and mental health conditions (WHO, UNAIDS, & UNICEF, 2011; World Health Organisation, 2012).

Overall, results of this study highlight the importance of affording more attention to the social environment when designing and implementing mental health interventions

(Prince, et al., 2007), and suggest that social support could be a valuable component of such interventions. This may be particularly important in situations of limited formal mental health facilities and low uptake of existing services, such as that of South Africa. On the one hand, social support components could be included within broader health programmes, for example through support groups, health providers or interventions aimed at strengthening existing networks (Davies, Hortona, Williams, Martin, & Stewart, 2009; S. Mason & Vazquez, 2007; Mitrani, McCabe, Robinson, Weiss-Laxer, & Feaster, 2010). On the other, there may be opportunity for existing informal support networks and initiatives to serve as a platform for psycho-educational initiatives and higher uptake of formal health services.

For example, the qualitative data from this research indicate that access to support groups (e.g. through clinics or other community channels) may be an effective component of caregiver health interventions in these communities. Support groups were highlighted by caregivers in this study as important sources of instrumental, informational and emotional support. Similarly, HIV-positive parents participating in pilot intervention studies in the U.S. (Davies, et al., 2009; S. Mason & Vazquez, 2007) also highlighted the benefits of psycho-educational support groups that combined self-care and caregiving information/education with longer-term informal interaction between individuals with similar stressors. In line with our data, they showed the importance of confidentiality, trust and, more generally, a safe space where participants are understood and not stigmatised (Davies, et al., 2009; S. Mason & Vazquez, 2007).

Moreover, while caution should be exercised in making policy and practice recommendations based on qualitative findings with a small sample, it is worth noting that the qualitative data from this study, together with findings of previous studies, point to some dimensions of social support that should be afforded greater attention within applied

interventions. These relate to the types of support most effective for health, the possible mediating variables explaining effects of support, and the nature of support providers.

First, with regard to types of support, qualitative findings suggest that health interventions working with caregivers, especially HIV-positive caregivers, should seek to combine both emotional and tangible support, for example: home-based care initiatives that provide advice, encouragement and comfort as well as practical assistance with health care, transport to health facilities and caregiving tasks (Davies, et al., 2009).

Second, the qualitative data from this study and previous studies suggest that, besides encouraging practical health behaviour and facilitating access to health resources, it is important for health interventions working with caregivers to focus on strengthening resourcefulness factors, such as hope, self-esteem and self-efficacy, and more active coping responses to stressors. Providing the hope of being able to live a normal life and have a better future appears to be especially important for HIV-positive caregivers. Also, the qualitative data suggest that HIV-positive, and especially female, caregivers should be protected from social isolation to avoid the potential adverse mental health effects of ruminative thinking around their illness and imminent death.

Third, qualitative findings suggest that support interventions should pay particular attention to the qualities of support providers and caregivers' relationship to these providers. Home-based carers or other support providers recruited by health programmes working with ill caregivers should be individuals with characteristics that allow them to relate to the caregivers' situations and provide empathy. Once again, this may be particularly important for HIV-positive caregivers; given the presence of HIV-related stigma in many communities, it is essential that the individual(s) providing care and other support are able to identify with, and do not stigmatise, people living with the disease.

It should, however, be noted, that there is likely no ‘one-size-fits-all’ solution. Individual social support interventions should be designed and evaluated taking into account the social and cultural characteristics of the specific context and target population, the objectives of the intervention and the available resources.

9.4.2 Evidence of health impacts of applied social support interventions

In considering the potential value of findings of this research for interventions, it may be useful to look at existing health interventions with similar populations that incorporate elements of social support, and consider their degree of success. Most past or current initiatives of this nature include one or more of the following components: support groups; professional assistance and/or education (including cognitive behavioural therapy); and measures intended to improve existing social relations or networks.

Unfortunately most interventions aimed at strengthening or utilising social support to promote health with HIV-positive caregivers of children appear to be fairly recent and have been implemented mainly in the USA²⁰. Moreover, in some cases impact evaluations have

²⁰ It should be noted that two interventions with pregnant HIV-positive women (though not specifically caregivers of children), implemented in South Africa, have shown promising results on psychosocial variables, coping and mental health. The first is a pilot trial of a peer mentoring programme and a culturally adapted cognitive behaviour intervention (CBI) from the USA, rolled out in conjunction with PMTCT in two South African townships. The programme included the support of a ‘mentor mother’ and an eight-session cognitive behavioural intervention. Its evaluation suggests it improved social support and reduced depression scores (Futterman et al., 2010). The second intervention consisted of a 10-session psychosocial support group intervention with newly-HIV-diagnosed pregnant women in South Africa recruited from antenatal clinics.

not been carried out or have shown mixed results. For example, both Mason and Vasquez (S. Mason & Vazquez, 2007) and Davies et al (Davies, et al., 2009) documented the implementation of programmes employing group sessions to enhance social support and provide health education and awareness among HIV-positive parents in the USA. Though positive participant feedback was reported, to date no assessments of health or treatment adherence outcomes have been conducted. Hansell et al (Hansell, Hughes, Caliandro, & Russo, 1999) reported results of a modified case management approach intervention which assisted HIV-positive and HIV-negative caregivers of AIDS-affected children in the USA in identifying and accessing support resources; these showed success in boosting social support of the HIV-negative caregivers, but not of the HIV-positive caregivers. The authors concluded that boosting social support alone may be insufficient to buffer the numerous sources of stress faced by caregivers who are dealing with their own health crises (Hansell, et al., 1999).

Instead researchers based at the university of Miami have, for years, been implementing and evaluating interventions defined as ‘Structural Ecosystems Therapy‘ (or SET), an extension of family therapy designed to identify and correct maladaptive social interactions between the individual, the family and the broader social environment (e.g., health care providers) (Szapocznik et al., 2004). Evaluations through randomised clinical trials have, however shown mixed results, including better adherence to antiretroviral medications, less family hassles and lower psychological distress among low-income African American women with HIV, but not increased family support; moreover, this approach is

Positive effects were found on (more active, less avoidant) coping styles, disclosure of HIV status and self-esteem (Mundell et al., 2011).

resource intensive (Feaster et al., 2011; Szapocznik, et al., 2004) and likely not feasible or appropriate for resource-deprived settings. It is clear that intervention research in this area, with HIV-positive individuals and/or caregivers, still has a way to go and that interventions need to be further developed and refined and their longer-term benefits assessed. Moreover, these programmes may not be appropriate for very different contexts in the developing world, and would have to be adapted for and assessed in these settings.

More broadly, the international literature documenting the application of social support interventions for health promotion among (ill and healthy) adult populations have also shown mixed and, in some cases inconclusive, results. Based on a review of social support interventions, Ertel et al (2010) conclude that, while there is some evidence of interventions improving networks through self-help groups and skills-building, and enhancing support for positive health behaviours, many other initiatives (including clinical trials) have not provided evidence of long-term health benefits (Ertel, et al., 2010; Uchino, 2006). The authors suggest that, in some instances, the absence of an observed impact of these interventions may be a result of methodological limitations (e.g. small samples and sampling bias, the absence of an adequate social support measure). However, they argue that the absence of observed long term positive health impacts could also be reflecting shortcomings of the interventions themselves and the assumptions driving them. For example, these interventions may not alter social support enough, or (in the case of individuals with existing health conditions) may not intervene at the 'appropriate etiological period' (Ertel, et al., 2010, p. 83) or it may simply be that social support was not the key causal agent. The authors conclude by highlighting a number of areas that merit greater theoretical and empirical attention in order to improve the success of future interventions. These include questions around: which individuals to best target (e.g. those most at risk or those who could potentially benefit most); whether to focus on individuals or situations (e.g.

whether to intervene after the occurrence of a stressful event); the type of support provided and the nature of the support provider(s); the potential to alter an individual's social environment (Ertel, et al., 2010). Also, as pointed out by Uchino et al (2006), we do not know how much of a change in social support may be needed or how long an intervention is necessary to influence health outcomes that have a long-term aetiology.

As indicated previously, an important question that emerges from the intervention literature is the extent to which dimensions of existing informal social networks can be successfully replicated and/or included in formal programmes, or used as a platform for health promotion. Many existing social support interventions are based on support provided by health professionals or other people outside of the recipient's close informal social network. Instead, much of the empirical evidence on associations between social support, health and mortality is based on "naturally occurring social relationships" (Holt-Lanstad, et al., 2010, p. 14), linked to broader social integration. Holt-Lanstad et al (2010) argue that "facilitating use of naturally occurring social relations and community-based interventions may be more successful than providing support through hired personnel" (p. 14). They also suggest that "multifaceted community-based interventions may have a number of advantages because such interventions are socially grounded and include a broad cross-section of the public" (p. 14). This may be particularly relevant in the context of rural or semi-urban HIV-endemic Southern African communities for example, where living conditions and cultural norms often foster a strong sense of community and social regulation.

Another related issue to consider is the temporal dimension of social support interventions in relation to "naturally occurring relationships". Relationships with close network members are typically long-term, whereas applied social support interventions may be relatively short-term (e.g. consist of a limited number of psychosocial support sessions). Further research and interventions should pay more attention to assessing whether shorter-

term initiatives can indeed have positive effects in the longer run, as this would be essential for better health and longevity. As summed up by Ertel et al (2010; pp. 86 - 87):

The notion of intervening in complex social relationships and structures is inherently difficult and complicated. Given this complexity, along with the state of the science and the limitations discussed above, it seems that we have a lot of work before us to figure out how and when to best intervene to enhance the social environment... Perhaps the most effective interventions will be those that enable people to maintain durable, deep social relationships and those that mobilize health-promoting resources that can flow through such networks.

9.5 Limitations and strengths of the research

9.5.1 Conceptual limitations of this research

As explained in Chapters 1 and 2, this research focuses on social support as a functional dimension of social relationships, and as such, on its positive role as a coping and general health resource. Thoits (2011) highlights that ‘social support’ is a term that has positive connotations, referring to beneficial consequences of actions or at least to beneficial intentions. This excludes, however, the ‘dark side’ or potential negative aspects of social relationships (Thoits, 2011), including social conflict or relationship sources of stress or strain, which have been shown to be negatively associated with health outcomes and to even cancel or outweigh the positive effects of support (Ingram, Jones, Fass, Neidig, & Song, 1999; Thoits, 2011). While these negative aspects of social relationships were beyond the

scope of this work, it could be useful for future research to investigate both these positive and negative aspects and their relevance for health. It should, however, be noted that this study did allow for potential negative effects of social *support* to be identified (for example, well-intended supportive actions that may have had unintended negative consequences), both through quantitative associations investigated and/or through questions on negative effects of support in the qualitative interviews. However, neither the quantitative nor the qualitative data provided evidence of negative health effects of social support²¹.

Moreover, as previously indicated, the social support construct and measurement tool used in the survey component of this study focused on the *functional* dimension of social support, that is: the perceived availability of both emotional and instrumental support. This study did not collect data on the structural dimensions of social support (e.g. size of support networks, types of relationships). The decision to focus on the functional, versus structural, aspects of social support was based on both conceptual and methodological considerations. First, as indicated previously, measures of functional aspects of support have been found to be more important for health outcomes (especially for mental health) than structural properties of support (S. Cohen & Wills, 1985; Ryan & Willits, 2007). Second, the quantitative survey instrument, designed for a broader household health survey, would not have been well suited to collect complete and high quality data on social networks. An investigation into the social networks of caregivers would best be achieved by means of a separate focused study employing social network theory and methodology.

²¹ As indicated in reporting the qualitative findings of this study in 8, the only mention of negative effects of support on health referred to the stress and anxiety related to support seeking or not receiving the support needed. This is, however, distinct from support available or actually received, which was always associated with positive health effects.

9.5.2 Methodological limitations of this research

Since the quantitative component of this doctoral research was part of a larger health survey, the instrument was designed to investigate the health of children aged 10-17 and their primary caregivers more broadly, as opposed to a survey focusing on social support and health. Besides the social support instrument, the variables used in this analysis were therefore limited to health indicators and other information included in the survey instrument, selected by the research team (including the doctoral candidate) based on the broader survey objectives. While this allowed for the inclusion of various health indicators to test the relationship between social support and health, potential mediating variables of interest (such as coping styles and psychosocial variables) were not included in this survey and therefore were explored qualitatively rather than quantitatively. As explained above, this limited the ability to link effects of support (found quantitatively) with potential mediating variables (emerging from the qualitative evidence).

It should also be noted that the quantitative analysis did not include a measure of background life stressors. This precluded the assessment of whether social support was a significant predictor of depression and anxiety after controlling for background life-stress. Where possible, it would be useful for future analyses quantitatively exploring the protective role of social support for mental health to include an indicator of other background life stressors, in order to assess whether the effect of HIV or other illness may be explained by the presence of these stressors. This understanding would be useful to determine whether interventions should (also) be aimed at the other concomitant stressors.

A further limitation of this research, particularly for the quantitative component, is the reliance on self-report data. This is a common challenge for both social support research

(Haber, et al., 2007) and health surveys more generally, as most have to rely on self-report measures of key support and health indicators. These measures are likely to be influenced, to some extent, by perceptions, reporting bias and/or inaccuracies.

Moreover, most of the available psychometric assessment tools for the key (health and other) constructs of interest had not been validated in South Africa. This posed a challenge for the cross-cultural validity of tools, once again common to most survey research conducted in the developing world. In order to minimize the effects of these limitations, where scales validated in South Africa were not available, the team prioritised scales with excellent psychometric properties and/or that had been previously used in South Africa or in similar settings. Also, all tools included in the survey instrument had been piloted and/or used in previous studies conducted by members of the broader research team.

A related challenge was presented by the need to translate assessment tools originally conceptualised in English into the local language (in this case isiZulu). While every effort was made to rigorously translate and back-translate assessment tools by means of a staged process, it should be acknowledged that translation may still not have perfectly captured equivalent constructs. However, this risk is common to most cross-cultural health research (Casale, et al., 2011; Hanna, Hunt, & Bhopal, 2008; Jain & Jadhav, 2009) and is less of a concern for certain tools (e.g. the CES-D) for which studies have tested the conceptual equivalence of translations for South African populations (Smit, van den Berg, et al., 2006; Ware, et al., 2007).

The particular limitations of the physical health indicators have already been highlighted. The quantitative study did not collect biological indicators, to cross-check measures of self-reported health and/or HIV status. Specific limitations in the measurement of physical health using the (self-report) SF-12 general health and functioning tool have

already been discussed. The verbal autopsy method also entails a margin of error in classifying HIV-related illness or death, as indicated by its validation studies, cited in Chapter 5 (Kahn, et al., 2000; Lopman, et al., 2006). Nevertheless, the VA remains the best tool available in the absence of bio-indicators and/or reliable data on cause of death. It should also be noted that the indicator for HIV/AIDS in this study does not take into account individual stage in disease progression, and does not separate caregivers with symptomatic and asymptomatic HIV. Where possible, it would be useful for future analyses to investigate differences in the social support – health relationship for HIV-positive individuals at different stages of disease progression. It should also be noted that the ‘chronic illness’ indicator, used to identify the ‘other ill’ subgroup of caregivers, took into account various conditions, including hypertension, cancer and diabetes, which likely have very different impacts and care needs; future analyses may be able to explore these differences and/or further disaggregate this indicator. A further limitation of the survey research is presented by its cross-sectional design, which limits the ability to infer causality. It is possible for social support to influence health, for health to influence social support or for both of these effects to co-exist, representing a circular form of causation. Turner’s (1981) synthesis of findings of four empirical studies linking social support and psychological wellbeing at two points in time suggests, in fact, that part of the causation goes from social support to health and part in the opposite direction (Turner, 1981). Reverse causality could be explained by the potential influence that a person’s pre-existing physical and mental health status, or psychosocial traits, could have on his/her social relationships (Thoits, 2011). While the theoretical framework and research questions guiding this work are based on the assumption that social support is influencing health outcomes, it should be noted that longitudinal research would be best suited to investigate causal directionality.

Spuriousness, on the other hand, is a challenge common to most social support and health research, and refers to ‘third factors’ that could affect both levels of social support and wellbeing, thus ‘explaining away’ observed positive or negative associations (House, Umberson, et al., 1988; Thoits, 2011). Examples of these include personality factors, such as optimism, pessimism, neuroticism and social competence. However, despite limitations represented by reverse causality and spuriousness, there is agreement among key authors that these phenomena cannot completely explain repeated – and in some cases longitudinal - observations of significant associations between social support, mortality and morbidity (Green, 1993; House, Umberson, et al., 1988; Thoits, 2011; Uchino, et al., 2012).

Lastly, the main limitation of the qualitative component, as for all qualitative research with small samples, is that the sample population cannot be considered representative of caregivers in this or other similar communities, and findings therefore have limited generalizability. However, as previously discussed, there are also advantages of having explored mediating processes explaining the support-health relationship qualitatively: it allowed for a more exploratory and grounded approach, through which new or more nuanced mechanisms, relevant to this specific community and population, would have been able to emerge. This speaks to recent calls, by key authors in the social support – health field, for greater openness to identifying and exploring new mediating variables (Uchino, et al., 2012).

9.5.3 Research strengths

It should be noted that this research also has a number of strengths. Some of these strengths derive from its links with the broader Young Carers project. A quantitative component of this dimension would not have been possible to achieve within the scope of

this doctoral research if it had not been linked to a broader health survey, given the resources, coordination and partnerships required to carry out similar large-scale survey research. The quantitative component of this doctoral research (n = 2477) represents the largest known study ever conducted in Southern Africa to quantitatively investigate the relationship between social support and caregiver mental and physical health. As highlighted by the systematic review findings (presented in Chapter 3), it is the first study conducted in Southern Africa to quantitatively assess the relationship between social support and health outcomes among HIV-positive caregivers of children. The ability to distinguish between HIV-positive, other ill and healthy caregivers adds additional value to this study and renders it the first known study in the world to conduct similar analysis with these comparison groups.

The positioning of this doctoral work within the broader national Young Carers study also allows for greater potential for findings to be used to inform further cross sectional analysis (for example, to link the findings of this work to child health outcomes), as well as policy and practice. As previously indicated, findings of relevance to governments, NGOs and other development agencies will be disseminated as part of the larger Young Carers utilisation plan, through various tools including policy briefs and presentations at stakeholder meeting. Given the existing partnerships with government departments and NGOs, the channels for using findings from this research to inform policy and practice are already open.

Finally, this study has the potential to make a unique contribution to the empirical and theoretical literature, as a result of its mixed methodology and focus on both effects and pathways explaining the relationship between social support and health. The opportunity to design the qualitative component after conducting preliminary quantitative analysis allowed the qualitative work to be in part informed by the quantitative work and to be used to further explain key quantitative findings. As is evident from the theoretical and empirical literature (described in Chapters 2, 3 and 4), linking potential mediating processes to observed

associations is currently of particular relevance to the field of social relations and health, given gaps in the understanding of pathways and processes explaining the support-health relationship.

9.6 Conclusion

Overall, findings of this study provide evidence of the important protective role of social support for the health of adult caregivers of children living in HIV-endemic South African communities, particularly for mental health. The quantitative findings with regard to symptomatic anxiety and self-reported mental health showed social support to be a general mental health resource for caregivers of children in the two researched communities, regardless of whether these caregivers were facing specific stressors related to HIV or other illness. Quantitative findings also suggest that social support may be a particularly important protective resource against depression, for caregivers of children living with chronic (non HIV-related) illness. This result is important to consider in the context of high risks for mental health among this sample and similar populations of caregivers, who are likely dealing with multiple stressors including illness, poverty and challenges linked to child caregiving. Moreover, these findings are relevant not only for caregiver health, but also for the health of children in their care, given the links between more parental social support and better parental health, and better child health and behavioural outcomes (Gay, 1995; Hough, et al., 2003; Reading, 2005).

The qualitative findings of this study suggest that multiple pathways and biopsychosocial mediating processes (House, Umberson, et al., 1988) may be explaining the

observed main and stress-buffering effects of social support on health among this sample of caregivers. The exploratory model diagram, developed to illustrate these findings (Figure 8.1), aims to contribute to the existing empirical gap on the pathways explaining positive health effects of support among populations of caregivers and HIV-affected individuals in Southern Africa. It may serve as a useful point of reference for future quantitative research in this area, conducted with similar populations.

To a large extent, the results of this research reinforce the broader empirical work on social support and health among HIV-positive and caregiver populations, conducted mainly in the developed world. However, they also provide a more in-depth and nuanced understanding of the dynamics explaining the support – health relationship in this specific population of caregivers.

This study has the potential to make a unique contribution to the empirical and theoretical literature in the field of social support and health. As previously indicated, it represents the first mixed methods research on social support and health with HIV-positive and HIV-negative individuals in the Southern African region. By employing quantitative and qualitative methods to explore both effects and processes explaining support-health associations among this particular population of caregivers of children in HIV-endemic South African communities, this research contributes to bridging the ‘first order questions’ (of whether there is a relationship between social support and health) with the ‘second order’ questions (of why and how these associations exist), referred to by various key authors in the field, for this particular population. As such, it furthers our general understanding of the relationship between social support and mental health among caregivers of children, as well as our specific understanding of these relationships in the context of HIV and illness. It can serve as a useful basis for future research with similar populations in this field.

Moreover, the findings of this mixed methods study have implications for policy and practice aimed at protecting caregiver and child health in Southern Africa. Overall, these findings expose the large scope for further research in the field of social support and health, with caregiver and/or HIV-affected populations, in the Southern African region. They point to the need for future focused quantitative social support research with representative caregiver populations, able to link support effects on health with hypothesised mediating processes. Findings of this study also suggest that the social support - health relationship may not be consistent for all groups of caregivers and all outcomes, but instead may differ based on characteristics such as illness status, gender and the type of health outcome investigated. Future research should seek to further explore these differences and the reasons behind them.

In Southern Africa, the HIV epidemic is having and will continue to have considerable health and broader social impacts on households, communities and social systems. In similar developing world contexts, where the availability and uptake of formal health services are often limited (Seedat, et al., 2009), 'informal' social resources, such as social support, may be of particular importance for caregiver and child wellbeing. It should not, however, be forgotten that providing support has a cost. The increasing dependence on family and community support, in the presence of HIV and difficult livelihood conditions, can place strain on communities and informal social networks, possibly weakening them or - in extreme cases - even leading to their collapse. Qualitative evidence from HIV-affected Southern African communities suggests that family and social networks in these communities are, in effect, taking strain (Belsey, 2005; Casale, 2011; The Joint Learning Initiative on Children and HIV/AIDS, 2008; Yamano, et al., 2006). This is particularly concerning for the wellbeing of children, given the central role that informal caregivers and families play in protecting children from the impact of HIV, and providing them with sustainable long-term assistance (The Joint Learning Initiative on Children and HIV/AIDS, 2008). Recent multi-

country research conducted in Southern Africa in fact exposes how the capacity of families to protect children is often fragile and highly dependent on the social context in which they find themselves (The Joint Learning Initiative on Children and HIV/AIDS, 2008).

A key focus for future research and practice should therefore be the development and evaluation of interventions aimed at boosting and protecting existing informal social networks and support, and increasing the availability and uptake of institutional support for caregivers and their families. Findings of this study suggest that greater attention should be paid to the social environment when designing and implementing mental health interventions (Prince, et al., 2007), and that social support could be a valuable component of health interventions working with ill and healthy caregivers.

However, in order to more effectively develop and evaluate social support interventions, it will be important to continue furthering our understanding of how the support that “naturally occurring” networks and relationships provide (or cease to provide) is able to positively affect health outcomes. This understanding is central to determining whether and how these naturally occurring supportive relationships may be replicated, incorporated within, or linked to formal health services and support. It would allow us to more effectively intervene to protect and strengthen informal and institutional support for caregivers and people living with HIV, as well as forge greater links between these two systems.

References

- Ahrons, C. (1979). The binuclear family: Two households, one family. *Alternative Lifestyles*, 2(4), 499-515.
- Ajrouch, K., Reisine, S., Lim, S., Sohn, W., & Ismail, A. (2010). Perceived everyday discrimination and psychological distress: Does social support matter? *Ethnicity & Health*, 15(4), 417-434.
- Akintola, O. (2006). Gendered home-based care in South Africa: More trouble for the troubled. *African Journal of AIDS Research*, 5(3), 237-247.
- Akintola, O. (2008). Defying all odds: Coping with the challenges of volunteer caregiving for patients with AIDS in South Africa. *Journal of Advanced Nursing*, 63(4), 357-365.
- Alfonso, V., Geller, J., Bermbach, N., Drummond, A., & Montaner, J. (2006). Becoming a 'treatment success'. What helps and what hinders patients from achieving and sustaining undetectable viral loads. *AIDS Patient Care & STDs*, 20(5), 326-334.
- Andrews, B., Brewin, C., & Rose, S. (2003). Gender, social support, and PTSD in victims of violent crime. *Journal of Traumatic Stress*, 16(4), 421-427.
- Andrews, S. (1995). Social support as a stress buffer among Human Immunodeficiency Virus-seropositive urban mothers. *Holistic Nursing Practice*, 10(1), 36-43.
- Antelman, G., Kaaya, S., Wei, R., Mbwambo, J., Msamanga, G., Fawzi, W., & Fawzi, M. (2007). Depressive symptoms increase risk of HIV disease progression and mortality among women in Tanzania. *Journal of Acquired Immune Deficiency Syndromes*, 44(4), 470-477.
- Antonucci, T. (1985). Personal characteristics, social support and social behavior. In R. Binstock & E. Shanas (Eds.), *Handbook of ageing and the social sciences* (2nd edition ed.). New York: Reinhold, V.
- Ashton, E., Vosvick, M., Chesney, M., Gore-Felton, C., Koopman, C., O'Shea, K., . . . Spiegel, D. (2005). Social support and maladaptive coping as predictors of the change in physical health symptoms among persons living with HIV/AIDS. *AIDS Patient Care & STDs*, 19(9), 587-598.
- Aspinwall, L., & Taylor, S. (1997). A stitch in time: Self-regulation and proactive coping. *Psychological Bulletin*, 121(3), 417-436.

- Atienza, A., Collins, R., & King, A. (2001). The mediating effects of situational control on social support and mood following a stressor: A prospective study of dementia caregivers in their natural environments. *Journal of Gerontology, 56B*(3), S129-S139.
- Atkins, J., Rubenstein, S., Sota, T., Rueda, S., Fenta, H., Bacon, J., & Rourke, S. (2010). Impact of social support on cognitive symptom burden in HIV/AIDS. *AIDS Care, 22*(7), 793-802.
- Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research, 1*(3), 385-405.
- Bachman DeSilva, M., Beard, J., Cakwe, M., McCoy, K., Nkosi, B., Parikh, A., . . . Simon, J. (2008). Vulnerability of orphan caregivers versus non-orphan caregivers in KwaZulu-Natal. *Vulnerable Children and Youth Studies, 3*(2), 102-111.
- Bakasa, R. (2007). *Stress, coping, social support and physical and mental health among family caregivers of HIV/AIDS patients in Zimbabwe*. Case Western Reserve University, Cleveland, USA.
- Barbee, A., Derlega, V., Sherburne, S., & Grimshaw, A. (1998). Helpful and unhelpful forms of social support for HIV-positive individuals. In V. Derlega & A. Barbee (Eds.), *HIV and social interaction* (pp. 83-105). Thousand Oaks, CA: Sage.
- Barnard, K. (1989). *Difficult life circumstances (dlc)*. Seattle: NCAST Publications.
- Barnett, T., & Whiteside, A. (2006). *AIDS in the 21st century: Disease and globalisation*. London and New York: Palgrave-MacMillian.
- Barrera, M. (1981). Social support in the adjustment of pregnant adolescents: Assessment issues. In B. Gottlieb (Ed.), *Social networks and social support* (pp. 69-96). Newbury Park, CA: Sage.
- Barrera, M. (1986). Distinctions between social support concepts, measures and models. *American Journal of Community Psychology, 14*(4), 413-445.
- Bauman, L. (1997). The Multidimensional Social Support Inventory. *Unpublished manuscript*.
- Bauman, L., & Weiss, E. (1995). *Multidimensional Social Support Inventory: Revised*. Bronx, New York: Albert Einstein College of Medicine.
- Beck, A., Epstein, N., Brown, G., & Steer, R. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology, 56*(6), 893-897.
- Beck, A., & Steer, R. (1993). *Manual for the Beck Anxiety Inventory*. San Antonio, TX: Psychological Corporation.

- Beck, A., Ward, C., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 561-571.
- Beck, A., Weissman, A., Lester, D., & Trexler, L. (1974). The measurement of pessimism: The hopelessness scale. *Journal of Consulting and Clinical Psychology*, 42(6), 861-865.
- Becker, E., Kuo, C., Operario, D., Moshabela, M., & Cluver, L. (2013). Assessing adult-child concordance for an HIV/AIDS verbal diagnostic tool: agreement between adult and child reports on the HIV/AIDS status of adults caring for children in South Africa. Paper presented at the American Public Health Association 2013 Annual Meeting, Boston, USA.
- Belle, D. (1982). Social ties and social support. In D. Belle (Ed.), *Lives in stress: Women and depression* (pp. 133-144). Thousand Oaks, CA: Sage.
- Belsey, M. (2005). *AIDS and the family: Policy options for a crisis in family capital*. New York: United Nations.
- Belue, R., Schreiner, A., Taylor-Richardson, K., Murray-Kolb, L., & Beard, J. (2008). What matters most: An investigation of predictors of perceived stress among mothers in Khayelitsha. *Health Care for Women International*, 29(6), 638-648.
- Benitha, R., & Tikly, M. (2007). Functional disability and health-related quality of life in South Africans with rheumatoid arthritis and systemic lupus erythematosus. *Clinical Rheumatology*, 26(1), 24-29.
- Bennett, S., Perkins, S., Lane, K., Deer, M., Brater, D., & Murray, M. (2001). Social support and health-related quality of life in chronic heart failure patients. *Quality of Life Research*, 10(8), 671-682.
- Bennetts, A., Shaffer, N., Manopaiboon, C., Chaiyakul, P., Siriwasin, W., Mock, P., . . . Clark, L. (1999). Determinants of depression and HIV-related worry among HIV-positive women who have recently given birth, Bangkok, Thailand. *Social Science & Medicine*, 49, 737-749.
- Bentley, J., & Thacker, P. (2004). The influence of risk and monetary payment on the research participation decision making process. *Journal of Medical Ethics*, 30 (3), 293-298.
- Berelson, B. (1952). *Content analysis in communication research*. Glencoe, IL: Free Press.
- Berkman, L. (1995). The role of social relations in health promotion. *Psychosomatic Medicine*, 57, 245-254.

- Berkman, L., & Breslow, L. (1983). *Health and ways of living: The Alameda county study*. London: Oxford University Press.
- Berkman, L., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social intergration to health: Durkheim in the new millennium. *Social Science & Medicine*, *51*(6), 843-857.
- Berkman, L., Leo-Summers, L., & Horwitz, R. (1992). Emotional support and survival after myorcardial infaction: A prospective, population-based study of the elderly. *Annals of Internal Medicine*, *117*(12), 1003-1009.
- Berkman, L., & Syme, L. (1979). Social networks, host resistance and mortality: A nine year follow-up study of Alameda county residents. *American Journal of Epidemiology*, *109*(2), 187-204.
- Blaney, N., Goodkin, K., Morgan, R., Feaster, D., Millon, C., Szapocznik, J., & Eisdorfer, C. (1991). A stress-moderator model of distress in early HIV-1 infection: Concurrent analysis of life events, hardiness and social support. *Journal Of Psychosomatic Research*, *35* (2-3), 297-305.
- Blazer, D. (1982). Social support and mortality in an elderly community population. *American Journal of Epidemiology*, *115*(5), 684-694.
- Booyesen, F. (2001). The measurement of poverty. In D. Bradshaw & K. Steyn (Eds.), *Poverty and chronic diseases in South Africa, a technical report* (pp. 15-37): Medical Research Council and World Health Organization.
- Bozo, O., Anahar, S., Ates, G., & Etel, E. (2010). Effects of illness representation, perceived quality of information provided by the health-care professional, and perceived social support on depressive symptoms of the caregivers of children with leukemia. *Journal of Clinical Psychology in Medical Settings*, *17*(1), 23-30.
- Brandt, R. (2007). *Does HIV matter when you are poor and how? The impact of HIV/AIDS on the psychological adjustment of South African mothers in the era of HAART*. Doctoral thesis, University of Cape Town, Cape Town.
- Brandt, R. (2009). Putting mental health on the agenda for HIV + women: A review of evidence from Sub-Saharan Africa. *Women and Health*, *49*, 215-228.
- Brandt, R., Dawes, A., & Bray, R. (2006). Women coping with AIDS in Africa: Contributions of a contextually grounded research methodology. *Psychology, Health & Medicine*, *11*(4), 522 - 527.
- Brehaut, J., Kohen, D., Garner, R., Miller, A., Lack, L., Klassen, A., & Rosenbaum, P. (2009). Health among caregivers of children with health problems: Findings from a

- Canadian population-based study. *American Journal of Public Health*, 99(7), 1254-1262.
- Breuer, E., Myer, L., Struthers, H., & Joska, J. (2011). HIV/AIDS and mental health research in Sub-Saharan Africa: A systematic review. *African Journal of AIDS Research*, 10(2), 101-122.
- Broadhead, W., Berton, B., James, S., Wagner, E., & Schoenbach, V. (1983). The epidemiologic evidence for a relationship between social support and health *American Journal of Epidemiology*, 117(5), 521-537.
- Brown, B. (2007). Children's special health care needs, mothers' coping and social support, and maternal mental health. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 68(6-A), 2675.
- Burgess, R. (1982). The unstructured interview as a conversation. In R. Burgess (Ed.), *Field research: A source book and field manual*. London: Allen and Unwin.
- Burgoyne, R. (2005). Exploring direction of causation between social support and clinical outcome for HIV-positive adults in the context of highly active antiretroviral therapy. *AIDS Care*, 17(1), 111-124.
- Burns, M., Feaster, D., Mitrani, V., Ow, C., & Szapocznik, J. (2008). Stress processes in HIV-positive African American mothers: Moderating effects of drug abuse history. *Anxiety, Stress, & Coping*, 21(1), 95-116.
- Butler, L., & Nolen-Hoeksema, S. (1991). Responses to depression and their effects on the duration of depressive episodes. *Journal of Abnormal Psychology*, 100(4), 569-582.
- Butler, L., & Nolen-Hoeksema, S. (1994). Gender differences in responses to depressed mood in a college sample. *Sex Roles*, 30(5-6), 331-346.
- Buyondo, F., Batamwita, R., Featherstone, A., & Mills, J. (2011). Meeting the challenges of disability and HIV in east africa. *Acquired Immune Deficit Syndrome*, 57(3), 68-69.
- Campbell, C., & Foulis, C. (2004). Creating contexts for effective home-based care of people living with HIV/AIDS. *Curationis*, 27(3), 5-14.
- Campbell, C., Nair, Y., Maimane, S., & Sibiya, Z. (2008). Supporting people with AIDS and their carers in rural South Africa: Possibilities and challenges. *Health and Place*, 4(1), 507-518.
- Carter, R. (2006). Solutions for missing data in structural equation modeling. *Research & Practice in Assessment*, 1(1).
- Carver, C. (1997). You want to measure coping but your protocol's too long: Consider the Brief Coping. *International Journal of Behavioral Medicine*, 4(1), 92-100.

- Casale, M. (2011). ' I am living a peaceful life with my grandchildren. Nothing else.' Stories of adversity and 'resilience' of older women caring for children in the context of HIV/AIDS and other stressors. *Ageing and Society*, 31(8), 1265-1288.
- Casale, M., Drimie, S., Quinlan, T., & Ziervogel, G. (2009). Understanding vulnerability in Southern Africa: Comparative findings using a multiple-stressor approach in South Africa and Malawi. *Regional Environmental Change*, 10(2), 157-168.
- Casale, M., Flicker, S., & Nixon, S. (2011). Fieldwork challenges: Lessons learned from a north-south public health research partnership. *Health Promotion Practice*, 12(50), 734-743.
- Casale, M., Lane, T., Sello, L., Kuo, C., & Cluver, L. (2013). Conducting health survey research in a deep rural South African community: Challenges and adaptive strategies. *Health Research Policy and Systems*, 11(14), doi:10.1186/1478-4505-1111-1114.
- Casale, M., & Whiteside, A. (2006). *The impact of HIV/AIDS on poverty, inequality and economic growth*. IDRC Working Papers on Globalization, Growth and Poverty Working. International Development Research Centre.
- Cassel, J. (1976). The contribution of the social environment to host resistance. *American Journal of Epidemiology*, 104(2), 107-123.
- Catalan, J., Harding, R., Sibley, E., Clucas, C., Croome, N., & Sherr, L. (2011). HIV infection and mental health: Suicidal behavior - systematic review. *Psychology, Health & Medicine*, 16(5), 588-611.
- Catania, J., Turner, H., Choi, K., & Coates, T. (1992). Coping with death anxiety: Help-seeking and social support among gay men with various HIV diagnoses. *AIDS* 6(9), 999-1005.
- Centers for Disease Control and Prevention. (1992). *1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults*. Retrieved from the Centers for Disease Control and Prevention website: <http://www.cdc.gov/mmwr/preview/mmwrhtml/00018871.htm>
- Chazan, M. (2008). Seven 'deadly' assumptions: Unravelling the implications of HIV/AIDS among grandmothers in South Africa and beyond. *Ageing & Society*, 28 (7), 935-958.
- Chesney, M., Neilands, T., Chambers, D., Taylor, J., & Folkman, S. (2006). A validity and reliability study of the coping self-efficacy scale. *British Journal of Health Psychology*, 11 (3), 421-437.

- Cheung, C., & Bagley, C. (1998). Validating an American scale in Hong Kong: The Center for Epidemiological Studies Depression Scale (CES-D). *Journal of Psychology*, *132*(2), 169-186.
- Chouinard, M., & Robichaud-Ekstrand, S. (2007). Predictive value of the transtheoretical model to smoking cessation in hospitalized patients with cardiovascular disease. *European Journal of Preventive Cardiology*, *14*(1), 51-58.
- Ciesla, J., & Roberts, J. (2001). Meta-analysis of the relationship between HIV infection and risk for depressive disorders. *The American Journal of Psychiatry*, *158*(5), 725-730.
- Clingerman, E. (2004). Physical activity, social support, and health-related quality of life among persons with HIV disease. *Journal Of Community Health Nursing*, *21*(3), 179-197.
- Clucas, C., Sibley, E., Harding, R., Liu, L., Catalan, J., & Sherr, L. (2011). A systematic review of interventions for anxiety in people with HIV. *Psychology, Health & Medicine*, *16*(5), 528-547.
- Cluver, L., & Gardner, F. (2007). Risk and protective factors for psychological well-being of children orphaned by AIDS in Cape Town: A qualitative study of children and caregivers' perspectives *AIDS Care*, *19*(3), 318-325.
- Cluver, L., Gardner, F., & Operario, D. (2007). Psychological distress amongst AIDS-orphaned children in urban South Africa. *Journal of Child Psychology and Psychiatry*, *48*(8), 755-763.
- Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, *38*(5), 300-314.
- Cohen, M., Arad, S., Lorber, M., & Pollack, S. (2007). Psychological distress, life stressors, and social support in new immigrants with HIV. *Behavioral Medicine*, *33*(2), 45-54.
- Cohen, S., & Hoberman, H. (1983). Positive events and social supports as buffers of life change stress. *Journal of Applied Social Psychology*, *13*(2), 99-125.
- Cohen, S., & Janicki-Deverts, S. (2009). Can we improve our physical health by altering our social networks? *Perspectives on Psychological Science*, *4* (Special Issue), 375-378.
- Cohen, S., & Wills, T. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310-357.
- Cook, K. (1997). *Psychological distress and mediating variables in HIV-positive mothers of young children*. Doctoral thesis, California School of Professional Psychology, United States, California.

- Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons and evaluative criteria. *Qualitative Sociology*, 13(1), 3-21.
- Cox, L. (2002). Social support, medication compliance and HIV/AIDS. *Social Work in Health Care*, 35(1-2), 425-460.
- Creswell, J., Piano Clark, V., Gutmann, M., & Hanson, W. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddie (Eds), *Handbook on mixed methods in the behavioral and social sciences*. Thousand Oaks, CA: Sage.
- Crigger, N., Holcomb, L., & Weiss, J. (2001). Fundamentalism, multiculturalism and problems of conducting research with populations in developing nations. *Nursing Ethics*, 8(5), 459-468.
- Critchley, J., & Capewell, S. (2003). Mortality risk reduction associated with smoking cessation in patients with coronary heart disease: A systematic review. *JAMA*, 290(1), 86-97.
- Crosier, T., Butterworth, P., & Rodgers, B. (2007). Mental health problems among single and partnered mothers: The role of financial hardship and social support. *Social Psychiatry and Psychiatric Epidemiology*, 42(1), 6-13.
- Cruess, S., Antoni, M., Kilbourn, K., Ironson, G., Klimas, N., Fletcher, M., . . . Schneiderman, N. (2000). Optimism, distress, and immunologic status in HIV infected gay men following Hurricane Andrew. *International Journal of Behavioral Medicine*, 7(2), 160-182.
- CSIR. (2012). About Manguzi Retrieved from the Community Development Activities (CDA) website: <http://www.cda.co.za/Manguzi/Overview/About/About.html>
- Cutrona, C., & Russell, D. (1987). The provisions of social relationships and adaptation to stress. In W. Jones & D. Perlman (Eds.), *Advances in personal relationships* (pp. 36-67). Greenwich, CT: JAI Press.
- D'Arcy, C., & Siddique, C. (1984). Social support and mental health among mothers of preschool and school age children. *Social Psychiatry* 19(4), 155-162.
- Davies, S., Hortona, T., Williams, A., Martin, M., & Stewart, K. (2009). MOMS: Formative evaluation and subsequent intervention for mothers living with HIV. *AIDS Care* 21(5), 552-560.
- Delongis, A., Folkman, S., & Lazarus, R. (1988). The impact of daily stress on health and mood: Psychological and social resources as mediators. *Journal of Personality and Social Psychology*, 54(3), 486-495.

- Demmer, C. (2011). Experience of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: An exploratory study. *AIDS Care*, 23(7), 873-879.
- Department of Health. (2003). The South African demographic and health survey. Retrieved from the South African Department of Health's website: <http://www.doh.gov.za/facts/sadhs2003/main.html>
- Department of Health. (2007). South Africa demographic and health survey 2003 (pp. 258-297). Pretoria: Department of Health.
- Department of Health. (2008). The national HIV and syphilis prevalence survey South Africa: Department of Health.
- Derlega, V., Winstead, B., Oldfield, E., & Barbee, A. (2003). Close relationships and social support in coping with HIV: A test of sensitive interaction systems theory. *AIDS & Behavior*, 7(2), 119-129.
- Derogatis, L. (1993). *Brief symptom inventory: Administration, scoring, and procedures manual*. Minneapolis, MN: National Computer Systems.
- Derogatis, L., & Spencer, P. (1982). The Brief Symptom Inventory (BSI) administration, scoring & procedures manual - i. *Clinical Psychometric Research*.
- Dignam, J., Barrera, M., & West, S. (1986). Occupational stress, social support, and burnout among correctional officers. *American Journal of Community Psychology*, 14(2), 117-193.
- DiMatteo, M. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology*, 23(2), 207-218.
- Dohrenwend, B., Shrout, P., Egri, G., & Mendelsohn, F. (1980). Nonspecific psychological distress and other dimensions of psychopathology: Measures for use in the general population. *Archives of General Psychiatry*, 37(11), 1229-1236.
- Dohrenwend, B. S., Krasnoff, L., Ashehasy, A., & Dohrenwend, B. P. (1978). Exemplification of a method for scaling life events: The Peri Life Events Scale. *Journal of Health and Social Behavior*, 19(2), 205-229.
- Donlou, J., Wolcott, D., Gottlieb, m., & Landverk, J. (1985). Psychosocial aspects of AIDS and AIDS-related complex: A pilot study. *Journal of Psychosocial Oncology*, 3, 39-55.
- Drimie, S., & Casale, M. (2009). Multiple stressors in Southern Africa: The link between HIV/AIDS, food insecurity, poverty and children's vulnerability now and in the future. *AIDS Care*, 21(S1), 28-33.

- Dunkel-Schetter, C., Folkman, S., & Lazarus, R. (1987). Correlates of social support receipt. *Journal of Personality and Social Psychology*, 53(1), 71-80.
- Durkheim, E. (1951). *Suicide*. New York: Free Press.
- Eaton, L., Flisher, A., & Aaro, L. (2003). Unsafe sexual behaviour in South African youth. *Social Science & Medicine*, 56(1), 149.
- Edwards, L. (2006). Perceived social support and HIV/AIDS medication adherence among African American women. *Qualitative Health Research*, 16(5), 679-691.
- Eller, L., Bunch, E., Wantland, D., Portillo, C., Reynolds, N., Nokes, K., . . . Tsai, Y. (2010). Prevalence, correlates, and self-management of HIV-related depressive symptoms. *AIDS Care*, 22(9), 1159-1170.
- Emmons, K., Barbeau, E., Gutheil, C., Stryker, J., & Stoddard, A. (2007). Social influences, social context and health behaviours among working class, multiethnic adults. *Health Education & Behavior*, 34, 315-334.
- Ertel, K., Glymour, M., & Berkman, L. (2010). Social networks and health: A life course perspective integrating observational and experimental evidence. *Journal of Social and Personal Relationships*, 26(1), 73-92.
- Fasce, N. (2008). Depression and social support among men and women living with HIV. *Journal of Applied Biobehavioral Research*, 12(3-4), 221-236.
- Feaster, D., Brincks, A., Mitrani, V., Prado, G., Schwartz, S., & Szapocznik, J. (2011). The efficacy of structural ecosystems therapy for HIV medication adherence with African American women. *Journal of Family Psychology*, 24(1), 51-59.
- Filmer, D., & Pritchett, L. (2001). Estimating wealth effects without expenditure data-or tears: An application to educational enrollments in states of India. *Demography*, 38(1), 115-132.
- Folkman, S., Chesney, M., Pollack, L., & Coates, T. (1993). Stress, control, coping and depressive mood in Human Immunodeficiency Virus-positive and -negative gay men in San Francisco. *Journal of Nervous and Mental Disease*, 181(7), 409-416.
- Folkman, S., & Lazarus, R. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 21, 219-239.
- Folkman, S., & Lazarus, R. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology*, 48(1), 150-170.

- Folkman, S., Lazarus, R., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping and encounter outcomes. *Journal of Personality and Social Psychology*, 50(5), 992-1003.
- Folkman, S., & Moskowitz, J. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55, 745-774.
- Franks, M., Stephens, M., Rook, K., Franklin, B., Keteyian, S., & Artinian, N. (2006). Spouses' provision of health-related support and control to patients participating in cardiac rehabilitation. *Journal of Family Psychology*, 20(2), 311-318.
- Freeman, M., & Nkomo, N. (2006). Guardianship of orphans and vulnerable children. A survey of current and perspective South African caregivers *AIDS Care*, 18(4), 302-310.
- Fukunishi, I., Hosaka, T., Negishi, M., Moriya, H., Hayashi, M., & Matsumoto, T. (1997). Avoidance coping behaviors and low social support are related to depressive symptoms in HIV-positive patients in Japan. *Psychosomatics*, 38(2), 113-118.
- Futterman, D., Shea, J., Besser, M., Stafford, S., Desmond, K., Comulada, W., & Greco, E. (2010). Mamekhaya: A pilot study combining a cognitive-behavioral intervention and mentor mothers with PMTCT services in South Africa. *AIDS Care*, 22(9), 1093-1100.
- Gaede, B. M., Majeke, S. J., Modetse, R. R. M., Naidoo, J. R., Titus, M. J., & Uys, L. R. (2006). Social support and health behaviour in women living with HIV in kwaZulu-Natal. *Journal of Social Aspects of HIV/AIDS*, 3(1), 326-368.
- Gay, C. (1995). *Psychological distress among mothers infected with HIV: A risk and resistance model*. Doctoral degree, University of Miami, Miami, U.S.A.
- Gerard, J., Landry-Meyer, L., & Guzell Roe, J. (2006). Grandparents raising grandchildren: The role of social support in coping with caregiving challenges. *International Journal of Aging and Human Development*, 62(4), 359-383.
- Gibbie, T., Mijch, A., Ellen, S., Hoy, J., Hutchison, C., Wright, E., . . . Judd, F. (2006). Depression and neurocognitive performance in individuals with HIV/AIDS: 2-year follow-up. *HIV Medicine*, 7(2), 112-121.
- Gillespie, N. (2004). Review: Mothers with HIV infection worked hard to protect their children and preserve a positive maternal identity. *Evidence-Based Nursing* 7(3), 90.
- Gjesfjeld, C. (2009). Economic hardship, social support, and maternal depression: A test of the social support deterioration model. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 69(7-A), 2876.

- Grady, C. (2001). Money for research participation: Does it jeopardize informed consent? *The American Journal of Bioethics*, 1(2), 40-44.
- Grant, R., & Sugarman, J. (2004). Ethics in human subjects research: Do incentives matter? *Journal of Medicine and Philosophy*, 29(6), 717-738.
- Green, G. (1993). Social support and HIV. *AIDS Care*, 5(1).
- Green, J., Caracelli, V., & Graham, W. (1989). Toward a conceptual framework for mixed method evaluation designs. *Educational Evaluation and Policy Analysis* 11 (3): 255-274.
- Haber, M., Cohen, J., Lucas, T., & Batles, B. (2007). The relationship between self-reported received and perceived social support: A meta-analytic review. *American Journal of Community Psychology*, 39(1-2), 133-144.
- Hackl, K., Somlai, A., Kelly, J., & Kalichman, S. (1997). Women living with HIV/AIDS: The dual challenge of being a patient and caregiver. *Health & Social Work*, 22(1), 53-62.
- Hallman, K. (2004). Socioeconomic disadvantage and unsafe sexual behaviors among young women and men in South Africa. New York: The Population Council.
- Hamad, R., Fernald, L., Karlan, D., & Zinman, J. (2008). Social and economic correlates of depressive symptoms and perceived stress in South African adults. *Journal of Epidemiology and Community Health*, 62, 538-544.
- Hamilton, M. (1960). A rating scale for depression. *Journal of Neurology, Neurosurgery and Psychiatry*, 23, 56-62.
- Hanna, L., Hunt, S., & Bhopal, R. (2008). Insights from research on cross-cultural validation of health-related questionnaires: The role of bilingual project workers and lay participants. *Current Sociology*, 56 (1), 115-131.
- Hansell, P., Hughes, C., Caliandro, G., & Russo, P. (1999). Boosting social support in caregivers of children with HIV/AIDS. *AIDS Patient Care & STDs* 13(5), 297.
- Harrell, S. (1994). *The urban life stress scale - revised*. Unpublished Instrument.
- Hart, G., Fitzpatrick, R., McLean, J., Dawson, J., & Boulton, M. (1990). Gay men, social support and HIV disease: A study of social integration in the gay community. *AIDS Care*, 2(2), 163-170.
- Hawkey, L., Bosch, J., Engeland, C., Marucha, P., & Cacioppo, J. (2007). Loneliness, dysphoria, stress, and immunity: A role for cytokines. In N. Plotnikoff, R. Faith, A. Murgo & R. Good (Eds.), *Cytokines, stress and immunity, second edition* (pp. 67-85). Boca Raton, FL: CRC Press

- Hawkey, L., Thisted, R., & Cacioppo, J. (2009). Loneliness predicts reduced physical activity: Cross-sectional & longitudinal analyses. *Health Psychology, 28*(3), 354-363.
- Health Systems Trust. (2006). South African health review 2006. Retrieved from the Health Systems Trust website: http://www.hst.org.za/publications/item.php?item_id=697
- Heaney, C., & Israel, B. (1997). Social networks and social support. In K. Glanz, F. Lewis & B. Rimer (Eds.), *Health behaviour and health education* (pp. 179-205). San Francisco, CA: Jossey-Bass.
- Hein, K., Dell, R., Futterman, D., & Shaffer, N. (1995). Comparison of HIV+ and HIV- adolescents: Risk factors and psychosocial determinants. *Pediatrics, 95*(1), 96-104.
- Hejoaka, F. (2009). Care and secrecy: Being a mother of children living with HIV in Burkina Faso. *Social Science & Medicine, 69*(6), 869-876.
- Herman, A., Stein, D., Seedat, S., Heeringa, S., Moomal, H., & Williams, D. (2009). The South African Stress and Health (SASH) study: 12-month and lifetime prevalence of common mental disorders. *South African Medical Journal, 99*(5), 339-344.
- Hlabyago, K., & Ogunbanjo, G. (2009). The experiences of family caregivers concerning their care of HIV/AIDS orphans. *South African Family Practice, 51*(6), 506-511.
- Hobfoll, S., Dunahoo, C., Ben-Porath, Y., & Monnier, J. (1994). Gender and coping: The dual-axis model of coping. *American Journal of Community Psychology, 22*(1), 49-82.
- Holman, C., English, D., Milne, E., & Winter, M. (1996). Meta-analysis of alcohol and all-cause mortality: A validation of NHMRC recommendations. *Medical Journal of Australia, 164*(3), 141-145.
- Holmbeck, G. (1997). Toward terminological, conceptual, and statistical clarity in the study of mediators and moderators: Examples from the child-clinical and pediatric psychology literatures. *Journal of Consulting and Clinical Psychology, 65*(4), 599-610.
- Holt-Lanstad, J., Smith, T., & Layton, B. (2010). Social relationships and mortality: A meta-analysis. *Plos Medicine, 7*(e1000316), doi: 10.1371/journal.pmed.1000316.
- Hosegood, V., Vannestea, A., & Timæus, I. (2004). Levels and causes of adult mortality in rural South Africa: The impact of AIDS. *AIDS, 18*(4), 663-671.
- Hough, E., Brumitt, G., Templin, T., Saltz, E., & Mood, D. (2003). A model of mother-child coping and adjustment to HIV. *Social Science & Medicine, 56*(2003), 643-655.
- House, J. (1981). *Work, stress and social support*. Reading, MA: Addison Wesley.

- House, J., & Khan, R. (1985). Measures and concepts of social support. In S. Cohen & S. Syme (Eds.), *Social support and health*. Orlando: Academic Press.
- House, J., Landis, K., & Umberson, D. (1988). Social relationships and health. *Science*, *241*(4865), 540-545.
- House, J., Robbins, C., & Metzner, H. (1982). The association of social relationships and activities with mortality: Prospective evidence from the Tecumseh. *American Journal of Epidemiology*, *116*(1), 123-140.
- House, J., Umberson, D., & Landis, K. (1988). Structures and processes of social support. *Annual Review of Sociology*, *14*, 293-318.
- Howard, B., Phillips, C., Matinhure, N., Goodman, K., McCurdy, S., & Johnson, C. (2006). Barriers and incentives to orphan care in a time of AIDS and economic crisis: A cross-sectional survey of caregivers in rural Zimbabwe. *BMC Public Health*, *6*(27), doi:10.1186/1471-2458-1186-1127.
- Hudson, A., Kathryn, L., Miramontes, H., & Portillo, C. (2001). Social interactions, perceived support, and level of distress in HIV-positive women. *Journal of the Association of Nurses in AIDS Care*, *12*(4), 68-76.
- Hughes, J., Jelsma, J., Maclean, E., Darder, M., & Tinise, X. (2004). The health-related quality of life of people living with HIV/AIDS. *Disability and Rehabilitation*, *26*(6), 371-376.
- Ice, G., Zidron, A., & Juma, E. (2008). Health and health perceptions amongst Kenyan grandmothers. *Journal of Cross-Cultural Gerontology*, *23*(2), 111-129.
- Ickovics, J., Hamburger, M., Vlahov, D., Schoenbaum, E., Schuman, P., Boland, R., & Moore, J. (2001). Mortality, CD4 cell count decline, and depressive symptoms among HIV-seropositive women: Longitudinal analysis from the HIV epidemiology research study. *JAMA*, *285*(11), 1466-1474.
- Ilfeld, F. (1976). Further validation of a psychiatric symptom index in a normal population. *Psychological Reports*, *39*(2), 1215-1228.
- Ingram, K., Jones, D., Fass, R., Neidig, J., & Song, Y. (1999). Social support and unsupportive social interactions: Their association with depression among people living with HIV. *AIDS Care*, *11*(3), 313-329.
- Ivankova, N., Creswell, J., & Stick, S. (2006). Using mixed-methods sequential explanatory design: From theory to practice. *Field Methods*, *18*(1), 3-20.
- Jain, S., & Jadhav, S. (2009). Pills that swallow policy: Clinical ethnography of a community mental health program in northern India. *Transcultural Psychiatry*, *46*(1), 60-85.

- Jessop, D., Riessman, C., & Stein, R. (1988). Chronic childhood illness and maternal mental health. *Journal of Developmental and Behavioral Pediatrics*, 9(3), 147-156.
- Jia, H., Uphold, C., Wu, S., Reid, K., Findley, K., & Duncan, P. (2004). Health-related quality of life among men with HIV infection: Effects of social support, coping, and depression. *AIDS Patient Care And STDs*, 18(10), 594-603.
- Joslin, D., & Harrison, R. (1998). The "hidden patient": Older relatives raising children orphaned by AIDS. *Journal of the American Medical Women's Association*, 53(2), 65-71.
- Joslin, D., & Harrison, R. (2002). Self-reported physical health among older surrogate parents to children orphaned and affected by HIV disease. *AIDS Care*, 14(5), 619-624.
- Kagee, A. (2008). Symptoms of depression and anxiety among a sample of South African patients living with a chronic illness. *Journal of Health Psychology* 13(4), 541-549.
- Kaharuza, F., Bunnell, R., Moss, S., Purcell, D., Bikaako-Kajura, W., Wamai, N., . . . Mermin, J. (2006). Depression and CD4 cell count among persons with HIV infection in Uganda. *AIDS*, 10 (4 Suppl), S105-S111.
- Kahn, K., Tollman, S., Garenne, M., & Gear, J. (2000). Validation and application of verbal autopsies in a rural area of South Africa. *Tropical Medicine & International Health*, 5(11), 824-831.
- Kamya, H., & Poindexter, C. (2009). Mama Jaja: The stresses and strengths of HIV-affected Ugandan grandmothers. *Social Work in Public Health* 24(1), 4-21.
- Kaplan-Solms, K., & Solms, M. (2000). *Clinical studies in neuro-psychoanalysis*. London: Karnac.
- Kaplan, B., Cassel, J., & Gore, S. (1977). Social support and health. *Medical Care*, 15(5 Suppl), 47-58.
- Katzmarzyk, P., Janssen, I., & Ardern, C. (2003). Physical inactivity, excess adiposity and premature mortality. *Obesity Reviews*, 4, 257-290.
- Kawachi, I., & Berkman, L. (2001). Social ties and mental health. *Journal of Urban Health*, 78(3), 458-467.
- Kessler, R., & McLeod, J. (1985). Social support and mental health in community surveys. In S. Cohen & S. Syme (Eds.), *Social support and health*. Orlando: Academic Press.
- Kiggundu, E., & Oldewage-Theron, W. (2009). Coping: A challenge for guardians of children orphaned by HIV/AIDS in a South African township. *Development Southern Africa*, 26(3), 383-397.

- Kimuna, S., & Makiwane, M. (2007). Older people as resources in South Africa: Mpumalanga households. *Journal of aging & social policy, 19* (1), 97-114.
- Kipp, W., Matukala Nkosi, T., Laing, L., & Jhangri, G. (2006). Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasha, Democratic Republic of Congo. *AIDS Care, 18*(7), 694-697.
- Klein, K., Armistead, L., Devine, D., B, K., Forehand, R., Morse, E., . . . Clark, L. (2000). Socioemotional support in African American families coping with maternal HIV: An examination of mothers' and children's psychosocial adjustment. *Behavior Therapy, 31*(1), 1-26.
- Kohl, A., Rief, W., & Glombiewski, J. (2013). Acceptance, cognitive restructuring, and distraction as coping strategies for acute pain. *The Journal of Pain, 14*(3), 305-315.
- Krause, N. (1987). Life stress, social support, and self-esteem in an elderly population. *Psychology and Aging, 2*(4), 349-356.
- Kuo, C. (2010). *Health impacts amongst carers of orphans and other children in a high HIV prevalence community in South Africa*. Doctoral dissertation, University of Oxford, Oxford.
- Kuo, C., & Operario, D. (2009). Caring for AIDS-orphaned children: A systematic review of studies on caregivers. *Vulnerable Children and Youth Studies, 4*(1), 1-12.
- Kuo, C., & Operario, D. (2011). Health of adults caring for orphaned children in an HIV endemic community in South Africa. *AIDS Care, 23*(9), 1128-1135.
- Kuster, P., & Merkle, C. (2004). Caregiving stress, immune function, and health: Implications for research with parents of medically fragile children. *Issues in Comprehensive Pediatric Nursing, 27*(4), 257-276.
- KwaZulu-Natal Department of Health. (2011). Manguzi hospital. Retrieved 02/07/2011, 2011, from <http://www.kznhealth.gov.za/manguzi/demographic.htm>
- Lakey, B., & Cohen, S. (2000). Social support theory and measurement. In S. Cohen, L. Underwood & B. Gottlieb (Eds.), *Social support measurement and intervention: A guide for health and social scientists* (pp. 29-52). New York: Oxford University Press.
- Lakey, B., & Cronin, A. (2008). Low social support and major depression: Research, theory and methodological issues. In K. Dobson & D. Dozois (Eds.), *Risk factors for depression* (pp. 385-408). San Diego, CA: Academic Press.

- Lahey, B., & Orehek, E. (2011). Relational regulation theory: A new approach to explain the link between perceived social support and mental health. *Psychological Review*, doi: 10.1037/a0023477.
- Lara, M., Leader, J., Klein, D., & Kendler, K., 14(12), 6-7. (1998). What is social support? *Harvard Mental Health Letter*, 14(12), 6-7.
- Launer, J. (2005). Anna o and the 'talking cure'. *QJM: An International Journal of Medicine* 98(6), 465-466.
- Lazarus, R. (1966). *Psychological stress and the coping process*. New York McGraw-Hill.
- Lazarus, R., Averill, J., & Opton, E. (1974). The psychology of coping: Issues of research and assessment. In G. Coelho, D. Hamburg & J. Adams (Eds.), *Coping and adaptation*. New York: Basic Books.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Leder, S., Grinstead, L., & Torres, E. (2007). Stressors, social support and health outcomes. *Journal of Family Nursing*, 13(3), 333-352.
- Lee, M., & Fielding, N. (1996). *Qualitative data analysis: Representations of a technology: A comment on coffey, holbrook and atkinson*. Retrieved from the Sociological Research Online website: www.socresonline.org.uk/socresonline/1/4/1.html.
- Leserman, J. (2003). HIV disease progression: Depression, stress, and possible mechanisms. *Biological Psychiatry*, 54(3), 295-306.
- Leserman, J., Jackson, E., Petitto, J., Golden, R., Silva, S., Perkins, D., . . . Evans, D. (1999). Progression to AIDS: The effects of stress, depressive symptoms, and social support. *Psychosomatic Medicine*, 61(3), 397-406.
- Leslie, M., Stein, J., & Rotheram-Borus, M. (2002). The impact of coping strategies, personal relationships, and emotional distress on health-related outcomes of parents living with HIV or AIDS. *Journal of Social and Personal Relationships*, 19(1), 45-66.
- Li, L., Seltzer, M., & Greenberg, J. (1997). Social support and depressive symptoms: Differential patterns in wife and daughter caregivers. *Journals of Gerontology Series B, Psychological Sciences and Social Sciences*, 52(4), S200-211.
- Li, L., Sung-Jae, L., Thammawijaya, P., Jiraphongsa, C., & Rotheram-Borus, M. (2009). Stigma, social support, and depression among people living with HIV in Thailand. *AIDS Care*, 21(8), 1007-1013.
- Lindsey, M., Browne, D., Thompson, R., Hawley, K., Graham, J., Weisbart, C., . . . Kotch, J. (2008). Caregiver mental health, neighborhood, and social network influences on

- mental health needs among African American children. *Social Network Research*, 32(2), 29-88.
- Linn, J., Lewis, F., Cain, V., & Kimbrough, G. (1993). HIV-illness, social support, sense of coherence, and psychosocial well-being in a sample of help-seeking adults. *AIDS Education and Prevention*, 5(3), 254-262.
- Linn, J., Poku, K., Cain, V., Holzapfel, K., & Crawford, D. (1995). Psychosocial outcomes of HIV illness in male and female African American clients. *Social Work in Health Care*, 21(3), 43-60.
- Linsk, N., & Mason, S. (2004). Stresses on grandparents and other relatives caring for children affected by HIV/AIDS. *Health and Social Work*, 29(2), 127-136.
- Lopman, B., Barnabas, R., Boerma, J., Chawira, G., Gaitskell, K., Harrop, T., . . . Gregson, S. (2006). Creating and validating an algorithm to measure AIDS mortality in the adult population using verbal autopsy. *PLoS Medicine*, 3(8), e312. DOI:310.1371/journal.pmed.0030312.
- Luszczynska, A., Sarkar, Y., & Knoll, N. (2007). Received social support, self-efficacy, and finding benefits in disease as predictors of physical functioning and adherence to antiretroviral therapy. *Patient Education And Counseling*, 66(1), 37-42.
- Lv, Y., Zhao, Q., Li, X., Stanton, B., Fang, X., Lin, X., . . . Zhao, J. (2010). Depression symptoms among caregivers of children in HIV affected families in rural China. *AIDS Care*, 22(6), 669-676.
- Lynch, J. (1979). *The broken heart*. New York: Basic Books.
- Madavahnu, D., Segalo, P., & Fourie, E. (2008). Grandmothers caring for their grandchildren orphaned by HIV and AIDS. *New Voices in Psychology*, 4(1), 76-97.
- Makhatini, M. (2009). Lamontville Retrieved from the eThekweni Municipality website: <http://www.durban.gov.za/durban/discover/history/our-town/lamontville>
- Mapstudio. (2009). Map of Lamontville [Demographic map]. Retrieved from: <http://www.mapstudio.co.za/locationmap.php?loc=Lamontville>
- Martinez, A., Israelski, D., Walker, C., & Koopman, C. (2003). Post-traumatic stress disorder in women attending Human Immunodeficiency Virus outpatient clinics. *AIDS Patient Care and STDs*, 16(6), 283-291.
- Mason, J. (Ed.). (2002). *Qualitative researching*. 2nd edition. London: Sage.
- Mason, S., & Vazquez, D. (2007). Making positive changes: A psychoeducation group for parents with HIV/AIDS. *Social Work With Groups*, 30(2), 27-40.

- Mathee, A., Harpham, T., Naicker, N., Barnes, B., Plagerson, S., Feit, M., . . . Naidoo, S. (2010). Overcoming fieldwork challenges in urban health research in developing countries: A research note. *International Journal of Social Research Methodology*, *13*(2), 171-178.
- May, J., Carter, M., Haddad, L., & Maluccio, J. (1999). *KwaZulu-Natal Income Dynamics Study (KIDS) 1993-1998: A longitudinal household data set for South African policy analysis* (Working Paper No. 21). Durban: School of Development Studies, University of Kwazulu-Natal.
- McDowell, T., & Serovich, J. (2007). The effect of perceived and actual social support on the mental health of HIV-positive persons. *AIDS Care*, *19*(10), 1223-1229
- McInerney, P., Ncama, B., Wantland, D., Bhengu, B., McGibbon, C., Davis, S., . . . Nicholas, P. (2008). Quality of life and physical functioning in HIV-infected individuals receiving antiretroviral therapy in KwaZulu-Natal, South Africa. *Nursing & Health Sciences* *10*(4), 266-272.
- McNair, D., & Lorr, M. (1964). An analysis of mood in neurotics. *Journal of Abnormal Social Psychology*, *69*(6), 620-627.
- Mead, G. (1934). *Mind, self and society*. Chicago: University of Chicago Press.
- Meadows, S. (2011). The association between perceptions of social support and maternal mental health: A cumulative perspective. *Journal of Family Issues*, *32*(2), 181-208.
- Mellings, T., & Alden, L. (2000). Cognitive processes in social anxiety: The effects of self-focus, rumination and anticipatory processing. *Behaviour Research and Therapy*, *38*(3), 243-257.
- Mellins, C., & Ehrhardt, A. (1994). Families affected by pediatric Acquired Immunodeficiency Syndrome: Sources of stress and coping. *Developmental and Behavioral Pediatrics*, *15*(3), S54-S60.
- Mellins, C., Ehrhardt, A., & Grant, W. (1997). Psychiatric symptomatology and psychological functioning in HIV-infected mothers. *AIDS & Behavior*, *1*(4), 233-245.
- Mellins, C., Ehrhardt, A., Rapkin, B., & Havens, J. (2000). Psychosocial factors associated with adaptation in HIV-infected mothers. *AIDS and Behavior*, *4*(4 Health Module), 317-328.
- Mellins, C., Kang, E., Leu, C., Havens, J., & Chesney, M. (2003). Longitudinal study of mental health and psychosocial predictors of medical treatment adherence in mothers living with HIV disease. *AIDS Patient Care & STDs*, *17*(8), 407-416.

- Miles, M. (1995). Psychometric properties of the child health worry scale. *Unpublished manuscript*.
- Miles, M., & Huberman, A. (1984). Drawing valid meaning from qualitative data: Toward a shared craft. *Educational Researcher, 13*(5), 20-30.
- Mitrani, V., McCabe, B., Robinson, C., Weiss-Laxer, N., & Feaster, D. (2010). Structural ecosystems therapy for recovering HIV-positive women: Child, mother and parenting outcomes. *Journal of Family Psychology, 24*(6), 746-755.
- Molteno, C., & Lachman, P. (1996). Stress in mothers of handicapped children. *Southern African Journal of Child and Adolescent Mental Health, 8*(1), 13-20.
- Moneyham, L., Hennessy, M., Sowell, R., Demi, A., Seals, B., & Mizuno, Y. (1998). The effectiveness of coping strategies used by HIV-seropositive women. *Research in Nursing & Health, 21*(4), 351-362.
- Montgomery, M., Gragnotati, M., Burke, K., & Paredes, E. (2000). Measuring living standards with proxy variables. *Demography, 37*(2).
- Moroka, T. (2005). Family economic pressure and health outcomes in low-income Francistown, Botswana: The reverse buffering role of social support. *Journal of Social Development in Africa, 20*(1), 106-127.
- Morse, E., Simon, P., Forehand, R., Armistead, L., Clark, L., & Stock, M. (1993). The descriptive interview. *Unpublished questionnaire*.
- Mudavanhu, D., Segalo, P., & Fourie, E. (2008). Grandmothers caring for their grandchildren orphaned by HIV and AIDS. *New Voices in Psychology, 4*(1), 76-97.
- Mundell, J., Visser, M., Makin, J., Kershaw, T., Forsyth, B., Jeffery, B., & Sikkema, K. (2011). The impact of structured support groups for pregnant South African women recently diagnosed HIV positive. *Women Health, 51*(6), 546-565.
- Murphy, D., Greenwell, L., Mouttapa, M., Brecht, M., & Schuster, M. (2006). Physical health of mothers with HIV/AIDS and the mental health of their children. *Journal Of Developmental And Behavioral Pediatrics, 27*(5), 386-395.
- Murphy, D., Marelich, W., Dello Stritto, M., Swendeman, D., & Witkin, A. (2002). Mothers living with HIV/AIDS: Mental, physical, and family functioning. *AIDS Care, 14*(5), 633-644.
- Murphy, D., Steers, W., & Dello Stritto, M. (2001). Maternal disclosure of HIV serostatus to their young children. *Journal of Family Psychology, 15*(3), 441-450.

- Murphy, L., Koranyi, K., Crim, L., & Whited, S. (1999). Disclosure, stress and psychological adjustment among mothers affected by HIV. *AIDS Patient Care And STDs*, 13(2), 111-118.
- Murphy, N., Christian, B., Caplin, D., & Young, P. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*, 33(2), 180-187.
- Musil, C., Warner, C., Zauszniewski, J., Wykle, M., & Standing, T. (2009). Grandmother caregiving, family stress and strain, and depressive symptoms. *Western Journal of Nursing Research*, 31(3), 389-408.
- Myer, L., Smit, J., Le Roux, L., Parker, S., Stein, D., & Seedat, D. (2008). Common mental disorders among HIV-infected individuals in South Africa: Prevalence, predictors, and validation of brief psychiatric rating scales. *AIDS Patient Care and STDs*, 22(2), 147-158.
- Myezwa, H., Buchalla, C., Jelsma, J., & Stewart, A. (2011). HIV/AIDS: Use of the ICF in Brazil and South Africa - comparative data from four cross-sectional studies. *Physiotherapy*, 97(1), 17-25.
- Myezwa, H., Stewart, A., Musenge, E., & Nesara, P. (2009). Assessment of HIV-positive in-patients using the international classification of functioning, disability and health (ICF), at Chris Hani Baragwanath Hospital, Johannesburg. *African Journal of AIDS Research* 8(1), 93-106.
- Namir, S., Alumbaugh, M., Fawzy, F., & Wolcott, D. (1989). The relationship of social support to physical and psychological aspects of AIDS. *Psychology and Health*, 3(2), 77-86.
- Namir, S., Wolcott, D., & Fawzy, F. (1989). Social support and HIV spectrum disease: Clinical research perspectives. *Psychiatric Medicine*, 7(2), 97-105.
- Namir, S., Woolcott, D., Fawzy, F., & Alumbaugh, M. (1987). Coping with AIDS: Psychological and health implications. *Journal of Applied Social Psychology*, 17(3), 309-328.
- Namir, S., Woolcott, D., Fawzy, F., & Alumbaugh, M. (1990). Implications of different strategies for coping with AIDS. In L. Temoshok & A. Baum (Eds.), *Psychosocial perspectives on AIDS: Etiology, prevention, and treatment* (pp. 173-190). Hillsdale, NJ:: Lawrence Erlbaum Associates.

- Ndlovu, U., Jon, A., & Carvalhal, A. (2010). "My children and my home": The most recent and challenging stressors of HIV-positive women. *Archives of Women's Mental Health, 13*(3), 2-15.
- Nduna, M., Jewkes, R., Dunkle, K., Jama Shai, N., & Colman, I. (2013). Prevalence and factors associated with depressive symptoms among young women and men in the Eastern Cape Province, South Africa. *Journal of Child and Adolescent Mental Health, 25*(1), 43-54.
- Nel, A., & Kagee, A. (2013). The relationship between depression, anxiety and medication adherence among patients receiving antiretroviral treatment in South Africa. *AIDS Care, 25*(8), 948-955.
- Neuman, W. (2006). *Social research methods: Qualitative and quantitative approaches. 7th Edition*. Upper Saddle River, New Jersey: Pearson Education.
- Ng, D., & Jeffery, R. (2003). Relationships between perceived stress and health behaviors in a sample of working adults. *Health Psychology, 22*(6), 638-642.
- Nixon, S., Forman, L., Hanass-Hancock, J., Mac-Seing, M., Munyanukato, N., Myezwa, H., & Retis, C. (2011). Rehabilitation: A crucial component in the future of HIV care and support. *South African Journal of HIV Medicine, 12*(2), 12-17.
- Noble, M., Babita, M., Barnes, H., Dibben, C., Magasela, W., Noble, S., . . . Zungu, S. (2006). The provincial indices of multiple deprivation for South Africa 2001: University of Oxford, UK.
- Noble, M., Babita, M., Barnes, H., Dibben, C., Magasela, W., Noble, S. N., P, . . . Zungu, S. (2006). The provincial indices of multiple deprivation for South Africa 2001. Oxford: Centre for the Analysis of South African Social Policy, University of Oxford.
- Nokes, K., Wheeler, K., & Kendres, J. (1994). Development of an HIV assessment tool. *Journal of Nursing Scholarship, 26*(2), 133-138.
- Nolen-Hoeksema, S. (1991). Responses to depression and their effects on the duration of depressive episodes. *Journal of Abnormal Psychology, 100*(4), 569-582.
- Nolen-Hoeksema, S., & Harrell, Z. (2002). Rumination, depression and alcohol use: Tests of gender differences. *Journal of Cognitive Psychotherapy: An International Journal, 16*(4), 391-403.
- Nolen-Hoeksema, S., Parker, L., & Larson, J. (1994). Ruminative coping with depressed mood following loss. *Journal of Personality and Social Psychology, 67*(1), 92-104.

- Norman, R., Bradshaw, D., Schneider, M., & Groenewald, P. (2006). *Revised burden of disease estimates for the comparative risk factor assessment, South Africa 2000*. Methodological Note. Cape Town: South African Medical Research Council.
- Nunes, J., Raymond, S., Nicholas, P., Leuner, J., & Webster, A. (1995). Social support, quality of life, immune function, and health in persons living with HIV. *Journal Of Holistic Nursing, 13*(2), 174-198.
- Nyamathi, A., Stein, J., & Brecht, M. (1995). Psychosocial predictors of AIDS risk behavior and drug use behavior in homeless and drug addicted women of color. *Health Psychology, 14*(3), 265-273.
- Nyamathi, A., Thomas, B., Greengold, B., & Swaminathan, S. (2009). Perceptions and health care needs of HIV-positive mothers in India. Progress in community health partnerships: Research, education, and action. *Progress in Community Health Partnerships, 3*(2), 99-108.
- O'Keefe, E., & Wood, R. (1996). The impact of Human Immunodeficiency Virus (HIV) infection on quality of life in a multiracial South African population. *Quality of Life Research, 5*(2), 275-280.
- O'Brien, K., Bayoumi, A., Strike, C., Young, N., & Davis, A. (2008). Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework. *Health and Quality of Life Outcomes, 6*(76).
- O'Brien, K., Wilkins, A., Zack, E., & Solomon, P. (2009). Scoping the field: Identifying key research priorities in HIV and rehabilitation. *AIDS and Behavior, DOI 10.1007/s10461-009-9528-z*.
- O'Connor, D., Green, S., & Higgins, J. (2011). Chapter 5: Defining the review question and developing criteria for including studies. *Cochrane Handbook for Systematic Reviews of Interventions. Version 5.1.0*. Retrieved from the Cochrane Collaboration Handbook website: <http://www.cochrane-handbook.org/>
- Olley, B., Gxamza, F., Seedat, S., Theron, H., Taljaard, J., Reid, E., . . . Stein, D. (2003). Psychopathology and coping in recently diagnosed HIV/AIDS patients - the role of gender. *SAMJ 93*, 928-931.
- Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care, 18*(3), 236-240.
- Ostrow, D., Whitaker, R., Frasier, K., Cohen, C., Wan, J., Frank, C., & Fisher, E. (1991). Racial differences in social support and mental health in men with HIV infection: A pilot study. *AIDS Care, 3*, 55-63.

- Oyserman, D., Bybee, D., Mowbray, C., & MacFarlane, P. (2002). Positive parenting among African American mothers with a serious mental illness. *Journal of Marriage and Family*, 64(1), 65-77.
- Pakenham, K., Dadds, M., & Terry, D. (1994). Relationships between adjustment to HIV and both social support and coping. *Journal Of Consulting And Clinical Psychology*, 62(6), 1194-1203.
- Patel, V. (2007). Mental health in low- and middle-income countries. *British Medical Bulletin*, 81 and 82, 81-96.
- Patel, V., & Kleinman, A. (2003). Poverty and common mental disorders in developing countries. *Bull World Health*, 81, 609-615.
- Patterson, T., Semple, S., Temoshok, L., Atkinson, J., McCutchan, J., Straits-Troester, K., . . . Grant, I. (1993). Depressive symptoms among HIV positive men: Life stress, coping, and social support. *Applied Biobehavioral Research*, 1(1), 64-87.
- Patton, M. (Ed.). (2002). *Qualitative research and evaluation methods. 3rd edition*. Thousand Oaks, CA.: Sage.
- Payne, R., & Jones, G. (1987). Measurement and methodological issues in social support. In S. Kasl & C. Cooper (Eds.), *Stress and health: Issues in research methodology* (pp. 167–205). New York: John Wiley.
- Pence, B. (2009). The impact of mental health and traumatic life experiences on antiretroviral treatment outcomes for people living with HIV/AIDS. *Journal of Antimicrobial Chemotherapy*, 63, 636-640.
- Pennebaker, J. (1993). Putting stress into words: Health, linguistic and therepeutic implications. *Behaviour Research and Therapy*, 31(6), 539-548.
- Persson, L., Gullberg, B., Hanson, B., Moestrup, T., & Ostergren, P. (1994). HIV infection: Social network, social support, and CD4 lymphocyte values in infected homosexual men in Malmö, Sweden. *Journal of Epidemiology And Community Health*, 48(6), 580-585.
- Peterson, I., & Govender, M. (2010). Theoretical considerations: From understanding to intervening. In I. Peterson, A. Bhana, A. Flisher, L. Swartz & L. Richter (Eds.), *Promoting mental health in scarce resource contexts. Emerging evidence and practice* (pp. 21-48). Cape Town, South Africa: HSRC Press.
- Pillay, A., Edwards, S., & Sargent, C. (2001). Anxiety among university students in South Africa. *Psychological Reports*, 88(3 part 2), 1182-1186.

- Pillay, A., & Sargent, C. (1999). Relationship of age and education with anxiety, depression, and hopelessness in a South African community sample. *Perceptual and Motor Skills*, 89(3 Pt 1), 881-884.
- Pinquart, M., & Sorensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences*, 62(2), 126-137.
- Poupard, M., Ngom Gueye, N., Thiam, D., Ndiaye, B., Girard, P., Delaporte, E., . . . Landman, R. (2007). Quality of life and depression among HIV-infected patients receiving Efavirenz- or protease inhibitor-based therapy in Senegal. *HIV Medicine*, 8(2), 92-95.
- Prachakul, W., Grant, J., & Keltner, N. (2007). Relationships among functional social support, HIV-related stigma, social problem solving, and depressive symptoms in people living with HIV: A pilot study. *The Journal Of The Association Of Nurses In AIDS Care*, 18(6), 67-76.
- Prado, G., Feaster, D., Schwartz, S., Pratt, I., Smith, L., & Szapocznik, J. (2004). Religious involvement, coping, social support, and psychological distress in HIV-seropositive African American mothers. *AIDS and Behavior*, 8(3), 221-235.
- Pretorius, T. (1991). Cross-cultural application of the centre for epidemiological studies depression scale: A study of black South African students. *Psychological Reports*, 69 (3 Pt 2), 1179-1185.
- Primomo, J., Yates, B., & Woods, N. (1990). Social support for women during chronic illness: The relationship among sources and types to adjustment. *Research in Nursing & Health*, 13(3), 153-161.
- Prince, M., Patel, V., Saxena, S., Maj, M., Maselko, J., Phillips, M., & Rahman, A. (2007). No health without mental health. *The Lancet*, 370 (9590), 859-877.
- Rackstraw, S. (2011). Hiv-related neurocognitive impairment - a review. *Psychology, Health & Medicine*, 16(5), 548-563.
- Radloff, L. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurements*, 1(3), 385-401.
- Ray, L., & Ritchie, J. (1993). Caring for chronically ill children at home: Factors that influence parents' coping. *Journal of Pediatric Nursing*, 8(4), 217-225.
- Reading, R. (2005). Depressive symptoms in mothers of pre-school children. Effects of deprivation, social support, stress and neighbourhood social capital. *Child: Care, Health and Development*, 31(4), 489.

- Reblin, M., & Uchino, B. (2008). Social and emotional support and its implication for health. *Current Opinion in Psychiatry*, *21*(2), 201-205.
- Reich, W., Lounsbury, D., Zaid-Muhammad, S., & Rapkin, B. (2010). Forms of social support and their relationships to mental health in HIV-positive persons. *Psychology, Health & Medicine*, *15*(2), 135-145.
- Rejeski, W., Thompson, A., Brubaker, P., & Miller, H. (1992). Acute exercise: Buffering psychosocial stress responses in women. *Health Psychology*, *11*(6), 355-362.
- Reynolds, W., & Kobak, K. (1995). *Hamilton Depression Inventory: A self-report version of the Hamilton Depression Rating Scale (HDRS)*. Professional manual. Odessa, FL: Psychological Assessment Resources.
- Ritchie, J., & Lewis, J. (Eds.). (2006). *Qualitative research practice: A guide for social science students and researchers*. London, Thousand Oaks, New Delhi: Sage Publications.
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. Burgess (Eds.), *Analysing qualitative data*. London: Routledge.
- Robbins, M., Szapocznik, J., Tejada, M., Samuels, D., Ironson, G., & Antoni, M. (2003). The protective role of the family and social support network in a sample of HIV-positive African American women: Results of a pilot study. *Journal of Black Psychology*, *29*(1), 17-37.
- Rodin, G., & Voshart, K. (1986). Depression in the medically ill: An overview. *The American Journal of Psychiatry*, *143*(6), 696-705.
- Rotheram-Borus, M., & Stein, J. (1999). Problem behavior of adolescents whose parents are living with AIDS. *American Journal of Orthopsychiatry*, *69*(2), 228-239.
- Rotheram-Borus, M., Stein, J., Jiraphongsa, C., Khumtong, S., Lee, S.-J., & Li, L. (2010). Benefits of family and social relationships for Thai parents living with HIV. *Prevention Science*, *11*(3), 298 - 307.
- Rusting, C., & Nolen-Hoeksema, S. (1998). Regulating responses to anger: Effects of rumination and distraction on angry mood. *Journal of Personality and Social Psychology*, *74*(3), 790-803.
- Ryan, A., & Willits, F. (2007). Family ties, physical health, and psychological well-being. *Journal of Aging and Health*, *19*(6), 907-920.
- Sarason, I., Johnson, J., & Siegal, J. (1978). Assessing the impact of life changes: Development of the life experiences survey. *Journal of Clinical and Consulting Psychology*, *46*(5), 933 -946.

- Sarason, I., & Sarason, B. (2009). Social support: Mapping the construct. *Journal of Social and Personal Relationships*, 26(1), 113-120.
- Sarason, I., Sarason, B., Shearin, E., & Pierce, G. (1987). A brief measure of social support: Practical and theoretical implications. *Journal of Social Personal Relationships*, 4(4), 497-510.
- Schlomer, G., Bauman, S., & Card, N. (2010). Best practices for missing data management in counseling psychology. *Journal of Counseling Psychology*, 57(1), 1-10.
- Schmitz, M., & Crystal, S. (2000). Social relations, coping, and psychological distress among persons with HIV/AIDS. *Journal of Applied Psychology*, 30(4), 665-685.
- Schneider, E., Whitmore, S., Glynn, K., Dominguez, K., Mitsch, A., & McKenna, M. (2008). Revised surveillance case definitions for HIV infection among adults, adolescents, and children aged <18 months and for HIV infection and AIDS among children aged 18 months to 13 years. Retrieved from the Centers for Disease Control and Prevention website:
http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5710a1.htm?s_cid=rr5710a1_e
- Schofield, H., Bloch, S., Nankervis, J., Murphy, B., Singh, B., & Herrman, H. (1999). Health and well-being of women family carers: A comparative study with a generic focus. *Australian and New Zealand Journal of Public Health*, 23(6), 585-589.
- Schoub, B. (1999). *AIDS and HIV in perspective: A guide to understanding the virus and its consequences*. Cambridge: Cambridge University Press.
- Schraedley, P., Gotlib, I., & Hayward, C. (1999). Gender differences in correlates of depressive symptoms in adolescents. *Journal of Adolescent Health*, 25(2), 98-108.
- Seedat, S., Williams, D., Herman, A., Momal, H., Williams, S., Jackson, P., . . . Stein, D. (2009). Mental health service among South Africans for mood, anxiety and substance disorders. *South African Medical Journal*, 99(5), 346-352.
- Seeman, T. (1996). Social ties and health: The benefits of social integration. *Annals of Epidemiology*, 6(5), 442-451.
- Semple, S., Patterson, T., Shaw, W., Straits-Troster, K., Atkinson, J., & Grant, I. (1997). HIV-seropositive parents: Parental role strain and depressive symptoms. *AIDS and Behaviour*, 1(4), 213-224.
- Serovich, J., Kimberly, J., Mosack, K., & Lewis, T. (2001). The role of family and friend social support in reducing emotional distress among HIV-positive women. *AIDS Care*, 13(3), 335-341.

- Shaw, B., Krause, N., & Chatters, L. (2004). Emotional support from parents early in life, aging, and health. *Psychology and Aging, 19*(1), 4-12.
- Sheppard, M. (1994). Childcare, social support and maternal depression. *British Journal of Social Work, 24*(3), 287-310.
- Sherbourne, C., & Stewart, A. (1991). The MOS Social Support Survey. *Social Science & Medicine, 32*(6), 705-714.
- Sherr, L., Clucas, C., Harding, R., Sibley, E., & Catalan, J. (2011). HIV and depression - a systematic review of interventions. *Psychology, Health & Medicine, 16*(5), 493-527.
- Sherr, L., Clucas, C., Lampe, F., Harding, R., Johnson, M., Fisher, M., . . . Team, S. (2012). Gender and mental health aspects of living with HIV disease and its longer-term outcomes for UK heterosexual patients. *Women Health, 52*(3), 214-233.
- Sherr, L., Nagra, N., Kulubya, G., Catalan, J., Clucas, C., & Harding, R. (2001). HIV infection associated post-traumatic stress disorder and post-traumatic growth - a systematic review. *Psychology, Health & Medicine, 15*(5), 612-629.
- Shimazu, A., & Shaufeli, W. (2007). Does distraction facilitate problem-focused coping with job stress? A 1 year longitudinal study. *Journal of Behavioral Medicine, 30*(5), 423-434.
- Silver, E., Bauman, L., Camacho, S., & Hudis, J. (2003). Factors associated with psychological distress in urban mothers with late-stage HIV/AIDS. *AIDS and Behavior, 7*(4), 421-431.
- Simoni, B., Montoya, H., Huang, B., & Goodry, E. (2005). Social support and depressive symptomatology among HIV-positive women: The mediating role of self-esteem and mastery. *Women & Health 42*(4), 1-15.
- Simons, R., Beaman, J., Conger, R., & Chao, W. (1993). Stress, support, and antisocial behavior trait as determinants of emotional well-being and parenting practices among single mothers. *Journal of Marriage and Family, 55*(2), 385-398.
- Singer, E., & Bossarte, R. (2006). Incentives for survey participation. When are they "coercive"? *American Journal of Preventive Medicine, 31*(5), 411-418.
- Skok, A., Harvey, D., & Reddihough, D. (2006). Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. *Journal of Intellectual & Developmental Disability, 31*(1), 53-57.
- Smit, J., Myer, L., Middelkoop, K., Seedat, S., Wood, R., Bekker, L., & Stein, D. (2006). Mental health and sexual behaviours in a South African township: A community-based cross-sectional study. *Public Health, 120*(6), 534-542.

- Smit, J., van den Berg, C., Bekker, L., Seedat, S., & Stein, D. (2006). Translation and cross-cultural adaptation of a mental health battery in an African setting. *African Health Sciences*, 6(4), 215-222.
- Smith Fawzi, M., Eustache, E., Oswald, C., Surkan, P., Louis, E., Scanlan, F., . . . Mukherjee, J. (2010). Psychosocial functioning among HIV-affected youth and their caregivers in Haiti: Implications for family-focused service provision in high HIV burden settings. *AIDS Patient Care STDS* 24(3), 147-158.
- Smith, J., & Alloy, L. (2009). A roadmap to rumination: A review of the definition, assessment, and conceptualization of this multifaceted construct. *Clinical Psychology Review*, 29(9), 116-128.
- Smith, L., Feaster, D., Prado, G., Kamin, M., Blaney, N., & Szapocznik, J. (2001). The psychosocial functioning of HIV+ and HIV- African American recent mothers. *Journal of AIDS and Behavior* 5(3), 219-231.
- Song, Y., & Ingram, K. (2002). Unsupportive social interactions, availability of social support, and coping: Their relationship to mood disturbance among African Americans living with HIV. *Journal of Social & Personal Relationships* 19(1), 67.
- Spangenberg, J., & Pieters, H. (1991). Factors related to postpartum depression. *South African Journal of Psychology*, 21(3), 159-165.
- Spielberger, C., Gorsuch, R., Lushene, R., & Jacobs, G. (1983). *State-trait anxiety inventory for adults: Sampler set, manual, test, scoring key*. Palo Alto, California: Mind Garden.
- Spitzer, R., Williams, J., Gibbon, M., & First, M. (1990). *Structured clinical interviews for DSM-III-R. Nonpatient edition (SCID NP, version 1.0)*. Washington DC: American Psychiatric Press.
- Ssengonzi, R. (2009). The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS Care*, 21(3), 309-314.
- Statistics South Africa. (2003a). Census 2001. Retrieved from the Statistics South Africa website: <http://www.statssa.gov.za/publications/CensusKey/CensusKey2001.pdf>
- Statistics South Africa. (2003b). Census 2001: Investigation into appropriate definitions of urban and rural areas for South Africa: Discussion document. Pretoria: Statistics South Africa.
- Statistics South Africa. (2005). General household survey 2005. Retrieved from the Statistics South Africa website: <http://www.statssa.gov.za/publications/P0318/P0318July2005.pdf>

- Statistics South Africa. (2007). Community survey 2007. Retrieved from the Statistics South Africa website:
http://www.statssa.gov.za/community_new/content.asp?link=basicresults.asp
- Statistics South Africa. (Census 2001. My Constituency: Ward Profiles 2003) Retrieved from the Statistics South Africa website:
http://www.statssa.gov.za/census2001/atlas_ward/index.html
- Steele, G., & Edwards, D. (2008). Development and validation of the Xhosa translations of the Beck Inventories: 2. Item analysis, internal consistency and factor analysis. *Journal of Psychology in Africa, 18*(2), 217-226.
- Stein, A., Ramchandani, P., & Murray, L. (2008). Impact of parental psychiatric disorder and physical illness. In M. Rutter, D. Bishop, D. Pine, S. Scott, J. Stevenson, E. Taylor & A. Thapar (Eds.), *Child and adolescent psychiatry, 5th edition*. Oxford: Oxford Blackwell Publishing.
- Steinberg, M., Johnson, S., Schierhout, G., & Ndegwa, D. (2002). Hitting home: How households cope with the impact of the HIV/AIDS epidemic. A survey of households affected by HIV/AIDS in South Africa. Washington DC: Henry J. Kaiser Family Foundation and Health Systems Trust.
- Stemp, P., Turner, R., & Noh, S. (1986). Psychological distress in the postpartum period: The significance of social support. *Journal of Marriage and Family, 48*(2), 271-277.
- Stevens, J. (1988). Social support, locus of control, and parenting in three low-income groups of mothers: Black teenagers, black adults, and white adults. *Child Development, 59*(3), 635-642.
- Stewart, K., Cianfrini, L., & Walker, J. (2005). Stress, social support and housing are related to health status among HIV-positive persons in the deep South of the United States. *AIDS Care, 17*(3), 350-358.
- Stock, M. (2001). *The effects of received and perceived social support on the health status of HIV-positive African-American women*. Doctoral thesis, Tulane University, U.S.A., Louisiana.
- Stone, A., Kennedy-Moore, E., & Neale, J. (1995). Association between daily coping and end-of-day mood. *Health Psychology, 14*(4), 341-349.
- Surkan, P., O'Donnell, E., Berkman, L., & Peterson, K. (2009). Social ties in relation to health status of low-income Brazilian women. *Journal of Women's Health, 28*(12), 2049-2056.

- Symister, P., & Friend, R. (2003). The influence of social support and problematic support on optimism and depression in chronic illness: A prospective study evaluating self-esteem as a mediator. *Health Psychology, 22*(2), 123-129.
- Szapocznik, D., Feaster, J., Mitrani, V., Prado, G., Smith, L., Robinson-Batista, C., . . . Robbins, M. (2004). Structural ecosystems therapy for HIV-seropositive African American Women: Effects on psychological distress, family hassles, and family support. *Journal of Consulting and Clinical Psychology, 72*(2), 288-303.
- Tamres, L., Janicki, D., & Helgeson, V. (2002). Sex differences in coping behavior: A meta-analytic review and an examination of relative coping. *Personality and Social Psychology Review, 6*(1), 2-30.
- Thai Department of Mental Health. (2006). *Depression Screening Test*. Retrieved from the Thai Department of Mental Health website: <http://www.dmh.go.th/test/depress/asheet.asp?qid=1>
- Thai Department of Mental Health. Ministry of Public Health. (1998). WHO-BREF- Thai. Retrieved from the Thai Department of Mental Health: <http://www.dmh.go.th/test/whoqol/>
- Thampanichawat, W. (2008). Maintaining love and hope: Caregiving for Thai children with HIV infection. *Association of Nurses in AIDS Care, 19*(3), 200-210.
- Thayer, R., Newman, J., & McClain, T. (1994). Self-regulation of mood: Strategies for changing a bad mood, raising energy and reducing tension. *Journal of Personality and Social Psychology, 67*(6), 910-925.
- The Joint Learning Initiative on Children and HIV/AIDS (JLICA). (2008). Synthesis report. Learning Group 1: Strengthening families. Retrieved from the JLICA website: <http://www.ccaba.org/wp-content/uploads/JLICA-Learning-Group-1-Synthesis-Paper.pdf>
- Theorell, T., Blomkvist, V., Jonsson, H., Schulman, S., & Berntorp, E. (1995). Social support and the development of immune function in Human Immunodeficiency Virus infection. *Psychosomatic Medicine, 57*(1), 32-26.
- Thoits, P. (1982). Conceptual, methodological, and theoretical problems in studying social support as a buffer against life stress. *Journal of Health and Social Behaviour, 23*(2), 145-159.
- Thoits, P. (1985). Social support and psychological well-being: Theoretical possibilities. In I. Sarason & B. Sarason (Eds.), *Social support: Theory, research and application* (pp. 51-72). Dordrecht, The Netherlands: Martinus Nijhoff.

- Thoits, P. (1986). Social support as coping assistance. *Journal of Consulting and Clinical Psychology, 54*(4), 416-423.
- Thoits, P. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of Health and Social Behavior, 52*(2), 145-161.
- Thomas, F. (2006). Stigma, fatigue and social breakdown: Exploring the impacts of HIV/AIDS on patient and carer well-being in the Caprivi region, Namibia. *Social Science and Medicine, 63*(12), 3174-3187.
- Thompson, H., Littles, M., Jakob, S., & Coker, C. (2006). Posttreatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent. *Cancer Nursing, 29*(6), 478-487.
- Thompson, R. (1992). Stress, coping and psychological adjustment of adults with sickle cell disease. *Journal of Consulting and Clinical Psychology, 60*(3), 433-440.
- Thompson, T., Keogh, E., Chen, M., & French, C. (2012). Emotion-focused coping and distraction: Sex differences in the influence of anxiety sensitivity during noxious heat stimulation. *European Journal of Pain, 16*(3), 410-420.
- Tilden, V. (1991). The Tilden Interpersonal Relationship Inventory (IPRI). Instrument development summary (Paper). Oregon: Oregon Health Sciences University School of Nursing.
- Tobin, D., Holroyd, K., & Reynolds, R. (1984). User's manual for the Coping Strategies Inventory. *Unpublished Manuscript*.
- Tompkins, T., Henker, B., Whalen, C., Axelrod, J., & Comer, L. (1999). Motherhood in the context of HIV infection: Reading between the numbers. *Cultural Diversity and Ethnic Minority Psychology, 5* (3; Special issue), 197-208.
- Tsai, S.-M., & Wang, H.-H. (2009). The relationship between caregiver's strain and social support amongst mothers with intellectually disabled children. *Journal of Clinical Nursing, 18*(4), 539-548.
- Turner-Cobb, J., Sephton, S., Koopman, C., Blake-Mortimer, J., & Spiegel, D. (2000). Social support and salivary cortisol in women with metastatic breast cancer. *Psychosomatic Medicine, 62*(3), 337-345.
- Turner, R. (1981). Social support as a contingency in psychological well-being. *Journal of Health and Social Behavior, 22*(4), 357-367.
- Uchino, B. (2004). *Social support and physical health: Understanding the health consequences of our relationships*. New Haven, CT: Yale University Press.

- Uchino, B. (2006). Social support and health: A review of physiological processes potentially underlying links to disease outcomes. *Journal of Behavioral Medicine*, 29(4), 377-387.
- Uchino, B. (2009). Understanding the links between social support and physical health: A life-span perspective with emphasis on the separability of perceived and received support. *Perspectives on Psychological*, 4(3), 236-255.
- Uchino, B., Bowen, K., Carlisle, M., & Birmingham, W. (2012). Psychological pathways linking social support to health outcomes: A visit with the "ghosts" of research past, present, and future. *Social Science & Medicine*, 74(7), 949-957.
- Uchino, B., Cacioppo, J., & Kiecolt-Glaser, J. (1996). The relationship between social support and physiological processes: A review with emphasis on underlying mechanisms and implications for health. *Psychological Bulletin*, 119(3), 488-531.
- Umberson, D. (1987). Family status and health behaviors: Social control as a dimension of social intergration. *Journal of Health and Social Behaviour*, 28(3), 306-319.
- Umberson, D., & Montez, J. (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behavior*, 51 (Special Issue), S54-66.
- Umhlabuyalingana Local Municipality. (2011). Final draft IDP 2010/11. Retrieved 01/08/2011, 2011, from the Umhlabuyalingana Local Municipality website: <http://www.umhlabuyalingana.gov.za/dist.php?prm1=000002>
- UNAIDS. (2010). Global report: UNAIDS report on the global AIDS epidemic 2010. Retrieved from the UNAIDS website: http://www.unaids.org/documents/20101123_GlobalReport_Foreword_em.pdf.
- UNAIDS. (2012). Global report: UNAIDS report on the global AIDS epidemic 2012. Retrieved from the UNAIDS website: http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120_UNAIDS_Global_Report_2012_with_annexes_en.pdf
- UNICEF. (2013). Orphans. Retrieved from the UNAIDS website: http://www.unicef.org/media/media_45279.html
- Vasquez, M. (2003). A comparison study of fathers: Parenting stress, psychological distress and coping in a sample of fathers caring for HIV-infected children and fathers caring for children with cancer. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 63(7-B).

- Vaux, A., Phillips, J., Holly, L., Thomson, B., Williams, D., & Stewart, D. (1986). The social support appraisals scale (SS-A): Studies of reliability and validity. *American Journal of Community Psychology* 14(2), 195-218.
- Waddell, E., & Messeri, P. (2006). Social support, disclosure, and use of antiretroviral therapy. *AIDS And Behavior*, 10(3), 263-272.
- Waldrop, D., & Weber, J. (2001). From grandparent to caregiver: The stress and satisfaction of raising grandchildren. *Families in Society*, 82(5), 461-472.
- Wallen, H., & Lachman, M. (2000). Social support and strain from partner, family and friends: Costs and benefits for men and women in adulthood. *Journal of Social and Personal Relationships*, 17(1), 5-30.
- Wang, H.-H., Wu, S.-Z., & Liu, Y.-Y. (2003). Association between social support and health outcomes: A meta-analysis. *The Kaohsiung Journal of Medical Sciences*, 19(7), 345-351.
- Ware, J. (2000). SF-26 Health Survey update. *Spine*, 25(24), 3130-3139.
- Ware, J. (2004). The SF-36 Health Survey: An update. In M. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes assessment*. 3rd Edn (pp. 693-718). Mahwah: Lawrence Erlbaum Associates.
- Ware, J., Kosinski, M., Bjorner, J., Turner-Bowker, D., Gandek, B., & Maruish, M. (2007). *User's manual for the SF-36v2 Health Survey*. 2nd Ed. Lincoln: Quality Metric Incorporated.
- Ware, J., Kosinski, M., & Keller, S. (1996). A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*, 34(3), 220-233
- Ware, J., Kosinski, M., Turner-Bowker, D., & Gandek, B. (2002). *User's manual for the SF-12v2 Health Survey with a supplement documenting SF-12 Health Survey*. Lincoln, RI: QualityMetric Incorporated.
- Ware, J., & Sherbourne, C. (1992). The MOS 36-item short-form health survey (SF-36): Conceptual framework and item selection. *Medical Care*, 30(473-483).
- Westaway, M., Seager, J., Rheeder, P., & Van Zyl, D. (2005). The effects of social support on health, well-being and management of diabetes mellitus: A Black South African perspective. *Ethnicity & Health*, 10(1), 73 - 89.

- Whetten, K., Reif, S., Whetten, R., & Murphy-McMillan, L. (2008). Trauma, mental health, distrust, and stigma among HIV-positive persons: Implications for effective care. *Psychosomatic Medicine*, 70(5), 531-538.
- White, N., Richter, J., & Fry, C. (1992). Coping, social support and adaptation to chronic illness. *Western Journal of Nursing Research*, 14(2), 211-224.
- WHO, UNAIDS, & UNICEF. (2011). Global HIV/AIDS response: Epidemic update and health sector progress towards universal access. Progress report 2011. Retrieved from the UNAIDS website: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/201111130_UA_Report_en.pdf
- Williams, A., Ware, J., Donald, C., & Donald, J. (1981). A model of mental health, life events, and social supports applicable to general populations. *Journal of Health and Social Behaviour*, 22(4), 324-336.
- Wolcott, D., Namir, S., Fawzy, F., Gottlieb, M., & Mitsuyasu, R. (1986). Illness concerns, attitudes towards homosexuality, and social support in gay men with AIDS. *General Hospital Psychiatry*, 8(6), 395-403.
- Wolf, T., Balson, P., Morse, E., Simon, P., Gaumer, R., Dralle, P., & Williams, M. (1991). Relationship of coping style to affective state and perceived social support in asymptomatic and symptomatic HIV-infected persons: Implications for clinical management. *Journal of Clinical Psychiatry*, 52(4), 171-173.
- World Health Organisation (WHO). (2001). *The World Health Report 2001. Mental health: New understanding, new hope*. Retrieved from the WHO website: <http://www.who.int/whr/2001/en/>
- World Health Organisation. (2005). *Interim WHO clinical staging for HIV/AIDS and HIV/AIDS case definitions for surveillance: Africa region*. Retrieved from the WHO website: <http://www.who.int/hiv/pub/guidelines/clinicalstaging.pdf>
- World Health Organisation. (2008). *HIV/AIDS and mental health. Report by the secretariat*. Retrieved from the WHO website: http://apps.who.int/gb/ebwha/pdf_files/EB124/B124_6-en.pdf
- World Health Organisation. (2011). *Mental health atlas 2011*. Retrieved from the WHO website: http://www.who.int/mental_health/publications/mental_health_atlas_2011/en/index.html

- World Health Organisation. (2012). *Gender and women's mental health*. Retrieved from the WHO website: http://www.who.int/mental_health/prevention/genderwomen/en/
- World Health Organization. (2002). *The impact of AIDS on older persons in Africa: Zimbabwe case study*. Retrieved from the WHO website: http://whqlibdoc.who.int/hq/2002/WHO_NMH_NPH_ALC_02.12.pdf
- World Health Organization. (2004). *The World Health Organization Quality of Life-BREF (Thai)*. Retrieved from the WHO website: http://www.who.int/substance_abuse/research_tools/en/thai_whoqol.pdf
- Wu, A. (1999). MOS-HIV Health Survey Manual. Retrieved from the Center for HIV Identification, Prevention and Treatment Services (CHIPTS) website: <http://chipts.ucla.edu/assessment/pdf/assessments/MOS-HIV%20Users%20Manual%20%20Draft.pdf>
- Wyatt, A. (1997). *Prediction of hopelessness among HIV positive mothers: Evidence for the social support buffering and diathesis-stress models*. Doctoral thesis, Chicago Medical School, Illinois, U.S.A.
- Yadav, S. (2010). Perceived social support, hope, and quality of life of persons living with HIV/AIDS: A case study from Nepal. *Quality of Life Research* 19(2), 157-166.
- Yamano, T., Shimarura, Y., & SSerunkuuma, D. (2006). Living arrangements and schooling of orphaned children and adolescents in Uganda. *Economic Development and Cultural Change*, 54(4), 833-856.
- Yeji, F. (2009). *Does social support affect depression in patients on an antiretroviral treatment program in rural KwaZulu-Natal, South Africa?* Masters Thesis, University of the Witwatersrand, Johannesburg.
- Zich, J., & Temoshok, L. (1987). Perceptions of social support in men with AIDS and ARC: Relationships with distress and hardiness. *Journal of Applied Social Psychology*, 17(3), 193-215.
- Zich, J., & Temoshok, L. (1990). Perceptions of social support, distress, and hopelessness in men with AIDS and ARC: Clinical implications. In L. Temoshok & A. Baum (Eds.), *Psychosocial perspectives on AIDS: Etiology, prevention, and treatment*. Hillsdale, NJ: Lawrence Erlbaum Associates.
- Zinkernagel, C., Taffe, P., Rickenbach, M., Amiet, R., Ledergerber, B., Volkart, A., . . . Battegay, M. (2001). Importance of mental health assessment in HIV-infected outpatients. *Journal of Acquired Immune Deficiency Syndromes*, 28(3), 240-249.

APPENDIX 1: LOCATION AND METHODOLOGIES OF STUDIES INCLUDED IN THE SYSTEMATIC LITERATURE REVIEW

Study	Reference	Country	Sample	Study design and data collection methods	Main Data Analysis Method
1	Burns, M., et al. (2008). Prado, G., et al. (2004).	USA	265 urban, low-income 18+ HIV-positive African American mothers with at least 1 child. Participants recruited from an urban medical centre and affiliated clinics and social service agencies.	Cross-sectional Self-reported interview data.	Structural equation modelling.
2	Cook, K. (1997).	USA	54 HIV-positive women who were primary caregivers of at least 1 child below 12 years, mainly African American (51%) and Latina/Hispanic (24%). Participants recruited from HIV support organisations and clinics or through snowball sampling.	Cross-sectional. Self-reported interview data.	Bivariate statistical tests, such as correlations and inter-correlation.

3	Gay, C. (1995).	USA	50 mainly African American (80%) HIV-infected mothers of at least 1 HIV-infected child between 1 -7 years, recruited from a clinic at a large urban hospital.	Cross-sectional Self-reported interview data. Sub-sample of 35 mothers also observed interacting with their children.	Mainly bivariate statistical tests and selected simple regression models.
4	Hough, E., et al. (2003).	USA	147 HIV positive mainly African American (86%) mostly biological urban mothers living with at least 1 healthy child between 7 and 14. Mothers were recruited through a clinic.	Cross-sectional. Self-reported interview data.	Structural equation modelling.
5	Klein, K., et al. (2000).	USA	66 HIV-positive and 139 HIV-negative African-American mothers 18-45 with at least 1 biological child between 6 and 11 residing in the same household. HIV-infected mothers were recruited from an HIV Outpatient Programme Clinic. A demographically matched group of HIV-seronegative mothers and their children were recruited from public schools through a stratified random sampling procedure.	Longitudinal study with data taken from 2 assessment periods approximately 12 - 14 months apart. Self-reported interview data.	Hierarchical regression analysis conducted with both cross-sectional and longitudinal data.

6	Leslie, M., et al. (2002).	USA	<p>295 mainly Hispanic (45%) and African-American (34%) HIV-positive parents (81% mothers and 19% fathers) of at least one 11-18 year old child.</p> <p>Participants recruited through an AIDS Services agency.</p>	<p>Cross-sectional.</p> <p>Self-reported interview data.</p>	Structural equation modelling
7	Mellins, C., et al. (2000).	USA	<p>40 HIV-positive, mainly African American (47.5%) and Latina (35%) single mothers of children 2.5 - 6 years exposed to HIV in utero. Mothers recruited from paediatric HIV clinics and camp for HIV-affected families.</p>	<p>Cross-sectional.</p> <p>Self-reported interview data.</p>	Multiple regression analysis.
8	Miles, M., et al. (1997).	USA	<p>54 HIV-positive mainly African American (91%) biological mothers of infants who were born seropositive.</p> <p>Participants recruited through paediatric infectious disease clinics.</p>	<p>3 rounds of data collection via questionnaires, over a period of approx. 12 months.</p> <p>Medical records also checked for medical and socio-demographic data.</p>	Descriptive and inferential analysis involving a hierarchical linear model (HLM).

9	Murphy, D., et al. (2002).	USA	<p>135 mainly African American (39%) and Latina (36%) HIV-symptomatic or AIDS-ill mothers with at least 1 healthy child between 6–11 years.</p> <p>Mothers were recruited from urban clinical primary care sites and AIDS service organizations.</p>	<p>Cross-sectional.</p> <p>Self-reported interview data.</p> <p>Medical charts also examined.</p>	Bivariate tests, such as chi squared; T-tests and point-biserial correlations.
10	Robbins, M., et al. (2003).	USA	<p>38 African American HIV-positive women 18 + who had given birth within the 3 months prior to recruitment. The women were recruited from the medical clinics of a large public hospital.</p>	<p>Cross-sectional.</p> <p>Self-reported data though 2 administered interviews within 2 weeks of each other.</p> <p>Monthly CD4 cell counts obtained directly from participant's medical records.</p>	Multiple regression analysis.
11	Rotheram-Borus, M., et al. (2010).	Thailand	<p>409 HIV-positive caregivers (73% mothers) of at least one child between 6 and 17.</p> <p>Participants were recruited from 4 district hospitals.</p>	<p>Cross-sectional.</p> <p>Self-reported interview data.</p>	Structural equation modelling

12	Sharts-Hopko, N., et al. (1996).	USA	41 mainly African-American (68%) HIV-positive mothers. Participants recruited from a community programme at an infectious disease clinic over a 6-month period in 1992.	Cross-sectional. Self-reported interview data.	Bivariate analysis of data (Pearson product-moment correlations).
13	Silver, E., et al. (2003).	USA	220 low income mostly Black (54%) and Latino (37%) mothers with late stage HIV/AIDS living with at least 1 HIV negative child between 2 and 12. Participants recruited from a municipal AIDS services programme providing income support and case management to HIV symptomatic adults.	Cross-sectional. Self-reported interview data.	Multiple regression analysis.
14	Stock, M. (2001).	USA	65 HIV-positive African-American urban mothers 18-45 with non-infected children between 6 and 11. Participants recruited from 2 primary public HIV clinics.	Exploratory, longitudinal test-retest study that collected 2 waves of self-reported data, one at baseline and one 30-34 months later. Medical charts also reviewed to extract data pertaining to the participant's health status (CD4 count and CDC staging checked).	Multiple regression analysis.

15	Wyatt, A. (1997).	USA	50 HIV positive mothers mainly (72%) African-American. Mothers recruited from 3 sites where they received HIV related services.	Cross-sectional. Self-reported interview data.	Hierarchical multiple regression analysis.
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University of Cape Town

APPENDIX 2: IDENTIFICATION OF DWELLING AND SAMPLING SHEET FOR SURVEY

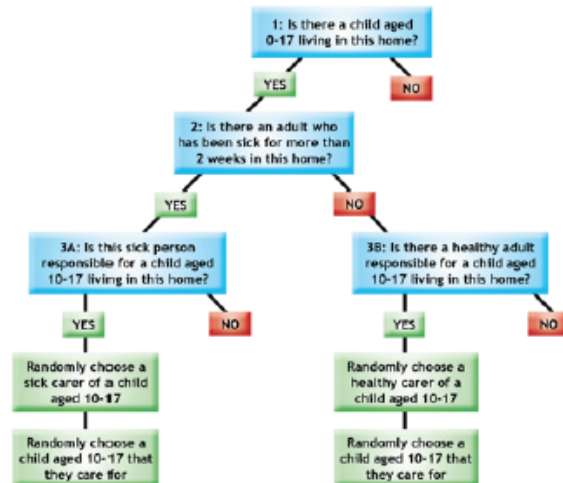
IDENTIFICATION OF DWELLING AND FIELD STAFF INFORMATION

A

Complete this page for ALL HOUSES!

1: Enumeration Area Number
 GPS latitude: 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:

APPENDIX 3: BILINGUAL ADULT CARER SURVEY



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

4

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 naweimininingwane. Ngicela ukukhombisa 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 lomininingwane 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 ngidweba amagumbi akhona kulendlu? Izindlu zifake omaka. Faka indlu yangasece 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. Ungabuzi 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 ecebaleni 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 | 5 = prefab / isakhiwo esithengwayo sesilungisiwe |
| 2 = mud / udaka | 6 = bare brick / cement block / izitini noma amabhulokisi angafikiwe usimende |
| 3 = mud and cement / udaka kanye nosimende | 7 = plaster / finished / kufakwe usimende noma kupalusteliwe kwaqedwa |
| 4 = corrugated iron/zinc / uthayela | 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 | 4 P = White / Omhlophe |
| 2 P = Coloured / Ikhalaadi | 5 P = Other (specify in drawing) / Okunye (cacisa) |
| 3 P = Indian/Asian / Umndiya | |

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 okuyilona 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 igama lakho? Bhala igama ngaphansi kweminyaka. Uma kukhona abanye abantu kulekhaya 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 kulekhaya.

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.

/Ingxenywe ebaluleke kakhulu kulolucwaningo ukuzwa ngezinsalelo ohlangabezana nazo njengomunakekeli. Imibuzo elandelayo izozama ukuzwa ngezinsalelo obhekana nazo ngesimo sakho sempilo okungenzeka zigcine ziphazamise umsebenzi wakho wokunakekela izingane. Lemibuzo elandelayo, ibuzo 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 njengenhlayenza 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 njengokugudluzisa itafula, ukuphusha umshini wokuhlansa, 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? / Isikhashana?	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 eminye 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 ngamunye, nikeza impendulo eshaya emhloveni ngobukuzwa. Isikhathi esingakanani emasontweni 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? / Isikhashana?	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 ekuphiliseneni kwakho nabanye abantu (njengokuvakasha 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 ukukhulasekwa ukugula ngezinye izikhathi. Singathanda ukukubuzwa ngezifo zakho. Lemibuzo ingahle ingene kakhulu ezintweni ezithinta wena kodwa iminininngwane izoba usizo kakhulu kuhulumeni ozama ukuqonda isimo sempilo yabanakekeli nokusekelwa kwabo. Ngakhoke lemibuzo ibaluleke kakhulu kulolucwaningo. 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.

<i>(Chronic Conditions / Izimo Ezikuxhwalisayo)</i>		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 isifuba somoya kulenyanga edlulile? ukukhulasekwa		
2.9b	When you have an attack, do you have a puffer spray you can take? / Uma ukhulasekwa 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

<i>(Physical disability / Ukukhubazeka ngokomzimba)</i>		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?)	0	1
	/ Nginolunye uhlobo lokukhubazeka (hloboluni?)		

<i>(Communicable TB) Have you had / (Izifo sofuba esithelelanayo) Uke waba no.....</i>		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		

<i>(Other general health questions) Have you had any of these symptoms? / (Eminyane imibuzo eyejwayelekile ngesimo sakho sempilo) Uke waba nalezizimpawu ezinjengalezi?</i>		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 nalezimpawu ongenani ezine kwezilandelayo: ukuphaphatheka, ukushintshelwa umbala wezinwele, ukuvuvuka kwezinyawo, ukushisa okukhulu ezinyaweni, isikhumba esomile esikhekhebukayo?	0	1
2.18c	Have you had jaundice where the whites of your eyes are yellow and no history of alcohol abuse? / Uke waba nejdondisi 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 yecela 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 candidiasis 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 elinkenethayo, 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 kuze-kube 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 esingakabuzi 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):		

<i>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.</i>		
2.19	<i>(WHO Clinical Staging) Are you able to do activities that you would normally do at work, at home, etc? / Ingabe uyakwazi ukwenza Imisebenzi yakho ejwayelekile emsebenzini, ekhaya, nakwezinye Izindawo?</i>	
	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	<i>(WHO Clinical Staging) How much time do you spend in bed? / Uchitha isikhathi esingakanani embhedeni?</i>	
	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, Ngangingakudingi ukuya → Yiya ku Q2.27	1 = No, I needed to but I couldn't → Go to Q2.25 / 1 = Cha, Ngangingidinga 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	0	1	2
	(Specify / Cacisa):			

.....2.22 continued from above /2.22 uqhuntswa okusukela phezulu		0 = No, I didn't need to → Go to Q2.27 / 0 = Cha, Ngangingakudingi ukuya → Yiya ku Q2.27	1 = No, I needed to but I couldn't → Go to Q2.25 / 1 = Cha, Ngangingidinga 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, ngangingidinga 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 kakhulu noma kuya gwala	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 kweyedwa 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, Ngangingakud-ingi ukuya → Yiya ku Q2.29	1 = No, I needed to but I couldn't → Go to Q2.28 / 1 = Cha, Ngangingakud-ingi 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 / inhlangotho 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 uku-thenga 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 gwala	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 / inhlangotho yokwesekelana	0	1
h) telephone hotline / ucingo oluphuthumayo yokwaluleka	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? / Kangingi masigula abantwana bethu bayasiza ukusinakelela. Ingabe umtwana okhona ekhaya lakho uyasiza akunakelele 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 esinakelela, kwezinye izikhathi 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 ongalalwa umzali wami	4	
	5 = child / Ingane	5	
	6 = grandchild or great-grandchild / umzukulwana 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 ongalalobene naye ngokobundeni	10	
	11 = other non-relative (specify) / okunye okungahlalobene 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 / Inombolo 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 zingihluphe nhlobo	1 = Mildly but it didn't bother me much. / Zike zangihlupha kancanyana, azangikhat-haza kangako	2 = Moderately - it wasn't pleasant at times / Zingihluphahluphile, bekuyisikhathi esingem-nandi	3 = Severely - it bothered me a lot / Kakhulu impela, kwangikhat-haza 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 / Isiyazi 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, azangikhat-haza kangako	2 = Moderately - it wasn't pleasant at times / Zingihluphaluphile, bekuyisikhathi esingemnandi	3 = Severely - it bothered me a lot / Kakhulu impela, kwangikhat-haza 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 ngezikhathana (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 ngezikhashana (izinsuku ezintathu kuya kwezine)?	4 = Most of the time (5-7 days)? / Isikhathi esiningi (izinsuku ezinhlanu kuya kweziyisikhombisa)?
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 zenzeke.

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? <i>(Circle all that apply)</i> / Awusho, kuke kwenzeka ukuba uhlanga bezane nezinye zalezimo ezilandelayo, noma uzibone zenzeka komunye umuntu, noma uzwe ngokuthi lezi zehlakalo zenzeke kumuntu omaziyo? <i>(kekelezela konke ovumelana nakho)</i>	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 kwenzeka
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 ibhому)?	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, ukuphoqeelwa 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: If 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 wahlangabezana 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 esihlukomezayo 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 ingxeny ebuhlungu kakhulu ngeshlakalo uvele uthinteki 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 iminingwane 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 iminingwane 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/D / 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

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. Bangingi abazali abangekho noma asebeshonile emiphakathini yethu lokhu okwenza lemibuzo elandelayo ibe nzima. Ngicela ukukhumbuzwa 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	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	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 athumele imali	1	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	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	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	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	5
	6 = don't know / Angazi	6	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	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	2a
	2b = stabbed / wagwazwa	2b	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	2c
	2d = poisoned / ufakelwe ubuthi	2d	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	2e
	2f = other (specify) / okunye (cacisa):	2f	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	3	

Question Number / Inombolo yombuzo	Iss biological mother part of this household? / Kungabe umama ka omuzalayo 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	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	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 athumele imali	1	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	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	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	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	5
	6 = don't know / Angazi	6	6	6	6	6	6	6	6	6	6	6	6	6	6	6

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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	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	2a
	2b = stabbed / wagwazwa	2b	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	2c
	2d = poisoned / ufakelwe ubuthi	2d	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	2e
	2f = other (specify) / okunye (cacisa):	2f	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	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

4.10a: When the child needs to take medication, I remind or watch them take it.... / Uma umtwana kufanele adle imithi yakhe ngiyamkhumbuzo noma ngimgade uma leyithatha....

- 1 = Every day / Zonke izinsuku
 - 2 = Some days / Ngezinye izinsuku
 - 3 = Never → Why not? / Angizange → Yini Indaba?
-

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

4.10b: 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 ngekhandela 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, ebukeya 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 yombuzo4.11 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 kangoono 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

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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 / Uyamshela 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 / Uyamshela umtwana wakho ukuthi ukubonga kangakanani ukuba wusizo kwakhe endlini	1	2	3	4	5

**SECTION 5: COPING
/ ISIGABA 5: UKUQINISELA**

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Question Number / Inombolo 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 / Kancanyana	3 = Some of the time / Kwezinye izikhathi	4 = Most of the time / Ngezikhathi eziningi	5 = All of the time / Ngasonke 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 nemfudumalo.	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 ongakunika iminingwan 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 ongakwenzela 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 ngemisebenzana 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 izinkinga zakho.	1	2	3	4	5

Question Number / Inombolo yombuzo5.2 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 / Kancanyana	3 = Some of the time / Kwezinye izikhathi	4 = Most of the time / Ngezikhathi eziningi	5 = All of the time / Ngasonke isikhathi
5.1s	Someone to love and make you feel wanted. / Umuntu onguathanda futhi akwenze uzizwe 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 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/ohle kisana naye (wesilisa)	Female partner/spouse/girl-friend / Umlingani wesifazane/inkosikazi/ohle kisana 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 bomuntu 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) / Wakuboleka 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 yombuzo5.2 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/boy-friend / Umtingani wesilisa/ umkhwenyana/ohleki/sana naye (wesilisa)	Female partner/spouse/girl-friend / Umtingani wesifazane/inko sikazi/ ohleki sana naye (wesifazane)	No one / Akekho	Doesn't apply: never needed this help / Akungeni kimi: angikaze ngiludingi lolusizo	Other(s) (specify relationship to carer and gender of each person by marking 'M' or 'F') / Abanye (cacisa ubudlelwane nomnakeleli, ubulili bomuntu 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-gwane eyakusiza ukuthatha isinqumo esihlakaniphile nokuxazulula inkinga? Uma 'cha'faka uphawu ku "akekho". Uma 'yebo,' buza: Ubani lowomuntu okunike ukusekelwa okukhulu ngeseluleko esihle noma iminin-gwane 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 cheering 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 yombuzo5.2 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 / Uababa	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/ umkhwenyama/ hlekisana naye (wesilisa)	Female partner/spouse/girl-friend / Umlingani wesifazane/inkosikazi/ ohlekisana naye (wesifazane)	No one / Akekho	Doesn't apply: never needed this help / Akungeni kimi: angikaze ngiludingi lolusizo	Other(s) (specify relationship to carer and gender of each person by marking "M" or "F") / Abanye (cacisa ubudlelwane nomnakeleli, ubulili bomuntu 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 ngokukukhuthaza 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 zansukuzonke.	Would you say... / Ungathi				
		1 = Not at all important / Azibalulekanga neze	2 = A little important / Zibaluleke kancane	3 = Neither important nor unimportant / kunokubaluleka noma akubalulekanga	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 ngokomphefumulo (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 ungenza ngcono kanjani	1	2	3	4	5
5.3e	Companionship (someone to socialise and do fun things with) / Ubungani (umuntu 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 bakuphatha 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 ebhizinisi 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**

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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 asebhodloleni	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/umhoshisa/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 okuneyama?	
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 NGAMAFANA 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 ezahlukahlukeni 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) / Ityipi 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	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	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	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 uqhubekelela 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	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	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 = Another reason (please specify by writing sideways): / Esinye isizathu (sicela uacise ngokubhala emaceleni):	4	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	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	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	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	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 uqhubekelela 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	1
2 = Waiting for a court order / Ulinde umyalelo wasenkantolo	2	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	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 = Another reason (please specify by writing sideways): / Esinye isizathu (sicela uacise 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

7.4e: 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	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	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	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	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 grant office / Akanayo 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 = 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

7.5a: 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. / Ngisiyabonga 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 .

APPENDIX 4: ADULT CARER CONSENT FORM FOR SURVEY



YOUNG CARERS PROJECT

Survey of Caregivers of Children - Participant Information and Consent Form

Purpose and Value of Study

Oxford University (England) and the Health Economics and HIV/AIDS Research Division (HEARD, University of Kwazulu-Natal), in collaboration with the South African Government (Departments of Social Development, Health and Education) are conducting a study to better understand the wellbeing of children and those caring for children. Marisa Casale from HEARD and Tyler Lane from Oxford are the researchers who will be carrying out the study with their teams. Dr Lucie Cluver and Caroline Kuo, from Oxford University, will be the Principal Investigators for the study.

Sharing your experience as a caregiver is very important because we know very little about who is caring for children and the challenges that caregivers face. The information you share will help government officials, and organisations helping children and caregivers to better understand your needs. This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee and the University of Kwazulu-Natal's Humanities and Social Science Ethics Committee.

Potential Participants and Procedures

You are being asked to participate in this study because you care for a child(ren). If you agree to be in the study, I will ask you some questions about you, your health, the children under your care, and your living circumstances. This will take about one hour. I will take notes on what we talk about. All of these notes will be stored in a locked file cabinet and only research staff working on this study can look at this information. If you agree to participate in this survey, we may contact you again and invite you to participate in an interview about your care experiences.

The child who you care for will also be filling in a questionnaire about their lives, health and education. We will ask you in a separate form whether you are happy to give permission for your child to participate. The child will also be asked if he or she wants to participate. If either of you do not want to take part, or want to stop at any point, then just tell a member of the research team.

Discomforts and Risks

This survey should not make you uncomfortable and does not pose any risks. You can refuse to answer some or all of the questions at any time. This decision will not affect any services or help which you or your child are getting or waiting to receive, or have any other penalties. If you want to stop the survey or do not feel comfortable answering questions, just tell any member of the research team at any time. Participation in this survey means that you share some personally identifying information with us such as your name, address, phone number. This personally identifying information will never be given to others. This means that only the research team will have access to this information about who you are. The research team will protect your personal information and comply with all applicable laws.

Benefits

You will receive no direct payment for participating in this research. However, the information you provide is aimed to improve the types of programs and services provided in your community and other communities.

Questions

Please ask Marisa Casale, Tyler Lane, Caroline Kuo, Lucie Cluver and their research teams if you have any questions, comments, or concerns about this study.

Marisa Casale
University of KwaZulu-Natal
Westville Campus
Private Bag X54001
Durban
4000 South Africa
Telephone: 031 260-2592
Fax: 031 260-2587
Email: casale@ukzn.ac.za

Tyler Lane
Visiting Scholar at University of KwaZulu-Natal
Westville Campus
Private Bag X54001
Durban
4000 South Africa
Telephone: 031 260-2592 or 083 342-8957
When not in South Africa, an SMS can be sent
to: +44 (0) 7912 648949
tyler.lane@gtc.ox.ac.uk

Dr Lucie Cluver
Dept of Social Policy & Social Work
Oxford University, England OX1 2ER
Telephone in UK: +44 (0) 1865 280370
Telephone while in South Africa: 082 650-5815
When not in South Africa, an SMS can be sent
to: +44 (0) 7980 85651
Email: lucie.cluver@socres.ox.ac.uk

Caroline Kuo
Dept of Social Policy & Social Work
Oxford University, England OX1 2ER
Telephone while in South Africa:
031 260-2592 or 076 811-5898
When not in South Africa, an SMS can be sent
to: +49 (0) 1520 458 8976
caroline.kuo@nuffield.ox.ac.uk

CONSENT

Participation in this study is voluntary. This means you can refuse to be a part of this study or you can decide to withdraw from this study at any point without penalty or loss of benefits. If you wish to stop at any time, just, tell Marisa Casale, Tyler Lane, Caroline Kuo, Lucie Cluver or their research teams.

Have you read or been read this information and understood the information given to you here?

Yes No

Have you had your questions answered by Marisa Casale, Tyler Lane, Caroline Kuo, Lucie Cluver or their research teams, received answers, and been able to ask for additional information?

Yes No

Do you understand that this study has been reviewed by the University of Oxford Central University Research Ethics Committee and the University of KwaZulu-Natal's Humanities and Social Science Ethics Committee?

Yes No

Do you understand that you can withdraw from the study without penalty at any time by telling any member of the Oxford/HEARD research team?

Yes No

Do you understand who will have access to your data, how this data is stored, and what happens to the data at the end of the study?

Yes No

Sign your name if you understand what is expected to take part in the study and agree to participate:

Signature of Person Giving Consent

Printed Name

Date

Signature of Researcher Gaining Consent

Printed Name

Date

Signature of Person Witnessing Consent
(only if participant is illiterate)

Printed Name

Date

APPENDIX 5: ETHICS APPROVAL LETTERS FOR SURVEY RESEARCH



RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL: sshrec@ukzn.ac.za

5 MAY 2010

DR. L. CLUVER
DEPARTMENT OF SOCIAL POLICY & SOCIAL WORK
UNIVERSITY OF OXFORD
c/o HEARD - UKZN

Dear Dr. Cluver

PROTOCOL REFERENCE NUMBER: HSS/0245/09
PROJECT TITLE: "The Carer-Child Wellbeing Project: KwaZulu Natal uKunakekela Project"

FULL APPROVAL NOTIFICATION – COMMITTEE REVIEWED PROTOCOL

This letter serves to notify you that your response in connection with the above study has now been granted full approval by the Social Sciences & Humanities Research Ethics Committee:

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol

Yours faithfully

.....
PROF. S COLLINGS (CHAIR)
SOCIAL SCIENCES & HUMANITIES RESEARCH ETHICS COMMITTEE

cc. Ms. Marisa Casale
cc. Prof. Don Operario
cc. Caroline Kuo
cc. Dr. Mosa Moshabela
cc. Tyler Lane

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,

Dr Chris. Ballinger

cc: Elaine Evers, Department of Social Policy and Social Work

HBP/CAJB



social development

Department:
Social Development
REPUBLIC OF SOUTH AFRICA

PRIVATE BAG X901
PRETORIA
0001

Enquiries: Dr M.C. Kganakga
Tel: (+27) 12 312 7962 / 7963
Fax: 086 615 5478
E-mail: malegak@socdev.gov.za

Attention: Dr Lucie Cluver and Dr Don Operario
Oxford University and Brown University

To Whom It May Concern:

The Department of Social Development wishes to offer support for your research to study health and psychological risk outcomes for South African children affected by HIV and AIDS. There is a need for rigorous research to guide prevention, intervention and policy initiatives for children affected by HIV and AIDS. This proposed work will provide a foundation for evidence-based responses.

We are pleased that this research focuses on children with unwell parents in addition to orphaned children, as this will help to clarify the processes by which children experience health and psychological adversity. This information can also point to strategies for ameliorating the stress experienced by children affected by HIV and AIDS.

The Department will be pleased to offer technical support during the various phases of the research effort. This will be accomplished through regular meetings and consultations with the National Action Committee for Children Affected by HIV and AIDS (NACCA). The Department wishes to acknowledge the institutions' involvement in the current and previous research efforts on orphans and other children made vulnerable by HIV and AIDS.

The Department wishes you every success in this research.

Kind Regards,

H DIRECTOR GENERAL
DATE 15/12/08



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

INHLOKHOVISI	PIETERMARITZBURG	HEAD OFFICE
Imbuzo: Enqulries: 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.

RESOURCES PLANNING DIRECTORATE: RESEARCH UNIT
Office No. G25, 188 Pietermaritz Street, PIETERMARITZBURG, 3201

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

University of Cape Town

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

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

APPENDIX 6: CARER CERTIFICATE OF PARTICIPATION



YoungCarers
PROJECT SOUTH AFRICA



This document certifies that

.....
*has participated in the
Young Carers Project KZN study.*

.....
Project Manager

.....
Date



We thank you for your participation. Here is a list of help lines should you need any assistance.

AIDS Helpline	0800 012 322
Alcoholics Anonymous	031 301 4659
Cancer Association of South Africa (CANSA)	0800 22 6622
Childline	0800 055 555
Child Protection Unit	031 307 7000
Children in Distress (CINDI)	033 345 2970
Compassionate Friends (support for bereaved families)	011 440 6322
Crime Stop	0800 600 10111
Department of Social Services & Poverty Alleviation	0800 220 250
Department of Health	031 312 0121
Diabetes	011 792 9888
Diet Line	0860 22 32 22
Drugwise (Gauteng)	011 483 3880
Durban Children's Society	031 312 9313
Durban AIDS Training Info & Counselling Centre (ATICC)	031 3003 104
Emergency Service	10177
FAMSA (Family & Marriage Society of SA)	031 202 8987
Flying Squad	10111

Heart Foundation SA	0860 22 32 22
HIV/AIDS Action Unit	0800 012322
Lifeline (national number)	0861 322 322
Lovelife (Advice on Sexual Matters)	0800 121 900
Medic Alert	021 425 7328
Organ Donor Foundation	0800 22 6611
Police Station (local)	10111
Rape & Trauma Line	0860 004 523
Rape Crisis Centre	0861 322 322
SA Federation of Mental Health	031 207 2717
SA Sexual Health Association	0860 100 262
Suicide Crisis Line	0800 567 567
Smokenders	011 784 7838
TREE	031 579 4711
Teenage Pregnancy	0800 035 553
Vaccine Helpline	0860 160 160
Woman Abuse	0800 150 150
Women's Health	0800 116 941

If you have any questions or concerns, feel free to contact Marisa Casale (031 260 2592, or casale@ukzn.ac.za) or Tyler Lane (083 342 8957, or lane@ukzn.ac.za) at HEARD, University of KwaZulu-Natal, Westville Campus, Private Bag X54001, Durban, 4000 South Africa

APPENDIX 7: TEXT OF CONSENT FORM FOR QUALITATIVE INTERVIEWS

Social Support and Caregiver Health Project:

Participant Information and Consent Form (English version)

Purpose and Value of Study

The Health Economics and HIV/AIDS Research Division (HEARD, University of KwaZulu-Natal) is conducting a study to better understand how social support affects the health and wellbeing of caregivers of children. Marisa Casale from HEARD is the lead researcher who will be carrying out the study with her team.

Sharing your experience as a caregiver is very important because we know very little about the support caregivers of children are receiving from family, partners, friends and the broader community, and how this helps them cope with the health and other challenges they are facing. The information you share will help government officials and organisations helping children and caregivers to better understand your needs. This study has been reviewed by and received ethics clearance through the University of Kwazulu-Natal Humanities and Social Sciences Research Ethics Committee.

Potential Participants and Procedures

You are being asked to participate in this study because you care for a child(ren) and you participated in the uKunakekela 'Young Carers' survey. If you agree to be in the study, I will ask you some questions about yourself, your health, your living circumstances, the type of support(s) you receive from family, friends and the community, and how you see this as affecting your health and ability to cope with challenges faced. I will conduct a maximum of two interviews with you and each will take about one hour. I will take notes on what we talk about. All of these notes will be stored in a locked file cabinet and only research staff working on this study can look at this information. If you do not want to take part, or want to stop at any point, then just tell a member of the research team.

Discomforts and Risks

These interviews should not make you uncomfortable and do not pose any risks. You can refuse to answer some or all of the questions at any time. This decision will not affect any services or help which you or your child are getting or waiting to receive, or have any other penalties. If you want to stop the survey or do not feel comfortable answering questions, just tell any member of the research team at any time. Participation in this study is voluntary. This means you can refuse to be a part of this study or you can decide to withdraw from this study at any point without penalty or loss of benefits. If you wish to stop at any time, just, tell Marisa Casale or her research team.

Participation in this study also means that you share some personally identifying information with us such as your name, address, phone number. This personally identifying information will never be given to others. This means that only the research team will have access to this information about who you are. The research team will protect your personal information and comply with all applicable laws.

Benefits

You will receive no direct payment for participating in this research. However, the information you provide is aimed to improve the types of programmes and services provided in your community and other communities.

Questions

Please ask Marisa Casale and her research team if you have any questions, comments, or concerns about this study. Her contact details are below.

Marisa Casale
Health Economics and HIV/AIDS Research Division
University of KwaZulu-Natal, Westville Campus
Private Bag X54001
Durban 4000
South Africa
Telephone: 031 260-2592 or 082 9090276
Fax: 031 260-2587
Email: casale@ukzn.ac.za

If you have questions about your rights as research subjects, you may ask to speak with Phume Ximba at the University of Kwazulu-Natal Human and Social Sciences Ethics Committee, at this number: (031) 260 3587

CONSENT

Have you read or been read this information and understood the information given to you here?

Yes No

Have you had your questions answered by Marisa Casale or her research team, received answers, and been able to ask for additional information?

Yes No

Do you understand that this study has been reviewed by *(enter name of ethics committee once ethics approval received)*?

Yes No

Do you understand that you can withdraw from the study without penalty at any time by telling any member of the HEARD research team?

Yes No

Do you understand who will have access to your data, how this data is stored, and what happens to the data at the end of the study?

Yes No

Sign your name if you understand what is expected to take part in the study and agree to participate:

Signature of Person Giving Consent	Printed Name	Date
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Researcher signature	Printed Name	Date
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Signature of Person Witnessing Consent	Printed Name
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(only if participant is illiterate)

Date

APPENDIX 8: TOPIC GUIDE FOR QUALITATIVE INTERVIEWS

Topic guide for Social Support and Caregiver Health project interviews

NOTE: text in italics are notes for the interviewers; text in normal font are questions to be asked to participants

Introduction to the project and carer

- *Remind the caregiver about the objectives of the project and the specific purpose of these interviews.*
- *Ask opening questions:*
 - *What is your name? How old are you?*
 - *How long have you been living in this area?*
 - *How many children are you caring for and what is your relationship to these children?*

Caregiver's general experience of 'social support'

- **When we talk about 'social support' we usually mean informal support from family, friends, support groups or anyone else. This can include companionship, help with material things such as food or money, advice, information, affection or anything else.**
Overall, do you feel social support is important in your life? Are there some types of support that are more important to you than others? Which types? Why?
- **Who is the most important person/people in your life that would provide you with support when you need it? Why? Why would you go to this person/people for support?**

Social support and health

- **Do you ever feel anxious (e.g. worrying a lot, nervous)? Do you think that the type of support you have been telling me about, or any support you receive, can have an effect on this anxiety? If not, why? If yes, how, i.e. what is it about this support that has the effects you are telling me about?**
- **Do you ever feel depressed (e.g. sad, upset, hopeless)? Do you think that the type of support you have been telling me about, or any support you receive, can have an effect on depression? If not, why? If yes, how, i.e. what is it about this support that has the effects you are telling me about?**

- **Do you think this support affects your physical health? If not, why? If yes, how?**

NOTE: For questions above on social support and health, where appropriate probe further for possible pathways and outcomes e.g.

- *effect on psychosocial factors such as self-esteem, sense of belonging or meaning in life*
 - *effects on coping*
 - *perceived effect on physical health through mental health*
 - *perceived direct effect on physical wellbeing*
 - *influence on health-related behaviours*
- Have you ever experienced a negative event/something horrible happen to you, for example death of someone close, accident, flood, fire etc? Did you receive more or less or the same amount of support than usual after this happened to you? Why do you think this is? How do you think the support you received affected your life (or how did it make you feel)?
 - **(Ask if carer has only spoken about positive effects of social support): Have you ever experienced support that you feel is unhelpful or has a negative effect on your health? (If yes) How? (If no) Do you think that it is possible that support can be unhelpful or even have a negative effect on your health? Why?**
 - Do you think that this social support you receive impacts the lives of the children you are responsible for? If so, how? If no, why not?

Sources of support

- The survey you participated in shows that mainly women are providing support to carers in this community. Why do you think this is?
- We also found that women tend to receive more support from family, whereas men from friends and neighbours. Why do you think this could be?
- Overall, do you think this is a supportive community? Why/why not?

Access to social support

- Do you think some people or households in your community are more able than others to access support when they need it? If yes, which types of individuals or households and why do you think this is?
- *(Unless carer has already spoken about these):*

- **Do you think caregivers who are HIV positive or AIDS-ill receive more or less support than other carers? Why do you think this is?**
- **Do you think HIV-positive or AIDS-ill carers receive different types of support compared to other carers?**
- **Do you think it affects their lives and health differently to that of other carers?**
 - *Probe for mental and physical health*
- Do you think caregivers who are physically ill with other illnesses receive more or less support than other carers? Why do you think this is?
- Do you think caregivers who are suffering from anxiety or depression receive more or less support than other carers? Why do you think this is?
- Our study showed that men caring for children receive more support than women caring for children. Why do you think this could be?

Suggestions for intervention and general

- Do you have any suggestions for initiatives to increase social support available to caregivers like yourself in this community?
 - *Government, NGOs, community members*
- Is there anything more we haven't spoken about that you could like to share with me?

Thank carer for his/her time and explain that we will return with feedback on our findings.

APPENDIX 9: ETHICS APPROVAL LETTERS FOR QUALITATIVE RESEARCH



UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

Research Office, Govan Mbeki Centre
Westville Campus
Private Bag x54001
DURBAN, 4000
Tel No: +27 31 260 3587
Fax No: +27 31 260 4609
Ximbap@ukzn.ac.za

31 October 2011

Ms M Casale (651492)
Health Economics and HIV/AIDS Research Division

Dear Ms Casale

PROTOCOL REFERENCE NUMBER: HSS/0473/011

PROJECT TITLE: Investigating the relationship between social support and the health of carers of children in a context of high HIV and AIDS

FULL APPROVAL NOTIFICATION – COMMITTEE REVIEWED PROTOCOL

This letter serves to notify you that your application in connection with the above was reviewed by the Humanities & Social Sciences Research Ethics Committee on 27 July 2011, has now been granted Full Approval following your responses to queries previously raised:

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study. **PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years**

Best wishes for the successful completion of your research protocol

Yours faithfully

.....
Professor Steven Collings (Chair)
Humanities & Social Sciences Research Ethics Committee

cc Dr L Wild
cc Dr K Govender



Graduate School in Humanities University of Cape Town

Room 3.08 Graduate School in Humanities Building
Private Bag X3, Rondebosch 7701
Tel: +27 (0) 21 650 4414 Fax: +27 (0) 21 650 5751
E-mail: anne.wegerhoff@uct.ac.za
Website: <http://www.humanities.uct.ac.za/postgraduate/gradschool/aboutus/>

23 November 2010

Email: casale@ukzn.ac.za

Dear Ms Casale

PhD PROPOSAL

I have pleasure in advising that your research proposal as detailed below has been accepted by the Department of Psychology and the Faculty of Humanities, and was recommended to the Doctoral Degrees Board for approval in the Dean's Circular HUM 07/2010. You will receive formal notification of your candidature from the DDB in due course.

I have attached the Doctoral Degrees Board guidelines for supervisors and candidates for your information.

Best wishes

ANNE WEGERHOFF
GRADUATE PROGRAMMES OFFICER

Name	Student #	Dept	1st Reg	Title
Casale MA	CSLMAR001	PSY	02-Mar-10	The relationship between social support and the health of carers of children in the context of high HIV and AIDS

cc Dr L Wild