CHILD, YOUTH & FAMILY DEVELOPMENT
HUMAN SCIENCES RESEARCH COUNCIL

AN EXPLORATORY STUDY OF THE IMPACT OF PRIMARY CAREGIVER HIV INFECTION ON CAREGIVING AND CHILD DEVELOPMENTAL OUTCOME IN THE ERA OF HAART: PILOTING THE METHODOLOGY

REPORT FOR THE ORGANIZATION FOR SOCIAL SCIENCE RESEARCH IN EASTERN AND SOUTHERN AFRICA (OSSREA): HIV/AIDS CHALLENGE FOR AFRICA RESEARCH PROGRAMME

Principal investigator: Leslie Swartz*
Research team: René Brandt*, Andy Dawes*, Rachel Bray*, Lindiwe Mthembu-Salter* and Mark Tomlinson**

May 2005

Author affiliations:

* Child, Youth and Family Development (HSRC)
** Child Guidance Clinic, University of Cape Town

Address for correspondence:

René Brandt
Child, Youth and Family Development (HSRC)
Private Bag X9182, Cape Town, South Africa
Phone: +27 21 466-7878 Fax: +27 21 466-7989 Mobile: +27 82 432 6400
Email: rbrandt@hsrc.ac.za

Contents

Acknowledgements and dedication 5

Abbreviations 6

Abstract 7

Preface 8

1. Review of the literature and study objectives 10

1.1 Methodology used to source literature 10

1.2 Maternal well-being, childcare and child outcome in the context of HIV/AIDS 11

1.2.1 Impacts on child development 12

(a) Psychological effects 13

(b) Cognitive effects 14

(c) Psychosocial effects 14

(d) Morbidity and mortality 15

1.2.2 Caregiver-child relationship and parental monitoring 16

1.2.3 Functional health and antiretroviral treatment 17

1.2.4 Caregiver's psychological well-being 19

(a) Mental health 19

(b) Coping and social support 21

(c) Stigma and disclosure 24

1.2.5 Contextual influences in the household and broader environment 25

1.2.6 Summary of key conceptual issues 26

1.3 Conceptualisation of caregiving: Dimensions of care 28

1.4 Methods to assess the quality of the caregiver-child relationship 32

1.4.1 Defining and measuring 'care' and 'caring relationships' 32

1.4.2 Psychological measures for assessing quality of care 33

(a) Social network-based measures of care 33

Home Observation Measurement of the Environment 34

Caregiver Language Observation Instrument 35

Child Behaviour towards Parenting Inventory 35

Hundeide's International Child Development Programmes 36

(b) Dyadic measures of care 36
Global Rating Scale (GRS) 37
Strange Situation Procedure (SSP) 38
1.5 Study aims and objectives 40
2. Research procedure / methodology 43
2.1 Site selection 43
2.1.1 Description of site 43
2.2 Selection of research participants 44
2.2.1 Sampling strategy 44
2.2.2 Description of sample 45
2.3 Selection and design of research tools 45
2.3.1 Interview part I: Questionnaire 47
(a) Centre for Epidemiologic Studies Depression Scale 48
(b) Spielberger State Anxiety Inventory 48
(c) Brief COPE 49
(d) Medical Outcome Study's Social Support Survey 49
2.3.2 Interview part II: Semi-structured/ exploratory interview 51
2.3.3 Home observation visits 51
2.3.4 Developmental assessments 53
2.4 Translation of instruments 53
2.5 Field testing of tools 54
3. Lessons learned – findings and observations from field testing 56
3.1 Challenges in the field 56
3.2 Interview procedures (Questionnaire and semi-structured/ exploratory interview) 58
3.2.1 Questionnaire 58
3.2.2 Semi-structured/ exploratory interview 64
3.3 Observation of childcare in the home setting 67
3.3.1 Description of observational tool 67
3.3.2 Description of the home-based informal interview 70
3.3.3 Application of the observational tools 71
3.4 Developmental assessment (Griffiths and brief tool) 74
3.5 The multi-method approach 76

3.5.1 Understanding the psychological well-being of HIV positive women caregivers 77
3.5.2 The wisdom of disclosure 80
3.5.3 Understanding the context of childcare 83
Chapter 4. Conclusions and recommendations 87
4.1 Concluding remarks 89
4.2 Recommendations 89
4.2.1 Recommendations for research practice 89
(a) Ethical and procedural issues in the context of HIV/AIDS 89
(b) Responsibility to the community that is being researched 91
(c) Local culture, languages and translation 91
(d) Assessment of young children 91
(e) Filming in the home 91
4.2.2 Recommendations for a more psychologically-oriented approach to caregiver-child observation 92
References 98

Appendix A. Questionnaire i
Appendix B. Household roster xviii
Appendix C. Record sheet for observation of childcare in the home setting xxi
Appendix D. Home-based interview guide xxii
Appendix E. Developmental assessment xxiv
Appendix F. Example of full case record: Case no. R3 xxvi

Figures, tables and boxes

Figure 1.1 Conceptual model of the impact of primary caregiver HIV infection on childcare and child well-being 12

Table 2.1 Summary descriptive data on caregivers and their children 46

Table 3.1 Example of data using observational tool 69

Box 1.1 Key findings on maternal well-being, childcare and child well-being 27

Box 1.2 Environmental conditions for healthy child development 34

Box 1.3 Description of dimensions of Global Rating Scale (GRS) 38

Box 3.1 Extract from example of revision to Social Support Survey 60

Box 3.2 Example of revised questions on household economic viability 61

Box 3.3 Example of revised question on disclosure of HIV status 62

Box 3.4 Example of revised questions on the caregiving niche 63

Box 3.5 Example of further questions for interview schedule 66

Acknowledgements and dedication

We would like to acknowledge and thank Lindiwe Mthembu-Salter who conducted the interviews for the study, and built the kind of relationships which allowed such rich material to emerge. Thanks also to Nthombesizwe Dondola who conducted the developmental assessments with the children, to Underé Deglon who assisted with the literature review; and to Amelia van der Merwe and Alison Breen who provided technical assistance. The support and assistance of the staff at Nomzamo Clinic, in particular Dr Catherine Orrell, helped to make the study possible. A special thanks to the women and their children who participated in the study and gave so willingly of their time to share the intimate details of their lives.

This paper is dedicated to the first respondent who, sadly, passed away shortly after the study's completion, under circumstances which have yet to be properly explained. Her narrative is a testament to courage and strength in the face of adversity.

Abbreviations

ART	antiretroviral therapy
C	child
CABA	Children affected by HIV/AIDS
CES-D	Centre for Epidemiologic Studies Depression Scale
DG	Disability Grant
E. Cape	Eastern Cape province (South Africa)
ECD	early childhood development
GRS	Global Rating Scale
HAART	highly active antiretroviral therapy
HOME	Home Observation Measurement of the Environment
ICDP	International Child Development Programmes
Masi.	Masiphumelele
MOS-SSS	Medical Outcome Study Social Support Survey
Mozam.	Mozambique
NGO	non-governmental organisation
PLWHA	People living with HIV/AIDS
R	respondent
SSP	Strange Situation Procedure
TB	tuberculosis

Abstract

The study's primary objective is to pilot the methodology for research into the effects of primary caregivers' HIV infection on child-care and child development in households. Five HIV positive women on antiretroviral therapy, who were the primary caregiver of an HIV negative child less than six years old, were administered a questionnaire and semi-structured interview. The children underwent a developmental assessment, and two home observations were conducted in each household. The multi-method approach produced a conceptually rich, dynamic understanding of the impact of caregiver infection that future research can build on by revising the examination of relational aspects of care.

Keywords: HIV/AIDS, methods, caregiving, child development, psychological effects

Preface

In mid 2002, the Organization for Social Science Research in Eastern and Southern Africa (OSSREA) launched a call for proposals for research to address the HIV/AIDS challenge in Africa. Financial support was provided by Sida/SAREC. The project sought to attract research in the following areas:

- Economic impacts of HIV/AIDS (including macroeconomic impacts, sectoral impacts, poverty impacts).
- Social impacts of HIV/AIDS (including changes in family structure, stigma and migration).
- Gender and HIV/AIDS (including power imbalances, women's rights, vulnerability differentials, gender sensitive policies).
- HIV/AIDS and response mechanisms (including coping, actors, modalities and types of social support and other intervention strategies).

The current research falls mainly into the final category and addresses two of the objectives outlined in the call, specifically, the manner in which HIV/AIDS impacts on women as mothers and their situation, how they cope with the syndrome, and the role played by social support.

This study is informed by the disciplines of Psychology and Social Anthropology. It is primarily a methodological contribution that seeks to explore the appropriateness of a range of psychological and anthropological techniques in contributing to our understanding of the effects of primary caregivers' HIV infection on their child-care practices and relationships with their young children. In addition, the study explores child development

outcomes. Apart from the methodological knowledge gained during this research, it provided us with many insights into the world of African women living courageously with the multiple burdens of AIDS, stigma, poverty and childcare. It was a humbling experience.

The authors and the Human Sciences Research Council of South Africa are grateful to OSSREA and Sida/SAREC for making the funds available to conduct this investigation. It is not often that grants are awarded for methodological enquiries. These are essential if we wish to improve the science and the quality of the interventions we provide to African women and children affected by AIDS.

CHAPTER 1. REVIEW OF THE LITERATURE AND STUDY OBJECTIVES

The key objective of this chapter is to present a critical review of the literature with a view toward informing the objectives and design of the present study. First, critical conceptual issues regarding the impact of primary caregiver HIV infection on caregiving and child well-being are discussed. The factors that impact on the quality of caregiving provided to young, HIV negative children by HIV positive caregivers living in impoverished communities will be explored, as well as the impact of quality of care on children's morbidity, morality and psychosocial, psychological and cognitive outcomes. Second, the review will more closely examine the conceptualisation and assessment of caregiving and caregiver-child relationships, given its important role in understanding the impact of primary caregiver HIV infection. Finally, the study's aims and objectives, as informed by the literature, will be stated.

1.1 Methodology used to source literature

The review draws on both published and unpublished material from 1990 to 2005 which was largely identified using keyword searches of electronic databases. Keywords used included HIV/AIDS, mother or caregiver, child or infant, caring or caregiving, psychosocial or mental health, depression or anxiety, stigma or disclosure, and social support or coping. Databases sourced were: PsycINFO and PsycARTICLES; Academic Search Premier; Medline; Family and Society Studies Worldwide; Child Abuse, Child Welfare and Adoption; Sociological Abstracts; Ebsco Electronic Journals Services; Index to South African Periodicals (ISAP); South African ePublications; and PubMed, ISI Web

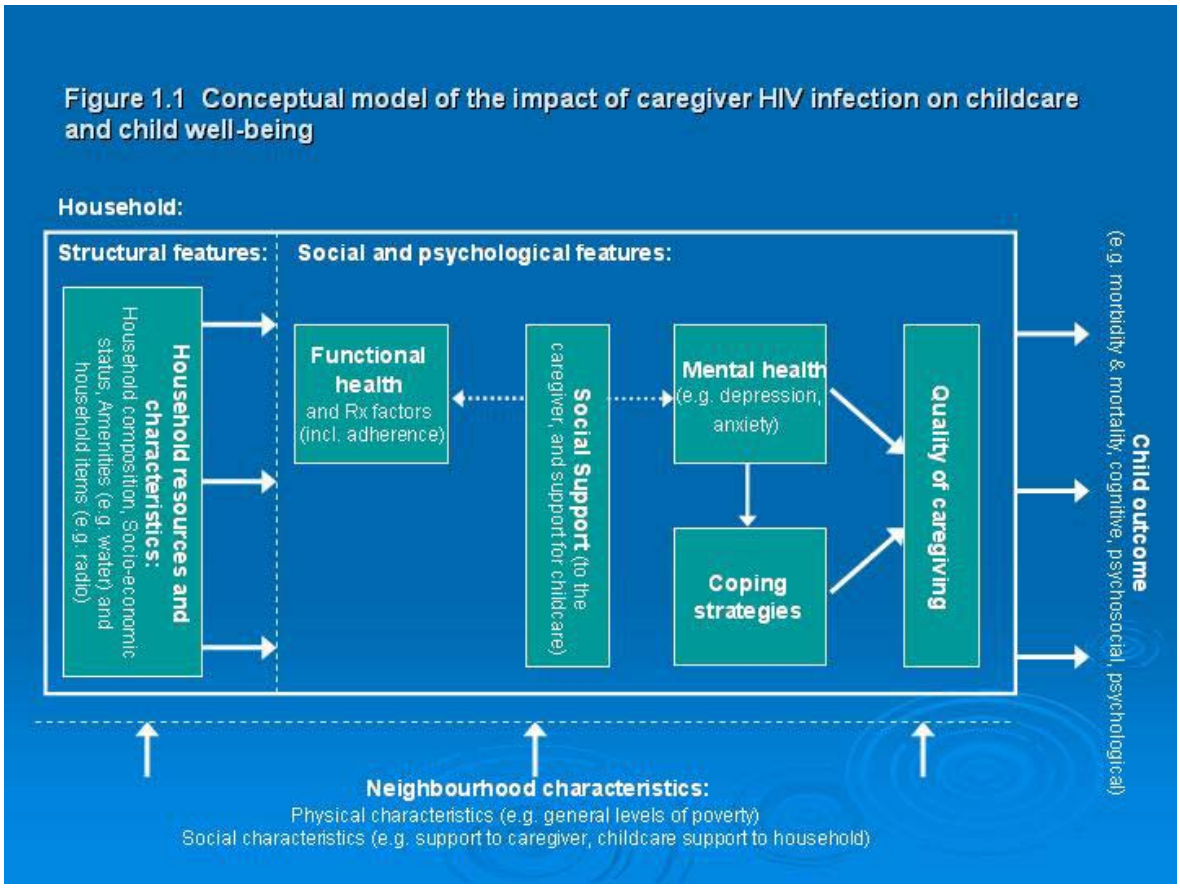
of Science and ProQuest. Further, a limited number of additional papers were identified by scanning the reference lists obtained through the above-mentioned sources.

It should also be noted that the majority of literature available draws on samples of North-American mothers and children. Further, many of the studies cited form part of Forehand et al.'s Family Health Project (2001), a 5-year longitudinal investigation of 249 inner-city African-American women and their 6- to 11-year-old children. Thus, rather than referring to the context of each specific study, details of sampling will be specified only where the research has been conducted in an African country or where it might be related to the milieu of interest in the proposed research.

1.2 Maternal well-being, childcare and child outcome in the context of HIV/AIDS

As already noted above, this section of the review aims to critically examine the literature on maternal well-being, childcare and child outcome in the context of HIV/AIDS. The model presented below will be drawn upon in order to structure the discussion, with a view towards substantiating the study's aims (see Figure 1.1 below).

The review will largely focus on the social and psychological features of the caregiver situated within the household (see Figure 1.1), and its implications for the care of children and, ultimately, their developmental outcomes, including morbidity, mortality, cognitive, psychosocial and psychological outcomes. This component of the model represented in Figure 1.1 has also been the focus of most of the psychological literature. As will be evident, caregiver's functional health, in particular their HIV status, has direct (and



indirect) implications for the levels and types of social support which they receive, which in turn affects their mental health and coping strategies. Further, these factors combine to influence the quality of caregiving that mothers and women caregivers are able to provide to their children. While less attention is paid in the literature to structural features of the household or characteristics of the neighbourhood and surrounding environment (e.g. general levels of poverty, childcare support to household), a few comments regarding these features and their role in the model will be made. This aspect of the model, however, is largely the contribution of the present study (as opposed to previous research), as will be discussed later.

1.2.1 Impacts on child development

Several studies have found that parental illness, and HIV/AIDS specifically, effects children's development in a range of ways.

(a) Psychological effects

There is considerable evidence to indicate that the children of HIV positive women are likely to be at high risk for emotional and psychological problems (Armistead, Klein and Forehand 1995; Forehand et al. 1998a; Wild 2001). The nature of HIV/AIDS itself has also been found to lead to children's experience being characterised by uncertainty, stigma, secrecy and isolation (Antle et al. 2001; Geballe, Gruendel and Andiman 1995; Wild 2001) resulting in their parents' experience of HIV/AIDS becoming "unnamed, unspoken, and often unspeakable to children" (Nagler, Adnopoz and Forsyth 1995:75).

Children have been reported to experience biopsychosocial symptoms such as malaise, loss of appetite and sleep disturbance, increased attachment behaviours, regression, frightening fantasies, and the reactivation of premorbid psychiatric symptoms (Lewis 1995). At least some of these symptoms, in particular regression and the reactivation of previous symptoms, are likely to be the consequence of children's feelings of hopelessness, loneliness, anger and confusion (Wild 2001). Adolescents report feeling different, having secrets, worrying and difficulties with caretaking, grappling with core assumptions about life, and fearing death (Reyland, Higgins-D'Alessandro and McMahon 2002). They are also more likely to display destructive coping behaviours such as acting out (Hudis 1995), impaired school performance (Woodring 2000), and to have (illegitimate) children and conflictual relationships with their mothers (Duggan 2000).

An important finding of the literature on the psychological effects of parental HIV/AIDS is that children are more likely to display internalising such as anxiety, depression, withdrawal and attention problems, than externalising symptoms such as aggression and behaviour problems (Elkin et al. 1995; Forehand et al. 2002; Forsyth et al. 1996; Gerstadt 2003; Kotchick et al. 1997b; Wild 2001). Consequently, symptoms can be masked from the attention of significant adults in the children's environments (Forehand et al., 2002; Forsyth et al., 1996; Gerstadt 2003; Kotchick et al. 1997b). Alternatively, others have suggested that children may under-report their symptoms and problems because they are not permitted by their mothers to discuss these topics openly (Gerstadt 2003).

(b) Cognitive effects

Research has shown that children of HIV positive mothers are at greater risk for lower levels of cognitive and social competence (Forehand et al. 1998a), as well as language disorders (Elkin et al. 1995).

(c) Psychosocial effects

HIV/AIDS also has a considerable range of psychosocial implications for children. Children are likely to be faced with the cumulative presence of "a set of material and psychosocial stressors" during the course of a caregiver/mother's illness, as well as following their eventual death (Hunter and Williamson 2002; Richter, Manegold and Pather 2004; Wild 2001:8). Studies show that children are likely to experience economic deprivation and disrupted schooling, which can result in them becoming care providers and assuming increasing household responsibility in order to ward off problems regarding shelter, material needs and access to adequate health services (Fair et al. 1995; Foster and Williamson 2000; Wild 2001). Consequently children become more vulnerable to abuse

and exploitation (Foster and Williamson 2000; UNICEF 2004), and may experience a loss of educational opportunities and health status, and even increased exposure to HIV infection (Hunter and Williamson 2002). Adolescents report frequent changes of residence (Duggan 2000), family role reassignments (Reyland, Higgins-D'Alessandro and McMahon 2002) and a lack of social supports and other resources (Hudis 1995; Reyland, Higgins-D'Alessandro and McMahon 2002); and experience multiple losses, including loss of caregivers, stigma and isolation (Hudis 1995; Reyland, Higgins-D'Alessandro and McMahon 2002; Woodring 2000), and difficulties identifying and maintaining custody placements (Hudis 1995).

(d) Morbidity and mortality

Several studies have drawn attention to the survival of children born to HIV positive mothers, an issue which is of particular relevance in Africa given the high rates of maternal, infant and child mortality on the continent relative to the developed world (UNICEF 2004). Several large-scale studies conducted in Africa, including a longitudinal study, found that child mortality is highly associated with the mother's HIV status. While some of these studies suggest that all children with infected mothers are at risk (Crampin et al. 2003), a study conducted in nine sub-Saharan countries showed that this finding holds only for children born to mothers who are at an advanced (as opposed to asymptomatic) stage of the disease, regardless of the HIV status of the child (Newell et al. 2004).

The increased risk of death among children has been shown up to the age of three (Sewankambo et al. 2000 in USAID 2004; Urassa et al. 2001 in USAID 2004) or five years (Crampin et al. 2003). Further, mortality rates are four times greater among infants and nearly three times greater among children (Nakiyingi et al. 2003 in USAID 2004). Boys

and children born to teenage mothers are at higher risk (ibid). Another important finding is that the death of HIV positive mothers, but not of HIV negative mothers or of fathers, was strongly associated with increased child mortality (Crampin et al. 2003).

1.2.2 Caregiver-child relationship and parental monitoring

While many of these findings are of interest in exploring children's experiences, it is perhaps more useful to understand the pathways which account for these impacts on children. There are several variables which the research shows tend to mediate or moderate the relationship between primary caregiver HIV infection and child outcome, indicating that few, if any, of the associations discussed above are direct.

Key among these moderators is the mother-child relationship. In the broader child development literature, as well as in the context of HIV/AIDS, the quality of caregiving provided to a child has been shown to constitute a significant pathway whereby environmental and individual factors impact on a child's development. Consequently, quality of caregiving, as well as parental monitoring, serve as key mechanisms whereby children are either placed at risk or protected from the adversity associated with parental HIV/AIDS (see Figure 1.1; Bauman et al. 2002; Dutra et al. 2000; Forehand et al. 2002). Research has shown that parental monitoring, regardless of age and ethnicity, is positively associated with a range of child and adolescent outcomes, including enhanced self-esteem and academic performance (Jones et al. 2002). Similarly, further research has found that parenting quality and consistency of the primary caregiver are more predictive of children's cognitive development than parents' HIV status (Holditch-Davis et al. 2001; Jacquess 1994).

The role of parental monitoring seems to be accounted for by the lower levels of effective parenting behaviours which have been found amongst HIV positive caregivers (Armistead, Klein and Forehand 1995; Fair et al. 1995; Forehand et al. 2001; Kotchick et al. 1997a; Wild 2001). These include: reduced parental support for the child, fewer efforts at discipline and supervision more generally, neglect of the child due to reorganisation of the family around illness, changes in family routines, and parental absence. The lack of adequate care and control may be the result of caregivers wrestling with their own feelings of guilt and anxiety (Fair et al. 1995; Foster and Williamson 2000; Wild 2001), together with the fact that the dynamic nature of symptoms in HIV disease can be distressing and frustrating to caregivers (Hudson, Lee and Portillo 2003).

1.2.2 Functional health and antiretroviral treatment

Clearly, living with HIV/AIDS has multiple implications for caregivers' functional health, with the extent of symptoms and consequent impairment differing with the stage of illness. In a study conducted in rural Uganda, Mast et al. (2004) found that HIV positive women (reported) poorer health and physical functioning, more pain, and poorer role functioning and overall quality of life than non-HIV positives in the same community. Furthermore, age and more general social problems like stress, housing and social isolation were found to be negatively associated with health status amongst persons living with HIV/AIDS (Stewart, Cianfrini and Walker 2005).

While the quality of the parenting relationship in general amongst infected parents has been found to mediate child adjustment (see 1.2.2 above), an important qualifier is that the research tends to show that disruptions are only evident in parents with advanced stage disease. The stage of the caregiver's illness or their functional health, is thus predictive of

disruptions in the quality of the caregiver-child relationship and children's security of attachment, rather than their HIV status per se (Black, Nair and Harrington 1994; Forehand et al. 1998b; Hale et al. 1999; Johnson and Lobo 2001; Peterson et al. 2001).

The role of functional health may be due to the fact that, in comparison with symptomatic mothers who are less able to interact positively with their infants and children (Peterson et al. 2001), asymptomatic mothers experience less stigma and rejection by society (Srisurapanont, Sombatmai and Jarusuraisin 2002), become more tolerant and involved than previously (Black, Nair and Harrington 1994), and attempt to compensate for their eventual absence (Johnson and Lobo 2001). Even in the face of HIV/AIDS, the well being of children is still (often) the primary concern of mothers (DeMatteo et al. 2002), and many women maintain their parental status, even at the cost of their own physical and emotional well-being (Ciambrone 2003; Freeman 2004). Alternatively, it has been argued that mothers may be in denial regarding the eventual outcome associated with their condition while still physically healthy, thereby decreasing the likelihood of potential impacts on the parenting relationship (Black, Nair and Harrington 1994). One study also found that infants themselves may attempt to compensate where HIV positive mothers exhibit difficulties in engaging in the mother-infant relationship (Byrne 1998).

For infected caregivers who have access to antiretroviral therapy (ART), it is also important to note that, in addition to the effects of the illness on functional health (and, potentially, their relationships with their children), the treatment itself can have side-effects. These include: numbness or pain in the feet, diarrhoea, headaches, skin rash, dizziness, sleep disturbances and hepatitis (Department of Health 2004). Further, the

treatment itself, partly due to the side-effects, can be a leading cause of psychological problems. Contrary to some assumptions, there is not equivocal evidence to indicate that patients on HAART experience significantly improved mental health (Bogart et al. 2000; Siegel, Karus and Dean 2004). Rather, some studies have shown that treatment is likely to change the nature of depression (and other mental health problems) rather than preventing them altogether, or significantly decreasing their prevalence (Freeman 2004).

Research has also begun to establish important links between functional health and quality of life, demonstrating that quality of life and HIV symptomatology, treatment effects and side-effects interact with each other. While treatment may result in improved functional health and quality of life, quality of life (mental health, coping and levels of social support) is also necessary to achieve the levels of treatment adherence required for sufficient viral load suppression (Baer and Roberts 2002; Gordillo, del Amo, Soriano and Gonzalez-Lahoz 1999; Judd et al. 2000). This is in addition to treatment-related factors such as fewer numbers of drugs, fewer side-effects, more advanced disease, and greater expectations regarding treatment, that are also associated with improved adherence and functional health.

1.2.4 Caregiver's psychological well-being

The evidence for the role of mental health, coping and social support in maternal well-being, caregiver-child relationships and child adjustment is fairly convincing, and, as demonstrated above, the association with the functional health and adherence to treatment of HIV-infected persons has also been increasingly recognised.

(a) Mental health

Several studies have shown that HIV positive women are at greater risk for depressive symptoms than HIV negative women (Jones, Beach and Forehand 2001a; Miles et al. 1997; Miles, Gillespie and Holditch-Davis 2001; Moneyham et al. 2000; Murphy, Marelich and Hoffman 2002; Morrison et al, 2002). Risk for depression has been associated with an accumulation of health-related factors such as number of physical symptoms, having non-HIV-related medical conditions, perceptions of health, an inability to perform usual activities, and difficulty caring for a child due to ill health; social or contextual factors such as lower education and experiencing more negative life events; and psychological factors such as poor self-esteem, inadequate social support, and lack of family cohesion (Jones, Beach and Forehand 2001b; Miles et al. 1997; Orlando et al. 2005; Silver et al. 2003 Tostes, Chalub and Botega 2004). In some instances, risks to emotional well-being have also been associated with women's need to maintain their parental status (Ciambrone 2003; Freeman 2004).

With respect to the impact on child outcome, mothers' poor psychological functioning has been shown to predict poor monitoring of children, as well as other more general adverse impacts on children's emotional and intellectual development (Jones et al. 2002). Child behaviour problems have been marginally associated with the mother having illness-related activity restrictions but no association was found to other measures of maternal physical health, stigma or disclosure of HIV status to the child (Bauman et al. 2002). The association to child behaviour problems was most marked in older children since this group is more likely to observe and understand the mother's ill health (ibid).

In studies with infants, however, the association between maternal depression and child outcome in the context of HIV/AIDS is equivocal. One study found that while HIV

positive mothers exhibited more depression than HIV negative mothers, depression was not associated with a noticeable reduction in the quality of their interactions with their infants (Johnson and Lobo 2001). Moreover, another study found no relationship between maternal depressive symptoms and children's development, concluding that in populations already at-risk for depression, quality of caregiving rather than depression per se affects children's developmental outcomes (Holditch-Davis et al. 2001).

(b) Social support and coping

Several studies have found evidence for the positive effects of social support for people living with HIV/AIDS (PLWHA), including the benefits to overall quality of life for those with and without access to antiretroviral treatments (Burgoyne and Renwick 2004; Kirksey, Hamilton and Holt-Ashley 2002). However, one study showed that HIV positive women and mothers are 50% more likely than HIV positive men to have unmet needs for social support (Sambamoorti, Crystal and Dermatis 1995), while another found that both HIV infected women and their children received lower levels of socioemotional support than a matched group of non-infected mothers and children (Klein et al. 2000). HIV positive women have also been found to experience significantly less socio-economic, spiritual and family support than HIV negative women (Majumdar 2004). Many infected mothers are either reluctant to, or desist altogether, from seeking assistance (Ciambrone 2003; Thorne 1990). For these women, soliciting support is equated with being a failure as a caregiver, thereby resulting in isolation that places their mental health at further risk (Freeman 2004).

Among the findings which have emerged from particular studies are that HIV-infected women received the highest support from medical personnel and the least from families

(Sienhold 1999), just over half of women are actively involved in a social support network, and less than half of all family members who are aware of their HIV status are supportive (Weiner and Lorber 1998). Similarly, some studies have reported a decline in traditional networks of support in the community (within the African context) (Mbaye and Mbaye 1998).

In contrast, many women receive relatively high levels of support from their children (Weiner and Lorber 1998), a factor which has been associated with increased levels of maternal distress (Kotchick et al. 1997b). This may be indicative of the fact that supportive children tend to act as substitutes in the absence of more adaptive sources of adult support, and further that children are unable to effectively meet the emotional needs of their ill parents/caregivers (Klein et al. 2000). Alternatively, mothers may be more likely to experience their children's need to support them as symptomatic of the failure of their caregiving role. This interpretation is further supported by the fact that higher levels of parenting support have been associated with reduced perceptions of parenting self-competence in HIV-infected women in contrast to non-infected women (Dorsey, Klein and Forehand 1999).

The lack of support for women and mothers is further likely to strain their caregiving capacity, given that support available to the caregiver can improve quality of caregiving, thereby protecting children from maladjustment (Black, Nair and Harrington 1994). Further, research has shown that support from parents is more protective of children's well-being than support from less significant or less proximal others. Thus while higher levels of emotional support from neighbours and friends are associated with less psychological distress amongst children (and women) (Klein et al. 2000), the association is

weaker than with children's perceptions of parental support (Kotchick et al. 1997b). Further, while extra familial support served as a buffer against internalising problems, parental support served as a buffer again both internalising problems (as reported by parents) and child-reported depression (Kotchick et al. 1997b).

In addition to HIV positive women's lack of support which has potential adverse implications for both their and their children's well-being, they frequently use ineffective coping strategies. Women, especially those with lower incomes, have been shown to disengage behaviourally and emotionally from coping with illness and to approach their interpersonal relationships in a less secure and more anxious style, resulting in higher levels of stress in their daily lives than those who use more adaptive strategies (Koopman 2000). Other ineffective strategies which HIV-infected women frequently use include emotion-focused ones such as denial (due to refusal to accept their status), concealment (due to fear of abandonment and the desire to avoid placing additional stressors on uninfected children), and isolation and crying (due to depression and attempts to avoid potential rejection) (Hackl et al. 1997; Uthis 2000). Another study, however, found that HIV positive mother's emotion-focused, as opposed to avoidant or problem-focused, coping was associated with lower levels of maternal depression and healthy infant cognitive development (Riccobono 1995).

Other research on coping has found that the appraisal of stress as challenge rather than threat or loss, and more problem-focused coping, tended to be associated with higher role satisfaction amongst HIV-infected caregivers (Uthis 2000). Further, children's increased use of avoidant coping strategies that gave rise to increased internalising problems was predicted both by parent-child relationship problems and parents' depressive symptoms

(Steele, Forehand and Armistead 1997). The latter finding provides support for the link between maternal well-being, parent-child relationships or caregiving, and child adjustment.

(c) Stigma and disclosure of HIV status

Among the many other challenges faced by mothers with HIV/AIDS that place their emotional well-being at risk, are AIDS-related stigma and decisions regarding disclosure. While disclosure may facilitate access to social support and health benefits, reduce risks of stigma and infecting significant others, and provide an opportunity to openly discuss custody planning (Khan 2004), the fear of stigma, rejection, relationship changes, social isolation, violence, and discrimination against the individual and other family members, remain significant barriers (Shaffer et al. 2001; Kirshenbaum and Nevid 2002; Murphy, Marelich and Hoffman 2002; Letteney and Heft LaPorte 2004). Clearly, all of the negative consequences of disclosure have potentially adverse effects on women's psychological well-being.

Most mothers with HIV/AIDS report carefully weighing the risks and benefits of disclosing their status to others (DeMatteo et al. 2002), with mothers more likely to disclose to older children and to girls (Shaffer et al. 2001). There do not appear to be clear guidelines on the benefits of disclosing to children, the most appropriate age at which to disclose and the most suitable method of disclosure. One study found that 68% of mothers did not disclose their HIV status to their children, and, of those who did, the majority told their child not to disclose her status to other people for fear of repercussions such as stigma and ostracism for both themselves and their child (Murphy, Marelich and Hoffman 2002).

Research has shown that mothers often perceive the consequences of disclosure as considerably more negative than their children. Two studies have found that children reported increased understanding of HIV/AIDS, displayed less aggression and lower levels of negative self-esteem than children who were unaware of their mother's status, and did not report significant psychological distress or behaviour change in response to disclosure (Murphy, Marelich and Hoffman 2002; Shaffer et al. 2001). However, their mothers perceived an increase in negative mood changes in their children immediately after disclosure (Murphy, Marelich and Hoffman 2002), as well as increased child behaviour problems and poorer mother-child relationship (Shaffer et al. 2001). A more consistent finding is that instructing a child to keep one's status a secret is likely to be burdensome to the child, and to be associated with more behaviour problems than found in children not asked to HIV status secret (Kirshenbaum and Nevid 2002; Murphy, Marelich and Hoffman 2002).

1.2.5 Contextual influences in the household and broader environment

Perhaps one of the more important points to emerge from the literature, which is of particular relevance for the present study, is that in the poverty environments that are common to the majority of infected persons, parental HIV/AIDS typically serves as an additional stressor to families and households who are already at-risk. Within the South African context, black women, for example, must deal with the cumulative effects of gender, race and socio-economic status (Owens 2003), a situation which the AIDS epidemic has heightened. Survey data suggests that between half and three-quarters of AIDS-affected households in South Africa are female-headed, with as few as 12.5% of these women having a partner present in the home (Steinberg et al. 2002; UNICEF 2003; Ziehl and Burns 2004). Also significant is the fact that these women frequently experience

an increased care burden, since both sick men and women tend to be cared for by female relatives (UNAIDS 2004). Women are also more likely than men to take in orphaned children (ibid).

The implication of this finding is that stressors other than HIV/AIDS present in the lives of HIV-infected mothers and their children might account in large part for their functioning, thus creating a level of disruption beyond which the impact of maternal HIV-infection does not result in a marked effect (Black, Nair and Harrington 1994). Consequently, the impact of the caregiver's illness on children must be understood within the context of a range of other existent risk and protective factors for both the caregiver and child (Forehand et al. 1998b; Wild 2001). Very few studies have adopted a thoroughly contextual approach in order to directly examine the implications of this finding (see, for example, Case and Ardington 2004).

1.2.6 Summary of key conceptual issues

Perhaps one of the defining features of the literature reviewed is the extent to which the issues it raises are interlinked. While necessary, it is oftentimes reductionistic to articulate clear, linear relationships between any of the model's elements (refer to Box 1.1). The relationships are typically bi-directional and the effects depend on a range of other existent factors, for example, stable life conditions, levels of poverty, and history of coping and mental illness. Despite these complexities, several key findings emerge from the review and point to some of the areas which this, and future studies, could usefully focus on. See Box 1.1 for a synthesis of the findings.

Box 1.1 Key findings on maternal well-being, childcare and child well-being

- Children are likely to be faced with a range of material and psychosocial stressors during the course of a caregiver/mother's illness, but particularly following her death. These may include disruption of schooling, relocation and increased household responsibility. Since many of these children live in families and households who are already at-risk due to issues of poverty, family fragmentation or unsafe neighbourhoods, parental HIV/AIDS typically serves as an additional stressor.
- The nature of the disease can also result in children experiencing multiple losses, as well as considerable uncertainty, stigma, secrecy and isolation.
- Children of HIV positive mothers are at greater risk for emotional and psychological problems than children of HIV negative mothers, and problems are more likely to manifest as internalising behaviour such as depression. Children may also under-report their symptoms and problems so that they remain masked from the attention of significant others in their environment.
- The death of HIV positive mothers, but not of HIV negative mothers or of fathers, has been found to be strongly associated with increased child mortality, particularly in infants and children under five years old.
- Two of the key factors in understanding the pathways to child outcome are: that the stage of the mother/caregivers' illness, rather than HIV status per se, is predictive of disruptions in children's adjustment; and the quality of the parent-child relationship is an important moderating variable.
- HIV positive women and mothers are at greater risk for depressive symptoms than HIV negative women. They also tend to display lower levels of effective parenting behaviours, such as monitoring and discipline, thereby reducing the protective parental / caregiving role.
- While general social problems like stress, housing and social isolation are negatively associated with health status, social support is positively associated with overall quality of life among adults living with HIV and taking antiretroviral therapy. However, HIV infected women and their children received lower levels of socio-emotional support than non-infected mothers and children. Parental support is more protective than extra-familial support for children's psychosocial adjustment, while support from children tends to be associated with maternal distress.
- Disclosure does not appear to have a detrimental effect on the child, but instructions to keep the knowledge a secret appears to be a stressor for some children. Mothers are less likely to disclose their HIV status to boys than to older children or girls. There are no clear guidelines on the benefits of disclosing to children, the most appropriate age at which to disclose, and the most suitable method of disclosure.
- Research has shown that several factors related to quality of life can promote adherence to antiretroviral therapy. These include better perceptions of health, higher levels of coping and perceived social support, lower levels of depression, and stable living conditions.

In light of the significance of the quality of caregiving as a pathway mediating the impact of caregiver HIV infection on child outcome, the remaining two sections of this review

examine the conceptualisation and assessment of caregiving more closely. The discussion of the conceptualisation of care draws primarily on the anthropological literature, and more specifically commentary on fieldwork focusing on the dimensions of care in a variety of settings. Its purpose is to highlight characteristics of the care relationship that should be understood prior to designing tools for measurement. The discussion of measurement which follows draws both on anthropological and psychological literature that informs our approach to the quality of the caring relationship between adults and young children.

1.3. Conceptualisation of caregiving: Dimensions of care

Studies from parts of the 'developing world' show that the notion of a singular carer, often assumed to be the mother, does not reflect either the ideals or the realities of most children's lives. Children are commonly cared for by a number of adults and children, some of them kin and others neighbours or friends. Bromer and Henly (2004:943) observe that non-family members, particularly neighbours and friends, may perform direct care roles and contribute to child care indirectly through support to carers in the family. For example, such indirect care might include advice about child rearing, personal and family matters, assistance with and information about employment, housing, education and financial matters. Further, Reynolds' (1991) notes that responsibility for a child covers a far larger portion of time than discrete child care activities. The methodological implications of these observations are that measurement tools should be able to capture the involvement of, not only siblings and other children in the care of young children, but also the direct and indirect input of non-family members.

According to Bromer and Henly (2004:944), “social support from informal networks has been associated with less material hardship in economically disadvantaged families, and may serve as a buffer against the stresses of poverty, which in turn, may lead to more effective parenting practices.” Interesting questions arise around the nature and level of such care supports in a context of poverty and high HIV prevalence. It would therefore seem appropriate that methods for capturing these inputs are able to distinguish between emotional support, instrumental support (shopping, transport etc), informational assistance and financial support (including lending money).

The anthropological literature points clearly to the effects of history, and in the case of South Africa, of particular social structures that were contrived under the apartheid regime. The labour and pass laws that came into force in the 1950s placed severe restrictions on the movements of people defined as ‘African’. Initially, men moved to cities to find work and the laws prevented their wives and children joining them. Over time, women began to migrate to seek work, often leaving children with extended family or moving children around with them. The result was that most children experienced repeated disruptions in their close care relationships. Recent survey findings show that elements of these labour-related movements continue resulting in the dispersal of family members and frequent interruptions in children’s care relationships (Bray 2003a).

A study of the relationship networks that surround fostered black children in the Northern Province of South Africa found that, due to resource shortages and parents’ consequent inability to care for their children, parents frequently accustomed children to fluid, non-exclusive family relationships: “Bonds between parents and their children in this context are thus very different from those established within nuclear families in affluent societies.

Not only are children's parents not permanently available, but the relationships that children develop are not exclusively or even mainly with family members. Nor are they centred around any one individual" (Van der Waal 1996 in Shelmerdine 2004).

Interestingly, research conducted in other settings finds that children living in families who have in the past, and do currently, experience a range of stressors (including poverty and illness) usually experience a range of care arrangements from kin and non-kin. Mellins' et al. (1996) study among HIV affected families in New York demonstrated that children are cared for by several caregivers, some of whom are considered 'family' but are not biological kin. The similarity in these patterns indicates the impact of socio-economic and political forces on family life, and warns against culturally deterministic notions of standards of care.

In the context of the probability of multiple carers and/or care environments in a child's current or recent experience, it is necessary to consider what constitutes adequate care from the point of view of the child's current and future well-being. LeVine (1990) refers to the child's "everyday expectable environment" as a starting point for capturing the basic elements of the care setting that the child expects to be present. These elements would include at least one person with whom the child can form an attachment and with whom s/he can develop a co-constructed understanding of how the day unfolds. Methodologically, LeVine's concept is useful because it does not prescribe the identity of that 'one person', and it focuses on a co-constructed set of activities and meanings that become familiar to the child. This is a helpful way of approaching the notion of the importance of 'routine' that comes across in standards of child care in the developed world.

An anthropological approach allows us insight into the diversity of care practices and of the meanings associated to them. For example, it has been observed that "the key dimension in parental relationships amongst black people in the Western Cape … is material rather than emotional, and these relationships are conceptualised in reciprocal terms, rather than in the unidirectional terms of parental relationships in the West" (Shelmerdine 2004). This is a somewhat reductionist approach however. While being alert to the potential significance of a material or economic dimension to care, it is important to recognise that material and emotional care are not mutually exclusive. In other words, the provision of money or clothes can be an expression of an emotional caring bond. As Shelmerdine then observes: "A father who lives in another city but sends money to support his children may be considered a good father even though he may never see his children, just as a son living far away who sends money to support his father may be considered a good son" (ibid.).

Research in other parts of Africa sheds light on ingredients of 'good quality care' that are not prioritised in models generated in the industrialised developed world. For example, Weisner (1989) found that amongst the Abaluyia (Kenya), children's work activity networks are a major context for offering and receiving support within and between generations. In other words, assigning a task to a child or asking her/him for help is experienced by the child as comforting and supportive as these behaviours signify integration in the family network (ibid:9). Weisner (ibid) also observed many interactions amongst Kenyan children and their carers that combined messages of support and integration with those of dominance and the importance of social hierarchy (for example teasing and aggression). His interpretation is that children's support network is in this way

like the adult support network they will move into. Such observations suggest a need for tools to measure care that can capture the inclusion of children in daily tasks, rituals and leisure activities because such participation contributes significantly to the child's current sense of belonging, and longer-term social and cognitive development.

1.4 Methods to assess the quality of the caregiver-child relationship

1.4.1 Defining and measuring 'care' and 'caring relationships'

Definitions of the care of children vary in the scope of activities and interactions that constitute 'care'. In their study of sibling caretaking, Weisner and Gallimore (1977:169) define care-taking as "all kinds of socialization, training and routine responsibilities…including simply 'keeping an eye out' for younger sibs". Such a broad definition of care is useful because it allows space for diverse, culturally mediated care practices. That said, any attempt to measure the quality of care requires some kind of benchmark or set of standards. Hundeide's (n.d.) notion of empathic care (as employed in the International Child Development Programmes - ICDP) is a useful starting point in terms of measuring adequate care.

In elaborating the notion of empathic care, Hundeide (n.d.) places strong emphasis on the inter-relational aspect of care. For example, "sensitive care is a communicative or dialectic process in which the caregiver's actions toward the child is [sic] dependent on the expressive appeal of the child's utterances, and conversely, the child's responses are dependent on the caregiver's actions; on how they are attuned to the child's state and how they are received and apprehended by the child" (ibid:3).

Importantly, care is not only what is provided by the carer to the child, but is an interactional relationship between the child and his or her carers. On the basis of her observation of Zimbabwean children, Reynolds (1991:77) noted small acts performed by children for adults and concluded that "the give and take in terms of status, help, exchange of food and companionship are important in both adults and children's lives". Reciprocity performs a key function in healthy care relationships for both individual children and carers. This would suggest that it is also important in producing positive child outcomes. The literature clearly suggests that any methodology for understanding care should be able to capture the child's role in prompting the care actions of others and in influencing the well-being of his or her carers. Clearly this approach goes beyond assessing the carer's actions and emotional inputs, and argues for a methodology that exposes children's participation in care relationships.

1.4.2 Psychological measures for assessing the quality of care

More psychological approaches to the assessment of quality of care comprise both fairly technicist measures of dyadic care and social network-based measures which adopt a broader approach. The selection of measurement frameworks discussed has been made on the basis of their correspondence with the overall approach to care adopted in the study (see 1.5 below) as well as their cross-cultural applicability. It is worth noting that none of the measures was developed in South Africa, or even on the African continent, and the implications of cultural context on their conceptual foundations are illustrated in the section that follows.

(a) Social network-based measures of care

Home Observation Measurement of the Environment (HOME) Inventory

One of the most widely used frameworks for studying care of children is the Home Observation Measurement of the Environment (HOME) Inventory. Items in the HOME were selected on the basis of empirical evidence of the importance of the following types of experience for nourishing the behavioural development of children (see Box 1.2 below; Caldwell 1968 in Bradley and Caldwell 1979).

Box 1.2 Environmental conditions for healthy child development
Source: Bradley and Caldwell (1979)

- The importance of an opportunity to form basic attachments to a mother or mother substitute
- An emotional climate characterised by mutual pleasure
- Sensitive need gratification
- Minimisation of restriction and punishment
- A stimulating and responsive physical environment that offers a variety of modal experiences
- Freedom to explore and master the environment
- Daily schedule that is reasonably orderly and predictable
- Opportunity to assimilate and interpret experience within a consistent cultural framework

The HOME is not as sensitive to differences between adequate and enriched home environments, as it is between adequate and deprived, and is not detailed enough to be a diagnostic, predictive instrument (Bradley et al. 1988). Rather, it is a screening tool which is useful to identify areas of strength and weakness which can inform more detailed assessments needed to formulate interventions. The HOME has also been shown to have cross-cultural applicability and to be sensitive in pointing to variation in norms and practices around child-rearing (Elardo and Bradley in Bradley and Caldwell 1981). This has been demonstrated in the work of South African psychologist, Jane Kvalsvig, who has successfully adapted the HOME Inventory for use in rural Zulu-speaking settings, with due attention to achieving appropriately nuanced concepts and phrasing for the particular

fieldwork setting. It must also be noted that studies of the HOME inventory in different cultural settings conclude that items assessing socio-emotional support have less cross-cultural applicability than those assessing aspects of the environment which provide cognitive stimulation (Bradley, Corwyn and Whiteside-Mansell 1996).

Caregiver Language Observation Instrument

The Caregiver Language Observation Instrument developed by Mary Knox Weir of the University of Illinois provides a scheme for observing the language behaviour of caregivers in an infant day-care setting using eleven categories (see Johnson, 1976).The categories are: approves, disapproves, cautions, soothes, talks to, questions, labels, imitates, elaborates, sings, reads, shows pictures and directs. Given the importance of language as a primary medium for communication within an interactional care relationship, these categories are potentially useful for coding the nature and tone of what carers say to their children in any setting.

Child Behaviour towards Parenting Inventory

Although designed for use with older children (10-18 years), the Child Behaviour towards Parent Inventory is potentially useful for research with young children since it provides a means of measuring the child's experiences of the reciprocal relationship between carers and children (see Schaefer and Finkelstein in Johnson 1976:747). Items on the inventory that provide insight into care interactions with children under five years (perhaps with some modification for this younger age group), include: "Tells me about her friends/ activities", "Tries to do things for herself", "Pushes me away when I get close", "Tries to show me his/her skills", "Likes to sit close to me" and "Smiles at me when I show her affection". The inventory offers the means of coding observed actions that demonstrate

care within a familial home setting, as well as a guide for questions to carers about their relationship with a young child.

Hundeide's International Child Development Programmes (ICDP)

The approach of Hundeide's (1990) International Child Development Programmes (as referred to in 1.4.1 above) emphasises the importance of elucidating the dominant concerns of the caregiver and the way in which his or her concerns for the child fit into this. Drawing on insights generated through the anthropological literature, Hundeide's model pays significant attention to the context of the particular care relationships. In addition to exploring current caregiver concerns, it also recommends asking questions that draw out attitudes and values relating to children and child care: "…we need to know the parents' [sic, read 'carer's'] conception of a good child, of good caregiving and upbringing; child rearing values, the typical course of development and what is expected of the child at different stages, the daily activities and the typical day of a child at different stages etc." (1990:18).

(b) Dyadic measures of care

In addition to the more social network based forms of assessment, there are also a variety of assessment instruments that have been widely used in behavioural research. The advent of cheap video technology facilitated the creation of an entirely new methodology to investigate the minutiae of the caregiver-infant relationship (Gopnik, Meltzoff and Kuhl 1999). The use of these techniques has resulted in a wealth of data that has not only shown the associations between early interpersonal interaction and attachment status and a variety of clinical conditions such as postpartum depression and anorexia nervosa (Murray et al. 1996; Stein et al. 1996), but also provided crucial data on the predictive power of aspects

of early disturbances in the mother-infant relationship and infant attachment on later infant and child social, emotional and cognitive functioning (Lyons-Ruth, Easterbrooks and Cibelli 1997; Murray et al. 1996). This section discusses two such techniques that have been successfully used in South Africa (Cooper et al. 1999).

Global Rating Scale (GRS)

The Global Rating Scale (GRS) was initially developed to investigate the associations between postpartum depression and mother-infant interaction (Murray et al. 1996), but has subsequently been used with a variety of clinical groups (Gunning et al. 2004; Riordan, Appleby and Faragher 1999) and shown to be both valid and reliable across a number of different cultures (Cooper et al. 1999; Gunning et al. 2004). It is an effective measure in that it is neither a time-consuming micro-analytic scale nor overly global, thus ensuring that clinical sensitivity is not lost at the expense of a relatively time-efficient coding system (Gunning et al. 2004). The GRS can be used to assess interaction with infants aged between two and six months.

Mothers are asked to settle their infants, and once settled, the infant is placed in an infant chair opposite the mother. A video camera is placed behind the mother's right shoulder in order to obtain a full view of the infant's face and body, as well as the profile of the mother to ensure that the existence of eye-to-eye contact during the interaction could be scored. A mirror is also placed alongside the infant (to their left) so that a full view of the mother appeared alongside that of the infant in the camera frame (Murray et al. 1996). The mother is asked to play with or talk to her infant, face-to-face, and without toys, for a five-minute period.

The ensuing interaction is videotaped by the researcher from an adjoining room behind a one-way-mirror and interactions rated by coders blind to maternal mental state or group, using the coding system developed by Murray et al. (1996). The system comprises scales which assess the contribution of the mother, the contribution of the child, as well as a rating of the overall quality of the interaction between mother and infant. The maternal scales comprise three dimensions (maternal sensitivity, intrusiveness and remoteness, positive affect) and the infant scales two (behaviour, attentiveness) (see Box 1.3 below for a description of each dimension). The internal consistency of these sub-scales has previously been found to be high (Murray et al. 1996).

Box 1.3 Description of dimensions of Global Rating Scale (GRS)

Dimensions on maternal scales:

1 – Maternal sensitivity: the extent to which the mother responds to her infant's cues in a way that is appropriately adjusted to the infant's behaviour and agenda, and is warm and accepting. Score based on ratings of maternal responsiveness, acceptance, warmth and sensitivity.
2 – Intrusiveness and remoteness: ranges from mothers who are overbearing and over-stimulating to those that withdraw into themselves and become remote
3 – Positive affect: the outward impression of the mother's affective state and the extent to which she is enjoying the interaction with her infant

Dimensions on infant scales:

1 – Infant behaviour: ranges from engaged and vocal in interaction to uncommunicative and engaged in little or no visual contact
2 – Attentiveness: describes the infant's attention either to the environment or to their mother and the infant's level of activity (inert-fretful)

Strange Situation Procedure (SSP)

Ainsworth et al. (1978) developed the Strange Situation Procedure (SSP) to assess the attachment status of infants and toddlers between the age of 12 and 18 months, although it has been used with toddlers up to two years of age (Teti and Nakagawa 1990). The original aim of the strange situation procedure was to assess how infants used adults as 'secure

bases' from which to explore the world, how they reacted to strangers, and finally their response to separation and reunion.

The (SSP) is administered in two adjoining rooms separated by a one-way mirror. The physical arrangements of the room and its contents should ideally remain constant in order to militate against differences in context accounting for differences between infants undergoing the procedure. Facing the mirror are two chairs (one for the stranger and one for the mother) and between the two chairs, on the floor, a collection of toys for the infant, including cuddly toys and dolls, blocks, a number of balls, a small doll's house and a variety of cars and planes.

Episodes are filmed from behind the one-way mirror for later coding of interactive behaviour between mother and child. The child's behaviour is rated on a seven-point scale for each of four dimensions, namely, proximity and contact seeking behaviour, contact maintaining behaviour, avoidance, and resistance (Ainsworth et al. 1978). Ratings on these dimensions are then used to classify children in one of four groups which describe their security of attachment to the caregiver (A-avoidant, B-secure, C-resistant, D-disorganised). Agreement between coders from the same laboratory on A, B, C is high and ranges from 85-95%, while intercoder agreement for the disorganised group ranges from 80%-88% (Solomon and George 1999).

Potential limitations of measures such as the SSP and the GRS are that they are laboratory based, labour intensive and time consuming. It could be argued however, that the wealth of data that they provide, both in terms of associations found, and in terms of firstly designing

effective early intervention programmes, and then in assessing the efficacy of such interventions, outweighs any possible limitations.

1.5 Study aims and objectives

As already noted, although previous research has pointed to the importance of viewing HIV/AIDS as part of a range of other existent risk and protective factors for both caregiver and child, few studies have adopted the contextual approach required to examine this finding more closely. Further, while research indicates that HIV/AIDS is typically an additional stressor, there is much to suggest that merely being diagnosed with HIV will impact on caregivers' psychological well-being both directly and indirectly, and thus on their capacity to care for their children. The impact of diagnosis alone may be particularly marked in South Africa where stigmatisation of PLWHA is a significant concern.

The primary objective of the study was to develop and pilot a multi-method approach to research on the effects of a primary caregiver's HIV infection on child-care and child development in households. The particular approach adopted is an in-depth, contextual one (as depicted in Figure 1.1) which is argued to have greater power to investigate the potential added impact of HIV, as well as the manner in which it is situated within caregivers and children's lives as a whole.

The chosen methods therefore aim to provide a way of deepening our understanding of:

- The manner in which the quality of the childcare *relationship* in vulnerable low-income home contexts affects the child's emotional development;

- The influence of the mental status and well-being of the carer on the caregiving context; and
- The *context* within which the care takes place, which bears on the carer's status and on the relationship between the two.

The chosen approach has two central characteristics. First, it includes intensive home-based observations of caregiver-child interaction, and an extensive exploration of the circumstances of care that is likely to have a bearing on an HIV positive person's capacity to care for the child. Second, the methodology enables the contextual investigation of factors such as the caregiver's depression and the quality of support available to the caregiver.

While psychological approaches have made very valuable contributions, in our view, they frequently they do not pay sufficient attention to the characteristics of the childcare niche (Gauvain 1992). Most of these studies have used structured questionnaires and related methodologies, rather than observation, which tend to treat the individual as separate from context. This is evident in studies of caregiver-child relationships that have been predominantly guided by a monotropic orientation to attachment, relationship formation and caregiving (see Black, Nair and Harrington 1994; Olds et al. 1998).

The approach developed for the study represents a departure from much of this work and is informed instead by developments within anthropological approaches to the study of childcare and child wellbeing, as well as the work of scholars such as Gauvain (1992), Harkness and Super (1992), Bray (2003b) and Henderson (1999). These approaches are

considered more appropriate for the cultural patterns that pertain in the African context where it is very common for children to be raised by a range of caregivers in addition to the biological parents.

The study therefore provides a methodological contribution to culturally-sensitive research into the impact of caregiver's HIV status on the quality of care in the case of young children, as well as its effect on child outcomes. It also has implications for the design of psychosocial interventions to improve the quality of caregiver-child relationships in low-resource contexts.

CHAPTER 2. RESEARCH PROCEDURE / METHODOLOGY

This section will outline the procedures employed to conduct the research, including the selection of the research site and participants, the design and selection of tools, and the field testing process.

2.1 Site selection

The community of Masiphumelele in the South Peninsula, Cape Town, was selected as an appropriate community for the study. The site was chosen for two reasons. Firstly, the socio-economic, demographic and HIV prevalence profile of Masiphumelele is representative of a large number of poor urban settlements in the Cape Town area. Secondly, the community has a range of HIV-related services, including an antiretroviral programme.

2.1.1 Description of site

Masiphumelele is a very poor community of approximately 12,000 residents on the outskirts of urban Cape Town, in the Western Cape Province of South Africa. The majority of residents are Xhosa speaking and have moved to the area to look for work and improve their quality of life. Most maintain links with family members and homes in rural parts of the Eastern Cape. Levels of temporary migration between the Eastern Cape, Masiphumelele and other urban settlements in Cape Town are high.

Official City of Cape Town estimates are that 1,700 families live in shacks and there are about 270 brick houses. Although most shacks are serviced with sanitation and electricity,

a large and increasing number of families are building shacks on wetlands (unserviced, illegal and at considerable risk of fire). Unemployment and HIV prevalence are both high. In terms of services, a primary health care clinic was established in the community in 1997 and an HIV clinic has operated from the same site since 2000. A twice-weekly, doctor-driven HIV clinic is run as a joint initiative of the South Peninsula Municipality and the University of Cape Town. Patients of the clinic also have access to weekly support groups and income generating projects through a local church-based NGO. Government began the roll-out of ARVs at Nomzamo Clinic in June 2004.

In terms of broader services for children and adults, Masiphumelele has one primary school, one high school and 14 Early Childhood Development (ECD) facilities (ranging from crèches run in homes to one large pre-school). There are a large number of churches, a library, a community hall and a community centre used by various NGOs offering social support services.

2.2 Selection of research participants

2.2.1 Sampling strategy

Purposive sampling was used in order to identity the caregivers through the local HIV treatment centre, Nomzamo Clinic. Doctors and nurses employed at the Clinic identified potential research participants, and obtained verbal consent for their contact details to be given to the study fieldworker. Following this, the fieldworker met with each woman individually in order to discuss the study and obtain written, informed consent for both the woman and her child's participation.

2.2.2 Description of sample

The study sample comprised five HIV positive women caregivers and their young children. The women had been on antiretroviral therapy for less than six months, and were the primary caregivers of the children who were recruited into the study. For the purpose of this study, the primary caregiver was defined as the person mainly responsible for the day-to-day care of the child, including feeding, bathing, playing with, transporting and monitoring. The children had to be HIV negative and less than six years old. One woman was excluded from the study due to the fact that her residence was not stable, and there were concerns regarding her emotional vulnerability. (The implications of this exclusion for the study methodology will be discussed further in section 3.3.3). See Table 2.1 below for summary data on each of the caregivers and their children.

2.3 Selection and design of research tools

The tools used in the study were either identified or designed based on a review of available material as well as consultation with relevant experts. Further, each method was selected in order to address a component of the conceptual model for the study detailed in chapter 1 (literature review). The approach therefore employed multiple methods which complemented one another and allowed for triangulation.

This section will discuss in detail the interview and developmental assessment, while only brief information will be provided regarding the home observation visits. The tools used during these visits had largely to be developed for the study, and will therefore be discussed at length as part of the findings of the study (in chapter 3).

Table 2.1 Summary descriptive data on caregivers and their children

			1	2	3	4	5
Caregivers:							
Identifying data	Age (years)		23	37	32	33	26
	Highest grade passed		11	Less than 7	6	5	11
	Relationship status		Single	Single; Lives with partner	Divorced; Lives with partner	Single; Lives with partner	Single
	Employment		Unemployed (lost job as domestic worker during study)	Informally employed (sells cigarettes, sewing jobs, beadwork)	Informally employed (occasional spaza shop)	Informally employed (runs hair salon from home)	Unemployed (has never had a job)
Household data	Monthly income to household (Rands)	Regular (incl. grants)	910	170	1 650	1 270	1 970
		Irregular (approx.)	None	200	750	500	100
		Total	910	370	2 400	1 770	2 070
	Other resources available to household		Some food assistance from brother (not local)	Monthly food parcel. Communal eating for children. Weekly meal with brother.	Monthly food parcel. Sometimes food from neighbours for C3.	None	Monthly food parcel. Occasional financial assistance from relative.
	Major household expenses		Rent	No rent. No utility bills.	Crèche. No rent.	No rent	No rent
	Household size		2	5	4	7	7
	Number of adults		1	3	3	3	5
	Number of children		1	2	1	4	2
Medical data	Years since diagnosis		2	1½	3	4½	1½
	Weeks on treatment		16	2	16	4	7
	Attend support group		Yes	Yes	Yes	No	Yes
Children:							
Identifying data	Date of birth		11/06/99	07/07/03	05/03/00	08/11/00	06/02/04
	Age (years . months)		5.5	1.4	4.9	4.1	0.11
	Sex		Male	Female	Female	Male	Male
Caregiving data	Consistency of caregivers		C1's carers at diff ages: 0-18months mother and grandmother; 18months-3yrs grandmother; 3 years onwards mother	Only biological mother	Only biological mother	Only biological mother	Only biological mother

The interview section employed two methods. A questionnaire was developed and administered first. This was followed by a semi-structured interview. These will be discussed in turn below.

2.3.1 Interview part I: Questionnaire

The questionnaire contained two sections, one of which included standardised scales, and another which consisted of questions designed specifically for the study. The purpose of part one (the specifically designed questions) was to fairly quickly capture background demographic information, information regarding household composition, a history of caregiving, and information about the caregiver's medical status and adherence to treatment (see Appendix A). Questions included the educational background and employment status of the caregiver as well as other household members, resources available to the household, the distribution of caregiving responsibilities for the caregiver's child, the date when the caregiver was diagnosed HIV positive, and markers of the caregiver's functional health status and adherence to treatment such as CD4 count and viral load. During the course of data collection, a household roster was added to the original questionnaire in order to facilitate the more efficient capturing of data regarding household composition and resources to the household, in particular welfare support and employment-related income (see Appendix B).

Part two of the questionnaire compromised four standardised scales which were selected in order to assess maternal psychological well-being. The four key elements of well-being were each assessed using a different scale, namely the Centre for Epidemiologic Studies Depression Scale (CES-D) to assess risk for depression, the Spielberger State Anxiety Scale to assess levels of anxiety, the Brief COPE to assess coping strategies, and the

Medical Outcome Study's Social Support Survey to assess the availability of support to the caregiver as well as her satisfaction with that support. Further details regarding each of the scales are provided below.

(a) Centre for Epidemiologic Studies Depression Scale (CES-D)

The Centre for Epidemiologic Studies Depression Scale (CES-D; Radloff 1977) was used to assess the caregiver's risk for depression. It is a self-report instrument developed to measure symptoms of depression in the general population. The 20 items ask the person to rate the presence and frequency of symptoms experienced for the past week on a 4-point scale ranging from "rarely or none of the time" (0) to "most or all of the time" (3). The total scores range from 0 to 60, with a score of 16 or above indicating significant risk for depression. The CES-D has repeatedly demonstrated high internal consistency, adequate test-retest reliability and good validity (Myers and Weissman 1980). It has been used in South Africa with a sample of university students (Pretorius 1993).

(b) Spielberger State Anxiety Inventory

The Spielberger (1983) State Anxiety Inventory was chosen to assess the level of anxiety amongst the caregivers. It is a self-report instrument that consists of 20 statements which evaluate how respondents feel "right now, at this moment". Respondents rate to what extent the statements describe their present state, ranging from "not al all" (1) to "very much so" (4). Total scores range from 20 to 80, with higher scores indicating more elevated levels of anxiety. The Spielberger is the most commonly used self-report measure of anxiety and has been extensively used and validated (Spielberger 1983). It has also been used in several studies in South Africa (Roberts et al. 1999; Spangenberg and Theron

1999; 2001; van Wijk 2001) and overseas, in numerous studies in the context of HIV/AIDS (All and Sullivan 1997; Bertucci 2000; Kalichman et al. 2002).

(c) Brief COPE

The Brief COPE (Carver 1997) was used to assess women's coping responses to HIV infection and being on antiretroviral therapy. It consists of 28-items and is an abridged version of the full COPE (Carver, Scheier and Weintraub 1989) which has been used in several health-related studies, including studies with HIV positive men and women (Antoni et al. 1995; Antoni et al. 1991; Ironson et al. 1994; Lugendorf et al. 1998). The Brief COPE includes items on active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement and self-blame, with two items on each of the 14 subscales. Respondents indicate to what extent they make use of each coping response on a 4-point Likert scale, ranging from 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot"). Higher scores indicate more frequent use of particular coping responses. Available data suggests that the Brief COPE has adequate reliability and validity (Carver, 1997; Fogel et al. 2002). The Brief COPE has previously been used in South Africa to assess the coping responses of HIV+ men and women attending an infectious diseases clinic at Tygerberg Hospital in Cape Town (Olley et al. 2004).

(d) Medical Outcome Study Social Support Survey (MOS-SSS)

The MOS-SSS was used to assess the role of social support in the psychological well-being of HIV positive women. It is a 19-item scale developed to assess various dimensions of functional social support received by persons with chronic conditions (Sherbourne and Stewart 1991). In addition to a question which elicits information regarding (support)

network size, respondents rate how frequently they perceive tangible support, affectionate support, positive social interaction and emotional/informational support to be available when they need it on a 5-point Likert scale. Responses range from 1 ("None of the time") to 5 ("All of the time"), with higher scores indicating that a particular type of support, as reflected by each of the four subscales, is more frequently available.

For the purpose of this study, two additions were made to the scale. Firstly, a further item regarding assistance with caregiving responsibilities ("Someone to help you take care of you children when you can't") was added in order to tap support related to child care which is a particular focus of this study (see Hough et al. 2003). Secondly, questions pertaining to satisfaction with the four types of social support assessed by the scale were included. The formulation of these questions was taken from the Social Support Questionnaire (Sarason et al. 1983). These items were added to the original inventory since satisfaction with support has been shown to be strongly associated with women's physical and psychological well-being, perhaps even more so than the constructs of network size and received support which were already contained in the MOS-SSS (Sarason and Sarason 1994). Respondents are asked to indicate their degree of satisfaction by choosing between a smiling and an unhappy face.

Available data on MOS-SSS indicates that it has excellent reliability and good validity (Sherbourne and Stewart 1991). While no evidence could be found to indicate that MOS-SSS had been used previously in South Africa, it has been used in several health-related studies conducted elsewhere, including studies on PLWHA (see Tang 2002; Vincent 1997). The modified version of the MOS designed for the present study is currently being

used in South Africa in a study of pediatric adherence to antiretroviral therapy (Michaels in progress).

2.3.2 Interview part II: Semi-structured/ exploratory interview

The interview was intended to allow for further exploration of some of the issues covered in the questionnaire, in particular those that might not have been anticipated or covered in earlier research, but which might have been of particular relevance given the caregiver and children's context. The interview focused on the history of the caregiving network, as well as obtaining a more personal history of HIV/AIDS and its relationship to the women's social and emotional well-being (see Appendix A). As stated in the questionnaire, the interview had the following two objectives:

- To find out how responsibility for childcare is shared across the HIV positive woman's household and its support network. This means who shares the woman's childcare role and also who provides other kinds of support to the woman directly (thereby making her available for her caregiving role).
- To explore in some detail the woman's history with HIV. This discussion will elicit a timeline of events and subjective states related to the woman's personal experience of being HIV positive (in particular, diagnosis, disclosure, commencing treatment, and how sick and incapacitated she felt at these points during the course of her illness).

2.3.3 Home observation visits

As noted in the literature review, a major shortcoming of standard psychological methodologies is the lack of attention to the characteristics of the childcare niche. While questions posed to individuals in a contrived environment shed light on personal experiences, well-being and opinions that influence a carer's approach to their child, they

cannot provide the kind of contextual data that is necessary to understand the environment in which care takes place.

For this reason, observations were conducted within the home environment during two visits. The aim was to generate data on day-to-day activities in the home, and particularly interactions between mother and child, which would enable the description of key aspects of care relationships and the context in which they were operating. The data gathered in these visits enabled an exploration of caregiving in the home setting as well as building on, and deepening, data collected in the individual interview session. The first visit was scheduled during the household main mealtime for the purpose of more structured observation, while the second was scheduled at another time of the day to allow for relatively unstructured observation.

In order to assist with data capturing during these visits, a childcare context observational tool was developed in order to ensure standardisation of data collected during home visits and an alignment with the theoretical underpinnings of the study. The tool consisted of a record sheet and an informal interview guide that focused specifically on carer's experiences of, and opinions around, the care of children (see Appendices C and D). (Both of these instruments will be discussed in detail in section 3.3.1).

Home observations were also video recorded in order to generate visual data that could be analysed outside the home setting and to pilot the viability of this method, given the difficulty in capturing fine-grained care interactions in detail in writing during relatively brief observations. The aim was to be as discrete as possible; to mount the camera on a

tripod in the corner of a room, use a wide angle setting and to leave it running for at least one hour of the observation.

2.3.4 Developmental assessment

A developmental assessment using the Griffiths (and supplementary questions) was used to measure the child's cognitive and socio-emotional status and development. The supplementary questions covered relevant background history, for example, the presence of complications during the mother's pregnancy or during birth, and any other known serious health or developmental problems which would impact on the child's test performance (see Appendix E). Two further questions were taken from the Bayley's Behaviour Rating Scale and were intended to determine the extent to which the child's test performance and behaviour in general during testing was typical of the child (Bayley 1993).

The Griffiths Scales of Mental Development for Young Children include five scales covering different domains of development: loco-motor development (Scale A), personal-social development (Scale B), hearing and speech (Scale C), eye and hand coordination (Scale D), and performance (Scale E) (Griffiths, 1976). Subscale scores as well as a general developmental quotient can be calculated. The test has been used extensively in South Africa and its validity is established (e.g. Adnams et al. 2001; Allan, Luiz and Foxcroft 1992; Cooper et al. work in progress; Luiz 1988; Stewart 1997). It has also been used in a recent study of the developmental profiles of black South African HIV infected children 0 to 2 years of age (Kotras 2001).

2.4 Translation of instruments

All instruments used during the study were translated from English into Xhosa, the language of the participants. Once the instruments had been translated, a back translation was conducted in order to determine the quality of the original translation and to identify difficulties which would require further consultation. Consultation was then undertaken with a multilingual researcher experienced in issues of translation and cross-cultural validity, as well as obtaining substantial input from members of the local community. Local input was considered particularly important in order to attempt to capture the local language and manner of expression, as well as any issues which might be contextually specific and which had not been anticipated by the researchers in the design of the instrument. This was in addition to the process of refining of the instruments which was undertaken during the course of the study. Finally, in order to facilitate the most effective possible use of the instruments, both the English and the Xhosa text was included in the final material in order to allow the fieldworker to switch between the languages if required by the participant, without losing the clarity and preciseness of expression. This was particularly important with respect to the standardised scales which formed part of the initial structured interview conducted with the caregivers.

2.5 Field testing of tools

The tools and methods were tested between October 2004 and February 2005. Data collection for each of the five pairs consisted of five separate meetings, the first three in a private room in a community centre adjacent to the Clinic, and the latter two in the participant's home. In addition, medical data was obtained from the caregiver's clinic file. Home observation visits were conducted together with an anthropologist experienced in

ethnographic research methods, while the other components of the data collection were either supervised or conducted by a psychologist. This meant that the relevant expertise was brought to bear in the application and testing of each of the tools and methods employed.

During the first visit, the questionnaire was administered to the caregiver. This was followed by a semi-structured interview during the second visit. The developmental assessment was then conducted with each child. Finally, two home observation visits were conducted with both the child and the caregiver present, one structured around a mealtime and the other at another time of the day.

Depending on participant's availability, data collection for each of the five caregiver-child pairs took place over between two and four weeks. In addition, researchers had subsequent contact with each of the women for the purpose of providing feedback and initiating contact with local service providers (see section 3.4 for an example), thereby creating an additional opportunity for informal data gathering.

CHAPTER 3. LESSONS LEARNED - FINDINGS AND OBSERVATIONS FROM FIELD TESTING

This section will discuss the lessons learned during the course of field testing. First, general challenges experienced in the field will be discussed, followed by more specific observations regarding the use of the tools. For the childcare observation tool, its development will also be discussed in some detail since it was designed specifically for the present study and therefore formed an important focus of the work. (Other methods have already been described in chapter 2). Finally, the contribution of the multi-method approach will be discussed and demonstrated through the presentation of case material.

3.1 Challenges in the field

In addition to certain issues which were specific to particular methods, a number of more general challenges were experienced during field testing.

A key challenge during the study, which also pertains to work in the context of HIV/AIDS more generally, was the availability of private space for the purpose of data collection. It was essential to maintain the participant's right to privacy and confidentiality, including during household visits, where household members who did not know the caregiver's HIV status were sometimes present. This placed constraints on the information which could be obtained by researchers. The issue of privacy has important implications in a community such as Masiphumelele where AIDS-related stigma is highly prevalent and was clearly a concern for some of the participants (for example, R4 who was not attending an HIV-

related support group for fear of being seen and thereby inadvertently exposed as HIV positive).

Another challenge was linking the project to local services in order to increase the efficiency of the research process and reduce the burden on participants. It proved useful to synchronise the timing of study visits with participant's routine clinic visits so that they did not incur the additional cost of travel (or loss of income associated with taking time off work). Sometimes women also had to bring their young children along to visits, due to the lack of available childcare arrangements. This had implications for the kinds of sensitive information which could be discussed during sessions, particularly for those participants whose children were old enough to understand the content of the conversation.

It was also important to consider the women's physical well-being, since women were less likely to feel healthy enough to engage in the research process at certain days of the week or times of the day, depending on the timing of treatment. Researchers working in the context of HIV/AIDS should reflect carefully on the important ethical responsibilities of their work, given the vulnerability of the population with which the research is conducted. The vulnerability of participants was particularly evident in this study, following the death of one of the women after the completion of the data collection. This, too, has implications for the emotional well-being of project staff who carry the burden of contact with study participants who are asked to share their difficulties and who may even, as in this case, die. The burden on fieldworkers was also heightened by the fact that rapport and relationship building was such an essential part of the (in-depth) research process, and hence the burden of loss was likely to be more weighty.

Finally, the cultural context posed several challenges to this study, which are also of importance in other studies in non-Western, culturally-diverse settings. Both the expression of mental health and the nature of childcare practices differ across, and even within, cultures, and it was therefore necessary to develop and apply methods in a way that was sensitive to local approaches. For example, mental health concepts such as depression and anxiety which were assessed using standardised scales had to be very carefully translated (see section 2.4), since it could not be assumed that Western mental health constructs would have the same, or even similar, meanings when transported into different contexts. Similarly, indigenous mental health constructs were not captured in instruments commonly used, and efforts needed to be made to capture this. This was also true of the framing constructs with which the childcare situation was approached, in which it was necessary to take on board approaches to childcare which were much more collective than is commonly the case in modern communities. This is also an important part of the ethical practice of research.

3.2 Interview procedures (Questionnaire and semi-structured/exploratory interview)

Provided the general conditions specified above in section 3.1 were met, the interview procedure could continue without major difficulties.

3.2.1 Questionnaire

In the main, the women were able to respond to the questions posed to them, including the items of the four standardised instruments. A few items in the scales did, however, pose difficulties, as had been anticipated during the process of translation. This is a challenge

that has been noted above. The most consistently problematic item was number 14 in the anxiety inventory that asks how often the person feels "high strung". It was necessary to rephrase and clarify this item as it appeared to convey a concept unfamiliar to the language of *is*iXhosa.

On the Brief COPE, items 4 and 11 presented some difficulties. Both have very similar wording and ask about the use of alcohol and drugs, one to 'make oneself feel better' and the other to 'help one get through it'. It was difficult for respondents to grasp the subtle differences between these items, and this appeared to influence the responses which were given.

On the Social Support Survey, the formulation of the last four items proved difficult for women to respond to. This was because the instrument asks for ratings for four types of support (viz. tangible, affectionate, emotional/informational and positive social interaction). The women in this study found it difficult to distinguish between them as within their world, support is not necessarily disaggregated in this manner, and the language used was therefore too technical. The current formulation would be improved upon by asking participants to indicate their satisfaction with the support specified in each individual item on the scale and then summing the responses, rather than eliciting satisfaction for types of support directly (see from item 2 onward in Box 3.1 below).

With respect to the more general section of the questionnaire, following initial piloting, a household roster with a section on income was included as it facilitated the collection of comprehensive household data (see Appendix B). Moreover, during the write-up of data, major household expenses was determined to be another category of information which

could improve the researchers' ability to make practically useful comments about household income and viability. Due to the diverse and irregular nature of income in low-income households in South Africa, many of the traditional approaches to exploring

Box 3.1 Extract from example of revision to Social Support Survey
(refer to Appendix A, xiii-xiv for formulation in current questionnaire)

Next are some questions about the support that is available to you.

1. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)? Write in number of close friends and close relatives.

Please state who these people are and where they live [use codes A to indicate relationship to participant].

No.	Relationship to participant	Place of residence 1 = household 2 = not in household, but in neighbourhood 3 = outside neighbourhood, but in Cape Town 4 = outside of Cape Town			
1.1		1	2	3	4
1.2		1	2	3	4
1.3		1	2	3	4
1.4		1	2	3	4

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?
Circle one number on each line:

1 = None of the time
2 = A little of the time
3 = Some of the time
4 = Most of the time
5 = All of the time

Now we'd like to know **whether or not you are satisfied** with the different kinds of support you receive.

1 = Happy with the support you receive (☺)
0 = Not happy with the support you receive (☹)

2	Someone to help you if you were confined to bed.	1	2	3	4	5	1	0
3	Someone you can count on to listen to you when you need to talk.	1	2	3	4	5	1	0
4	Someone to give you good advice about a crisis.	1	2	3	4	5	1	0
20	Someone to love and make you feel wanted.	1	2	3	4	5	1	0
21	Someone to help take care of your children when you can't.	1	2	3	4	5	1	0

household income were found to be reductionistic, or to give a false impression of the economic viability of households. One of the recommendations to address this potential problem is to ask specifically about the receipt of non-monetary forms of support (e.g. food parcels), and to ask questions which are likely to provide insight into the sustainability of household's over time (e.g. the regularity of income, how often people go without food) (see Box 3.2 below).

Box 3.2 Example of revised questions on household economic viability
(refer to Appendix A, ii-iii and xviii-xx for formulation in current questionnaire)

Does your household receive a regular food parcel (e.g. weekly or monthly) from a church, charity, clinic or a school feeding programme? [Do not include food received from friends or relatives on an occasional basis].

Yes	1
No	2

Does your household regularly receive food, clothing or other items which household members need from neighbours, friends, relatives? (e.g. about once a week)

Yes	1
No	2

How often do household members go without food?

Often	1
Sometimes	2
Rarely	3
Never	4

How regular is your household's total income? [grants included]

Very irregular	No pattern to how much we get and when. Often we might not get anything.	1
Irregular	We usually get some money each month, but the time and amount varies.	2
Regular	We get some money at the same time each month or week, but the amount varies.	3
Very regular	We get the same amount of money each month or week at the same time.	4

Other questions were also found useful and would serve as a valuable improvement on this study's questionnaire. These include: the date of positive diagnosis and the surrounding circumstances; the partner's HIV status; the date when treatment commenced; and participant's subjective perceptions of their physical well-being. Further, as will be demonstrated later (in section 3.5.2), disclosure was a key factor in understanding women's emotional well-being and social functioning, and consequently it is recommended that details regarding women's practices of disclosure be collected in greater detail (see Box 3.3 below).

Box 3.3 Example of revised question on disclosure of HIV status
(refer to Appendix A, xv-xvi for formulation in semi-structured interview schedule)

To whom have you disclosed your HIV status and where do they live? Also indicate who the first person was that you disclosed your status to, and who the easiest and most difficult person was to disclose to.

No.	Who	Place of residence	First person disclosed to	Easiest to disclose to	Most difficult to disclose to
	Relationship to participant	1 = household 2 = not in household, but in neighbourhood 3 = outside neighbourhood	√	√	√
1		1 2 3			
2		1 2 3			
3		1 2 3			
4		1 2 3			
5		1 2 3			

Finally, a more detailed, systematic approach to gathering data on caregiving and the child's caregiving niche might also be beneficial. Such an approach should capture both the distribution of unpaid care work for children in the household, and unpaid care to non-

biological children outside the household, and to adults in- and outside the household, all of which have implications for the caregiver's capacity to provide emotionally responsive care to her own children. (See Box 3.4 below for an example of this revised line of questioning). These modifications would assist in the collection of additional information which proved relevant to addressing the research questions, as well as streamlining the data collection process.

Box 3.4 Example of revised questions on the caregiving niche
(refer to Appendix A, iii-iv for formulation in current questionnaire)

Distribution of unpaid care work for children in the household

State which people, regardless of where they live or how old they are, help look after (e.g. care for and supervise) the children who live in your household? Also state when and in what way each person helps to care for each child. (Include your own care duties with the children in the household.)

No.	Recipient of care	Provider of care:		Nature of care:	
		who	place of residence	when	what
	Name		1 = household 2 = not in household, but in neighbourhood 3 = outside neighbourhood		
1			1 2 3		
2			1 2 3		
3			1 2 3		
4			1 2 3		

Unpaid care to non-biological children outside the household

Are there any children (less than 18 years) for whom you have to provide significant amounts of care who do not live in your household? If no, skip to the next section on care for adults.

Yes	1
No	2

How many children do you care for?

Please provide details by completing a row in the table below.

No.	Place of residence	Nature of care: when	Nature of care: what	Reason for care
	1 = household 2 = not in household, but in neighbourhood 3 = outside neighbourhood			
1	1 2 3			
2	1 2 3			
3	1 2 3			

Unpaid care to adults in- and outside the household

Are there any adults (18 years or older) for whom you have to provide significant amounts of special care (for example, because they are physically or mentally disabled, or elderly)? If no, do not complete the rest of the questions.

Yes	1
No	2

How many adults do you care for?

Please provide details by completing a row in the table below.

No.	Place of residence	Nature of care: when	Nature of care: what	Reason for care
	1 = household 2 = not in household, but in neighbourhood 3 = outside neighbourhood			
1	1 2 3			
2	1 2 3			
3	1 2 3			

3.2.2 Semi-structured/exploratory interview

The interview schedule (see Appendix A) was administered to all participants in a consistent manner. However, as this was a pilot study designed to improve methodology and provide recommendations for future work, alterations to procedures were undertaken

as the work progressed. These changes did not undermine the integrity of the instruments used.

One of the adaptations implemented was to explicitly ask participants to name the close friends or relatives identified in response to question 1 in the Social Support Survey (p. 60). While the original item asked only for the total number of people who were considered available for support, it was felt useful to know who these individuals were, including whether the caregivers tended to rely on family or non-family, and whether or not their support system consisted of people who lived fairly close by. (See Box 3.1 for how this can be incorporated into the structured questionnaire).

Further, in line with the prior discussion regarding the centrality of disclosure, participants were also asked whether they had disclosed their HIV status to these people. In this way, information regarding sources of support and disclosure could also be captured graphically on the genogram, thereby linking information provided through the genogram with that gathered in other sections of the interview. (See Appendix F's genogram for an example). The genogram is a useful tool for putting people at ease at the beginning of the interview process and provides the interviewer with a rapid picture of people and their world. Accordingly, it can be viewed as a useful tool for rapport building, particularly with participants who are defended or who find it difficult to speak about their experiences in more abstract, unstructured ways.

A further revision which was incorporated through the data collection process related to the cultural context of caregiving. In line with some of the questions included in the informal interview guide for the observation of care (see Appendix D), it was decided to

enquire about women personal constructions of caregiving, as well as their perceptions of the community's expectations related to caregiving (see Box 3.5 below). This line of questioning fitted with the study's attempt to situate women's caregiving of their young children within its relevant cultural context.

Box 3.5 Example of further questions for interview schedule
(refer to Appendix A, xv-xvi for formulation in current semi-structured interview schedule)

Personal and community constructions of caregiving:

How would you describe a 'good mother/caregiver' (how do they behave, what do they do, etc.)

How would you describe a 'bad mother/caregiver' (how do they behave, what do they do, etc)

Do you think that your views differ from other moms/carers in your community?

It should also be noted that while the semi-structured interview, more so than the other methods employed, was intended to explore the caregiver's personal sense of well-being, this proved challenging. It was not easy to achieve the objectives of covering support for the caregiver in her childrearing role, as well as support for her as someone living with HIV/AIDS, simultaneously. It appeared easier for the women to speak about childcare support than it was for them to discuss support for them more generally. It may also be important to consider the setting and the extent to which the respondent was primed to respond to childcare questions. Unless the interviewer is sensitive to this, insufficient data on the latter can be collected. It is therefore necessary for the interviewer to keep this in mind, both during the unstructured interview component of this work and during the home observation stage. Once all the data for a particular case is in, it is useful for the interviewer to review the extent to which both sides of the objectives have been met, and return to collect what may be missing. In general, this tendency resulted in the study

eliciting more subtle information about childcare experiences and less sophisticated material about women's individual experiences as separate from this.

3.3 Observation of child care in the home setting

3.3.1 Description of observational tool

The study adopted an approach to measuring the quality of care that is firmly rooted in the dyadic nature of caring relationships. At the same time, the design takes into account the fact that there are likely to be multiple dyadic caring relationships in households. Hence, the study focused on the caregiving context and niche as a whole, rather than simply focusing on the caregiving provided by the primary caregiver to one child.

Several key questions were generated (through a review of the literature) with a view to developing the observational tool:

- Who does the caring? Do different people perform different care-related tasks?
- What sort of relationship exists between two or more people caring for a young child?
- What influence do fathers and other 'non-primary' carers have on children?
- What role do siblings play in performing or mediating care?
- How is care given and displayed?
- What is the balance between attending to physical needs, comforting, showing affection, teaching/assisting, accompanying etc? Does this balance change for different children?

- Are the care relationships characterized by dominance or exchange and how is the balance between the two maintained (Scheinfeld parental interview in Johnson 1976)?
- Where does care fit on the hierarchy of pressing household and family tasks? For example, what priority do carers give to their young children when there are other urgent chores to be done?
- Are there observable patterns in care-related tasks? Does care seem to be more or less effective in households where there are observable patterns of care?
- How does the physical nature of the home influence care activities and the quality of care provided?
- How do the physical and social characteristics of the environment surrounding the home influence care activities and, potentially, the quality of care provided?
- Is there evidence of difference in level or style ('quality') of care in situations where the carer is relatively new, and/or the child has experienced disruptions in their care (different carers, residential mobility)?
- Do child carers who are not parents provide other types of support to the family than care of that one young child (see Bromer and Henly 2004)? If so, what form does this support take? How critical does it seem to be for the other carers/parents and the whole household?

While some of these questions can only be answered with observational data, others required a combination of observation in the home and responses from the principle carer. The intention therefore was for one fieldworker to pose questions outlined in the interview schedule (described below) during casual conversation with the carer at fitting moments in

the first observation period. The first fieldworker's remaining time and all the second fieldworker's time was to be used to record observational data (see Appendix C).

The primary purpose of the home observations was to record everyday care interactions and the context in which these take place. Hence, the tool was designed to facilitate documentation of the actions, words and emotions – and the often rapid responsive nature of these – as well as factors in the environment that may influence the quality of care. In terms of format, the tool comprises a grid with column headings generated from questions listed above. The intention was that a new row is begun with every new care interaction stimulated by either the child or the carer. The tool was piloted by both fieldworkers in a home setting with a one-year-old child, and the column headers refined appropriately. An example row of data is given to demonstrate the scope of each column (see Table 3.1 below).

Table 3.1 Example of data using observational tool

Care prompt and action	**Child's response** Shuts down or seeks more interaction?	**Actions by other carer(s)**	**Simultaneous activities of carer(s)**	**Emotional climate of communication** Any actions by carer expressing feelings toward child?
C3 picks up muffin (given by researchers) and looks at R3	R3 does not respond. C3 puts muffin back on table	R3's brother sits quietly in one corner looking at magazine pages on walls [R3 said she cannot care for C3]	R3 talking to researcher1.	Calm

Type of verbal interaction	**Evidence of 2-way relationship between child and carer?** Any intimate dialogue or emotional sharing?	**Factors in the home influencing care of child**	**Aspects of wider environment influencing care of child**
None, then C3 says 'I don't want it'. R3 says 'OK'	Eye contact	Shack is small and tidy. Few material goods in kitchen, no evidence of toys so far.	Shack situated in informal area (Wetlands). Lots of small children playing outside in the sand (and urinating).

3.3.2 Description of the home-based informal interview

The primary purpose of the carer interview in the home was to generate data on carer definitions of good quality care, on attitudes towards child rearing and on particular care practices. It was clear that a limited period of four hours observation in the home and the influence of the researcher's presence on people's behaviour would hinder access to the full range of care practices. Asking carers to report on their responses to particular care needs, for example in the arena of discipline, would therefore shed some light on these areas. However, it should be recalled that such responses are normative in nature and may not accurately reflect everyday practice.

The reason for asking carers about their attitudes towards child rearing and definitions of 'good care' is to gain insight into the particular set of beliefs that influences actions. It is acknowledged that such beliefs can be culturally nuanced, however the point is not to rarify the picture by looking for one 'Xhosa' way of conceptualising quality of child care. As pointed out by Tomlinson (2003), beliefs, attitudes and practices around care must be considered in their particular functional, historical and political context. Therefore there is

likely to be considerable variability between individuals in families and of different generations.

The design of the interview schedule drew on The Child Study Inventory (in Johnson 1976), Bavolek's (1984) Adult-Adolescent Parenting Inventory and Hundeide's (1990) ICDP framework (refer to Appendix D for interview schedule). As noted in chapter 1, these approaches advocate the investigation of parental expectations of their children, empathic care, and the demonstration of emotion on the part of both parent and child.

3.3.3 Application of the observational tools

One of the study's primary aims was to describe the relational aspects of care so as to enable its analysis. The observational tool was useful in ensuring the documentation of basic information regarding the range and nature of care interactions, as well as influencing factors in the wider environment. This encompassed: who performs the range of care roles for each child observed, the nature and emotional climate of interactions between the child and his/her carers, and the physical and social environments in which care takes place.

Despite some of the limitations or challenges posed by the method, it is important to note that the process was successful in many ways, and that researchers were able to establish an open and relaxed atmosphere. This was largely attributable to the rapport built between respondents and the first fieldworker during the initial meetings (for questionnaire, Griffiths testing and in-depth interview).

The cultural / linguistic context and the physical environment resulted in certain modifications being made to the original research procedure, which are also important

considerations for future work. Although the fieldworkers initially planned to move between interview questions (including clarification of any points missed in prior interview) and the home observation, it proved necessary to divide the tasks. The first fieldworker used casual conversation as an entry into the interview topics relating to attitudes towards and experiences of childcare while the second concentrated on observing care interactions (asking the first fieldworker to clarify any verbal interactions that she could not understand) and using the video camera. It therefore proved essential to have two fieldworkers present in the observation. This partly relates to the researchers' skills and experiences: The first fieldworker was new to the method but linguistically fluent, whereas the second was experienced in the method but had limited language skills.

Further, with respect to the video camera, it proved both impractical and inappropriate to mount the video camera and leave it running as originally intended. In all but one of the homes, the space was too small or too dark to use the tripod. The children moved in and out of the space in which the researchers conversed with the mother and other family members, many spending the majority of time outside the home itself. In the light of these factors, and the wish to avoid compromising established trust between the women and researchers, the second fieldworker used the video for short periods of time towards the end of each observation period. The intention was to capture the environment, key people within it and examples of care interactions where possible. The footage is therefore useful for illustrative purposes but has limited analytical value.

This is an important consideration given that the home visited during the course of the study are in many ways representative of the households of poor, HIV-affected households in South Africa, that would likely be the focus of future research.

Several other culturally-specific factors also challenged the methodological approach, raising some of the same concerns as mentioned above. For example, while the structured observation was defined as being around a mealtime, it was found that notions around routines for meals, washing and sleeping, methods of discipline and understandings of care needs were different to those in more traditional, middle-class homes, making a structured observation something of a misnomer. Consequently, the two observations were less different than originally intended, but were nonetheless revealing regarding the culturally nuanced nature of care and the fact that social and historical factors impact on both child and carer.

Two other points regarding the observations in the caregiving niche must also be made. First, insights into the care of each child were (largely) through the mothers' responses and it is quite possible that other significant carers, for example, siblings, aunts, uncles, grandparents and neighbours would have different perspectives. However, to have attempted to elicit these would have risked disrupting the relationships already built with the women and theirs with wider family or neighbours. Second, observations of interaction between children and young men, whether these are brothers, cousins or neighbours, were infrequent. Owing to the dominant position of women in the domestic sphere, generating these data would require considerably extending the observation component. Nonetheless, observations of men, and information about men's activities, did emerge.

It is worth drawing attention to the fact that one participant could not be recruited to the study because she was highly transient (moving between the street and a friend's house) and, as she did not have a home, a home observation could not be conducted. Fieldworkers

were also concerned about her emotional vulnerability. This experience sheds light on the fact that methodological design may unwittingly exclude cases where the care relationship stands to be most compromised. The design of future studies of the care niche should consider approaches that could include such cases, for example using a more flexible ethnographic approach to observation in a variety of contexts. This might be particularly important in more mobile populations, some of which are likely to be affected by HIV/AIDS (Ansell and Young 2004; Young and Ansell 2003).

3.4 Developmental assessment (Griffiths and brief tool)

The Griffiths, which constituted the key component of the developmental tool, is able to assess a range of abilities, and is appropriate in many ways for a study of this nature. However, one of the major difficulties experienced in its application was that it contains a number of questions which presuppose more modern forms of households and facilities rather than the environment provided by informal housing and poverty. For example, one of the questions asks parents whether their child assists them in the laying of the table. Many families living in households affected by HIV/AIDS, who live in poverty, may not have a dedicated eating table. In a similar vein, for many of the children assessed, knives and forks are not used rather spoons or hands are usually used for eating. Other examples included that children were less able to identify and describe objects that were unfamiliar in their environments; they could not easily fit puzzle pieces into their correct places on a board; and they were not able to hold pencils properly, a deficit that could be ascribed to the fact that none of the children were attending crèche and were not exposed to pencils and drawing at home.

In sum, it was clear that the range of experience available to the children in informal housing in Masiphumelele impacted negatively on their Griffiths' scores, therefore placing a ceiling on their levels of performance which was not necessarily a reflection of developmental capacity. Given these points, the data provided by the Griffiths should be interpreted and used with caution. It was therefore decided not to report further on this instrument.

However, some important methodological lessons can be learned from the application of the tool, the most important of which is that early childhood assessments must contain items appropriate to the affordances available in the child's home environments. Developmental tests of this nature, even when translated into an African language, are likely to require item modification when applied in low-resource communities where children's developmental niches do not prepare them adequately to answer the sorts of items contained in tests such as the Griffiths. In studies that seek to link the mental health and health status of HIV positive caregivers to the outcomes of their children, it will be essential that the measures of the child's psychological status are thoroughly adjusted to the context in which they will be administered.

Further, where very young children are assessed on developmental tests, it must be remembered that the development of the young child is characteristically uneven and that test performance fluctuates in the same domain across time. Where developmental measures (e.g. language; cognition; emotion) are used as dependent variables, for example to examine the influence of parental care, the instability of the child's performance can lead to insignificant findings that mask real impacts. For this reason, tests of developmental outcome with children under age three years are likely to be of very limited

value in studies of this nature. This is important to note since two of the children in the study were very young (11 and 16 months respectively).

In the face of limitations imposed by both endogenous and contextual factors, the data does provide a useful platform to begin to think about interventions which do not necessarily depend on the fine-grained interpretation of a sophisticated developmental assessment. Further, interventions which have the potential to improve children's cognitive development, may also benefit them in other ways. For example, a reading programme which was available at the local library in Masiphumelele provided children not only with the opportunity for added cognitive stimulation and learning, but also to spend quality time with their caregivers, thereby promoting positive mother-child interactions as well. This could be a particularly useful output in poor, HIV-affected environments in which there are well-documented challenges to children's cognitive (and socio-emotional) development (Bradley 1994; Richter and Grieve 1991), and threats to children's relationships with their caregivers are also present (Forehand et al. 2001; Wild 2001).

3.5 The multi-method approach

Having examined each of the tools and methods in turn, the final part of this section will attempt to demonstrate the benefits of the multi-method approach. Closer examination of the data collected for each of the five caregivers and their children very clearly indicated that had such an approach not been adopted, much less rich material would have been emerged. Further, some of the crucial issues that bear on the caregiving situation of women living with HIV/AIDS, which had not been explicitly anticipated in the study design (see chapter 1), may not have been identified. The discussion that follows draws out some of

the key issues raised using this approach, and points out how they emerged through the use of a combination of the methods over time. (See Appendix F for an example of a complete data record for one of the participants).

3.5.1 Understanding the psychological well-being of HIV positive women caregivers

A key issue which emerged from the data was the difficulty in making simplistic statements about the caregiver's psychological well-being. While data on women's individual well-being was the particular focus of the semi-structured interview and questionnaire (especially the four standardised scales), later data collection facilitated the refinement of material.

Through the use of multiple methods, administered over the course of several weeks of data collection, a more dynamic understanding of the women emerged. Women may exhibit high levels of resilience in some domains while appearing highly vulnerable in others, and new vulnerabilities and strengths may emerge and manifest over time (Luthar, Cicchetti and Becker 2000). This was evident in the finding that some of the women's experiences provided clear indications of social competence and active attempts to live positively with the illness, as well as clear indications of vulnerability, although sometimes with differing degrees of salience.

Respondent 1 (R1), for example, showed resilience and was comparatively outspoken in her community about her HIV status, particularly in comparison with the other four women in the study. She advised other people to be tested and to talk about their HIV status, and believed that she had become wiser since discovering her status, had a greater sense of

purpose, and was able to focus on the positive side of life. In these ways, she was attempting to take an active approach to living positively with her illness, a response which had evolved over time, and did not likely reflect her state of mind at the moment which she received her positive diagnosis. However, in addition to these positive factors, R1 had been treated for depression and migraines previously. Consequently, there were many layers to R1's level of psychological functioning as well as challenges to her well-being which emerged over time (such as new risks to her physical health).

This composite picture of R1's functioning was the result of interviews, questionnaire data which provided important objectives measures (i.e. scale scores) that could be used for comparative purposes, as well as observations which provided researchers with powerful interpretive tools. In this way, the experiences which R1 could articulate verbally could be blended with those which the researchers could observe directly. Further, during the course of data collection, researchers discovered that R1 had lost her job resulting in economic insecurity which could clearly pose a threat to her emotional stability and thereby her caregiving capacity as well. This finding emerged only as a result of the repeated visits approach which was taken.

The value of the multi-method was even more apparent in the case of respondent 3 (R3) who proved especially complex for the researchers to understand. After reflection on the data as a whole, it was apparent that R3 was in many ways 'at-risk'. She had a history of losses and rejections as a child and an adult, and had to care for both a young child (C3) and her mentally ill adult brother without any extended family support. Her current vulnerability was evident in her risk for depression (based on her score on the CES-D) as well as her alternately withdrawn and tearful behaviour during repeated interviews.

However, despite these risk factors, R3 was able to make very strategic decisions which reflected positive coping and her capacity to overcome adversity and demonstrate resilience over time. For example, she went away on holiday when there were tensions in her intimate relationship (a key source of her support), and used the support group and research interviews as opportunities to unburden herself emotionally, thereby managing the absence of other effective supports. R3 was also able to access welfare grants for herself, her brother and her young child, something which many other people living in similar communities are unable to do successfully even when they are eligible (for example, R5's father).

The different and shifting layers to her emotional state (for example, tearful and withdrawn, versus composed and resourceful) were revealed as a result of both repeated visits and the use of different methods with subtly different foci, that allowed researchers to make sense of apparent contradictions in the data. In addition, questioning during the initial interview revealed the fact that respondent 3 (R3) lived with her brother who, although an adult, was mentally ill and therefore dependant on her. Further, due to the rapport built through the research process, she was able to articulate that she experienced this living situation as a considerable burden to her, with clear implications for her emotional well-being as well as her availability to care for her young child (C3). Narrow questioning regarding household composition would not likely uncover the history of mental illness, or her present household dynamics, once again demonstrating the value and complementarity of the chosen methods in revealing highly relevant information.

Both cases demonstrate how the data collected was able to reflect some of the subtleties and complexities of the emotional lives of HIV positive women caregivers, both their risk

for mental illness (Freeman 2004; Jones, Beach and Forehand 2001a; 2001b; Morrison et al. 2002) and their strength and resilience over time. This was in contrast with the less nuanced picture of psychological well-being which has emerged through more traditional psychological approaches that are less contextually-based and ethnographically sensitive (Hough et al. 2003; Miles, Gillespie and Holditch-Davis 2001; Murphy et al. 2002; Riccobono 1995).

3.5.2 The wisdom of disclosure

A prominent coping strategy which emerged across all five of the narratives was a rational approach to the disclosure of HIV status. The research literature and service providers frequently view disclosure as a positive means for accessing social support and treatment, and potentially reducing AIDS-related stigma (Greene et al. 2003; Khan 2004). However, a close examination of the case material suggested that some of the women's decisions not to disclose were strategic, and aimed at protecting and managing the support available to them in ways which promoted their emotional well-being, and even the sustainability of their households. This is consistent with research which has found that most mothers with HIV/AIDS report carefully weighing the risks and benefits of disclosing their status to others (DeMatteo et al. 2002). Strategic disclosure, and in some cases non-disclosure, therefore had the effect of minimising risk and vulnerability and promoting resilience in women, especially in the shorter-term.

Respondent 2 (R2), for example, did not initially disclose her HIV status to her sister, even though they were very close, because she wished to protect her sister from the potential emotional burden her disclosure would create. Similarly, respondent 1 (R1), while disclosing her status to several community members and generally being very 'public'

about living with HIV, chose to delay her disclosure to her mother who lived in the Eastern Cape and was too far away to provide direct support. In contrast, however, she disclosed her status to her five-year-old son (C1) with whom she lived alone.

Being told about his mother's (R1) HIV status could have been burdensome to C1, and while this was not apparent in the short-term, longer-term implications are possible (Tompkins and Nelson 2005). However, R1 appeared to manage the disclosure, and C1's resulting knowledge, in a sensitive and developmentally-appropriate manner. Further, after initially wanting to return to the Eastern Cape to live with his maternal grandmother, C1 said that he would stay with his mother so that he could take care of her. He would often offer to bring her water, sit on her lap, or do small household tasks. R1's disclosure to C1 therefore resulted in the mobilisation of his support for her, a very important part of her support network. In addition, his behaviour, as well as observations of their relationship, indicated that the disclosure resulted in a strengthening of the relationship between mother and child, a factor of importance for both maternal and child well-being.

Both R1 and R2 therefore made conscious choices not to risk disclosures which might compromise a much-needed line of support or result in their isolation. In this way, their behaviour reflects an awareness of the 'private good' as individual woman living with HIV, if at the expense of what service providers and policy makers would term the 'public good' of disclosure, especially in communities where AIDS-related stigma is common.

Similar to the above-mentioned discussion regarding resilience and risk (section 8.5.1), this particular understanding of disclosure was largely one that was not anticipated by previous research. Moreover, the idea of disclosure as strategic emerged through repeated

questioning in order to attempt to better understand the behavior of participants, as well as observations of behaviour consequent on disclosure, or non-disclosure, during home observations. For example, the implications of R1's disclosure to her son could be more fully understood since their relationship was directly observed (see section 8.5.3 for further discussion). With regard to R2, the nature of her relationship with her sister emerged over the course of data collection visits, and in fact, during the course of this process, R2 was confronted by her sister about her status and subsequently disclosed. (R2's sister had in fact been withholding her own HIV status from R2.)

However, perhaps it was with respondent 4 (R4), that the researchers experienced the nature of strategic disclosure, as well as its potential negative implications. During the course of earlier data collection, using the questionnaire and semi-structured, R4 had reported her decision (at her partner's request) to keep her HIV status a secret from both her household and community. Consequently she did not attend a support group for fear of being seen by community members and thereby inadvertently exposed. Later, during home observation, the implications of this non-disclosure were readily apparent to researchers as the lack of disclosure meant that it was impossible for researchers to follow their prescribed procedures to the extent that it was possible in other households. Her situation appeared tenuous, as the entire household, including her teenage children, believed that her antiretroviral medication was medication she was taking as a result of her pregnancy. The silence within the household produced by R4's non-disclosure was therefore reflected in the silence during the data collection as well.

In terms of the implications of (non-)disclosure, while R4's strategy may have secured her the important ongoing support of her partner (she was expecting his baby at the time of the

study), it appeared that R4 might be depressed and anxious at times and that not attending a support group could have been a contributing factor. Once again, her self-report (during interviews) was inadequate in uncovering the multiple impacts of her non-disclosure, including the fact that her scale scores suggested that she was emotionally at-risk. A richer understanding of the manner in which she was living with HIV as a mother, was therefore more apparent through when analysing multiple levels of data collected through the different methods.

3.5.3 Understanding the context of childcare

The complementarity of methods in collecting information regarding childcare and child-caregiver relations was perhaps most evident because the method explicitly addressing this question (the observational tool and home-based interview guide) was employed last. It therefore served as an opportunity to re-visit or clarify data which had emerged in earlier stages of the process, a research strategy which proved particularly useful.

While the questionnaire and semi-structured interview provided information on the location, size and residential composition of the family dwelling, the precise nature of the physical environment in which the carer and her young child are living was only evident when researchers visited the home. R3 and C3 live in the wetlands, an informal area where self-built homes are not provided with electricity or sanitation. Upon visiting the home, it became clear that the 150 metre walk to the communal toilets posed a safety risk to C3 (a 4-year-old girl). Over the course of the four-hour observation, it was apparent that C3 spends the majority of her time playing with a group of friends of a similar age, either on the doorstep or in the sand between the shacks. The lack of sanitation poses health risks; the sand is littered with broken glass, nails and both animal and human waste.

During the interview at her home, R3 said that she asks one of these neighbours to keep an eye on C3 when she has to go out for long periods, but she said that she thinks C3 roams quite widely with her friends. The observation enabled us to see some of the low-level neighbourly monitoring in action: C3 and her friends were in view of two women chatting and sewing outside their homes, yet no-one followed them when they moved out of view. Conversations in the home clarified that C3 had not been attending crèche for several weeks and indicated that, despite her daughter's enthusiasm to return, R3 did not consider it a high priority.

R3's responses to her child's demands during the observation period were muted and weary, further supporting the indication from her psychometric test scores that she is either suffering from, or at risk for, depression. The combination of compromised maternal input, hazards in the physical environment, and the lack of formal care or early child development (ECD) provision paint a negative picture of C3's care. However, the second home visit and conversation during this observation period provided us with interesting insight into a very important positive component of the care scenario. R3's partner returned home from work and was greeted with joyous hugs by his daughter. Observing only a brief period of their interaction clearly illustrated what R3 had begun to say, namely that C3 had a very different relationship with her father within which she received aspects of care that her mother was not able to give (for example, games, jokes and rough and tumble play).

The data are full of such illustrations of the benefits of the multi-method approach for gaining insight into the ways that women's circumstances, including their HIV status, affect the context and nature of child care. Researcher's physical presence in the home

allowed them to put interview material in context and to follow up conversations in the light of evident household circumstances. For example, during R4's interview, she described a large dwelling and spoke about difficult relationships with her partner's sister (who is unaware of her status). The researchers' first impression during the home visit was of a spacious and well-stocked home. However, once shown around and informed how each room was used, including claims on space from within and outside those currently resident, the extent of R4's residential insecurity and accompanying anxiety became apparent. Both the questionnaire and interview conversations at home indicated that R4 had a very small support network. She did not visit neighbours or take her child (C4) to play at others houses. Further, clients to her hairdressing business came to her home, as did a few friends of C4's. The anxiety caused by poor relationships with her sister in-law and the housing situation, perhaps exacerbated by fears that her status would be discovered, appeared to restrict R4's movements and deny her access to friends' personal support and assistance with child care. It would not be unreasonable to propose that this mother's isolation would have a knock on effect on C3's care and development, especially in the context of the expected arrival of the new baby and the fact that C4 was not attending crèche.

The value of home-based observation and interviewing, within the context of a multi-method approach, relates to both space and time. Talking to caregivers in their own home, with an interview guide plus the natural prompts of setting, incidents and interactions with family members, opened doors into areas of caregivers' and children's relationships that could not have been explored in the same manner through the more formal methods. For example, when asking R1 questions in the home-based interview guide designed to explore caregiver's attitudes and values around child care, she linked her views on what children

need to thrive with how she cares for her own son and to their relationship. She said that they need a lot of love, attention, and to be listened to patiently rather than ignored. Her comment was that she differs from most other parents who think it better to avoid talking to children and giving them too much attention as it will spoil them. She justified her view by illustrating how she been very open with and attentive of C1 (even disclosing her status to him), and he now provides her with a lot of care and tenderness, especially if he thinks she is not well. This is an issue which was also discussed earlier (in section 3.5.2) and which was clearly more fully understood as a result of repeated visits using different, but complimentary methods.

CHAPTER 4. CONCLUSIONS AND RECOMMENDATIONS

This chapter aims to draw together some of the key points raised in the report, as well as making recommendations for future research.

4.1 Concluding remarks

The primary objective of this exploratory study was to pilot a multi-method and intensive approach to research into the effects of primary caregivers' HIV infection, mental health status and social support on their care relationships with their young children. In addition, we explored the appropriateness of the Griffiths Scales of development in order to assess their appropriateness as measures of child outcome in studies of this nature.

The theoretical model underpinning this research provides a broader and more complex formulation of the factors and pathways through which caregiver illness influences child care and outcomes than is commonly the case in this field. In a significant departure, the model (see Figure 1.1) points to the importance of including household and neighbourhood level factors in explanations of how women cope with the burden of care – particularly those who have very few material resources and live in poverty-stricken communities.

Building on these components of the model, the literature review stressed the importance of studying the lived context of the HIV positive caregiver as a prerequisite for understanding the manner of her child caretaking. Under harsh conditions of poverty and HIV/AIDS where only limited supportive affordances for the carer and the child may be evident, the child's developmental niche takes on a shape that is a function of these

conditions and of the carer's ability to cope with them. Furthermore, the review pointed to the fact that models of childcare and relationships between children and their caregivers are creatures of necessity and cultural practice. In the majority of the world's cultural settings, particularly in poor communities of the developing world, childcare is a shared responsibility among kin, including older siblings. While biological mothers commonly bear primary responsibility for the child during infancy, as this period ends, the range of carers in the household increases. Styles of parenting then, are adaptive strategies for maximising desired benefits while minimising risks in a particular setting.

It is important for psychological research into the nature of childcare, and the quality of caregiver-child relationships in HIV affected households to develop techniques that take this complexity into account. This is particularly important in rural and urbanising African communities. Furthermore, it is appropriate that research on these issues should draw on the attachment literature. Clearly this field has contributed enormously to our understanding of the threats to the emotional well-being and internal relationship schemata of children posed by carers who are emotionally (or physically) absent, intrusive, or inconsistent.

Without detracting from this contribution, and notwithstanding Ainsworth's (1967) original Ugandan work as well as recent innovations (Cooper et al. 2002; Murray et al. 1996), it is necessary to note that the body of theory and associated laboratory research techniques that drive this work have their roots in modern Western systems of child care and research settings (LeVine and Miller 1990). The methods are well suited to an understanding of relationship behaviour and attachments in the characteristic dyads that occur in modern child care arrangements, and have been demonstrated to have cross-

cultural validity. However, they are not adapted to investigations of the nature and quality of young children's relationships and attachments in settings in which children are typically cared for by several carers. This is the case in many African settings, including that in the current study.

The approach taken in this research tried to take these points into account, particularly in our employment of careful ethnographic home observations. However, as we found, studying care relationships and the quality of the child's inner relationship world within a reasonable period of time and in natural settings is a challenge. We will return to this point shortly.

In the remainder of this final chapter we present recommendations for future studies. We first provide general recommendations. As noted in Chapter 3, the childcare observation techniques developed for this study were informed more by an anthropological than a psychological orientation. In the concluding pages of the report, we provide methodological recommendations for research into the psychological quality of caregiver child relationships in households affected by HIV/AIDS. These recommendations build on the observational methods explored in this study. They also have implications for interventions with children living in households living with HIV/AIDS.

4.2 Recommendations

4.2.1 Recommendations for research practice

(a) Ethical and procedural issues in the context of HIV/AIDS

The study's findings suggest several important recommendations with regard to the kinds of ethical and procedural practices which are essential to both a study of this kind, and research in the context of HIV/AIDS in general:

- As with any research, ethical practice is imperative. However, in research with HIV positive populations there are special concerns, including the need to ensure confidentiality and proceed with sensitivity toward the needs of this stigmatised, physically and emotionally vulnerable group.
- Given the extent to which HIV/AIDS is stigmatised, it is important to make practical arrangements that ensure the research participant's right to privacy and confidentiality are maintained. It is therefore desirable to secure private spaces where the HIV positive person can be interviewed. Where the participant is not assured of privacy, this can be a threat to the validity of the information she supplies in the interview and therefore to the integrity of the study.
- It is important to minimise the burden of research participation, particularly for women who are poor and ill. One strategy used in this research was to synchronise the timing of research interviews and child assessments with participant's clinic visits. In this way they did not incur the additional cost of travel (or loss of income associated with taking time off work).
- Given the nature of HIV/AIDS and its social significance, it is necessary for researchers to take the time to establish the rapport with the participant and other household members. If this does not occur, the data obtained is likely to be very limited.
- Where participants and other household members are to be filmed or photographed, permission must be sought and the specific uses to which the film is to be put must be explained (including any audiences to which it might be shown). Where

audiences other than the researchers are to view the film or photographs, faces must be masked so as to prevent identification.

(b) Responsibility to the community that is being researched

Researchers should be in communication with local service providers (e.g. clinic staff) and community representatives for the purpose of providing feedback on the research that may be of benefit. This contact is also important should there be a need to facilitate service provision to particular participants.

(c) Local culture, languages and translation

Particular attention should be paid to translation *and*, as is often necessary, the culturally appropriate re-conceptualisation of research instruments that are imported from other cultural contexts. It is not good enough to simply translate the instruments into the participant's language. Particularly where psychological concepts are concerned, it is necessary to investigate the extent to which the local idiom and experience of mental states is equivalent or different to that assumed in the measure.

(d) Assessment of young children

Where the developmental and psychological status of children is assessed, it is essential that measures are appropriate for the situation in which the children have developed and are living. Where affordances in the child's developmental environment that are required to perform on the test are lacking or limited, this will compromise test performance.

(e) Filming in the home

We found that using video cameras in very crowded small dark spaces such as huts and shacks is very challenging. From a technical point of view, the settings to be filmed should be carefully assessed before using this technique so as to avoid the collection of material that adds little value to other data recording methods, and is unnecessarily expensive. That said, film record remains useful as an aid to the researcher when reflecting on the observation and writing up notes. See the note on film ethics above.

4.2.2 Recommendations for a more psychologically-oriented approach to caregiver-child observation

It will be recalled that the overall aim of the observation and accompanying interview used in this study was to *describe* the nature of the care relationship and niche, a component of the model developed in Figure 1.1, which was shown to be a key pathway whereby children are affected by primary caregiver HIV infection. The material generated by these methods produced a reasonably comprehensive picture of who performs the range of care roles for each child observed, the nature and emotional climate of interactions between the child and her/his carers, and the physical and social environments in which care takes place.

Essentially the current methodology provides a short form of a contextually rich account of the context of child care and well being in HIV/poverty environments. Despite our intention to provide a perspective on the multiple care roles evident in the household, our insights into the care of each child were primarily established through observation of mothers' responses. It is quite possible that other significant carers (who we could neither consult nor observe), for example siblings, aunts, uncles, grandparents and neighbours might have had a different perspective. However, time and operational constraints did not

permit us to observe these patterns in any depth. Quite clearly they were operating in these households.

Generating this sort of data requires considerably broadening the observation component. It would involve a long-term, embedded more classical anthropological approach with multiple informants commenting on the child's status and caregiver's relationship in- and outside the household. While such research is needed to unpack the full complexity of the care situation in HIV affected households in Africa and elsewhere, this is a high cost option in terms of time and resources. For many purposes, one needs a more rapid appraisal.

Action research provides another route. For example, researchers may attach themselves to a service provider undertaking interventions with HIV positive women with young children. The researcher is able to observe the patterns of care that are evident along the way as they change (or do not) in response to the intervention.

More importantly from a psychological point of view, however, our methods and those mentioned above are limited in their ability to provide data on the manner in which the inner worlds of the children and their caregiver(s) were reflected in their interactions. Our approach did not allow us to comment substantially on patterns in care-related tasks and their contribution to the psychological status of the care relationship – such as those outlined in the ICDP (e.g. sensitivity and emotional attunement). In addition, as noted above, we were not able to study relationship quality in multiple dyads involving the child and others who cared for her or him.

In order to address these limitations and provide a more nuanced picture of the psychological quality of these relationships, future studies could usefully draw on adapted forms of the observational methods developed for the study of attachment behaviour in natural settings. These contributions provide techniques that enable data to be gathered within a relatively short period of time (Cooper et al. 2002; Murray et al. 1996). We believe they can be employed usefully alongside instruments developed by Hundeide as part of the ICDP approach to the assessment of the quality of caregiver-child relations.

However, to provide for a picture of relationship quality in multiple dyads, they would need to be adapted. As we have noted, in extended African households, it is normally not just the mother or child's primary caregiver who provides the relationship structure for the child's attachment and development of psychological orientation to others. Rather a range of people care for the child. It is therefore difficult to know to what extent the HIV positive mother's orientation to the child is the primary determinant of the child's psychological orientation and emotional status, or whether these outcomes are moderated by the child's relationships with others who take care of her as well. For example, a carer other than the mother might in fact have a much more positive and sensitive way of interacting with the child. What role does this play in moderating the negative contact she has with her mother?

In short, if we only observe the mother-child dyad, and draw conclusions from this interaction, we may be missing important information that can help explain the child's behaviour.

We do not know to what extent observations of the several caregiving relationships of the child will advance our understanding. However, it would be very useful to mount studies that help us to find out. What follows are some brief suggestions in this vein.

One could imagine a study in which all those in the household are identified who care for the child for at least 20% of an average day. These would be identified by questioning all household members and cross-validating their responses. The researcher would record the proportions of time the child spends with each carer. Once this had been done, the techniques outlined below would be used to assess the quality of the relationship in each carer-child dyad. Once this had been done, it should be possible to discern whether the primary caregiver/mother's relationship is of a different quality to that displayed by others. Arguably, the more time the child spends with a particular carer, the greater would be the influence of that carer's approach to the child (regardless of whether it was the mother or not). However, the recommended methods would need to be used to test whether or not this hypothesis is correct. For example, where the mother was unwell due to her AIDS status, and is not able to care adequately for the child, if the quality of care provided by other household members was good, this could off-set the (negative) effects of that provided by the mother, reducing the risks of poor child outcomes.

In the review of methods used in the field, the Global Rating Scale (GRS) assessment of mother-infant interaction (Murray et al. 1996) was mentioned as a well-validated, brief (normally 5 minute) technique that can be adapted for use in field settings. We do not know whether it has been used to assess the multiple dyad situations to which we have drawn attention. We suggest that a future study adapt the technique to observe multiple dyads in the manner we have suggested and code the interactions in each case. A limitation

of the GRS is that it requires video equipment and experienced coders familiar with complex theory.

The ICDP assessment tools included in the ICDP Facilitators' Manual provide a technology-free set of simple observational tools that lay persons can be trained to use to observe carer-child dyads. It has been used in South Africa and Angola (among other countries) (Richter 2001). Again, the tools would be used to observe and gather data in the several care dyads within which the child participates.

In the context of the ravages of the AIDS epidemic in households already struggling with poverty and other risks to child survival and development, these tools must be used in conjunction with more crude indicators of compromised care and threats to child well-being.

In sum, our research for this study, as well as a long tradition of more ethnographic work in Africa, suggests that attention to the care niche and not just the mother-child relationship, is very important in addressing the psychological needs of children in these situations. Notwithstanding the recommendations for innovations such as those outlined above, home observations of childcare will remain essential to extract qualitative information about the niche. Apart from the interesting research applications suggested by our approach, in deepening our understanding of the factors that influence the psychological outcomes of children whose primary caregivers are HIV infected, a future research orientation to multiple dyads might also have implications for the modification of interventions such as the ICDP and Children Affected by AIDS (CABA) programmes. These have traditionally focused on strengthening the HIV positive mother-child dyad,

rather than considering the inclusion of all significant carers in the programme. It is time to extend these valuable approaches so that they take account of the full range of care in the niche which will often compliment and, in many instances (tragically), have to replace that provided by the mother.

References

Adnams, C. M., P. W. Kodituwakku, A. Hay, C. D. Molteno, D. Viljoen and P. A. May. 2001. Patterns of cognitive-motor development in children with fetal alcohol syndrome from a community in South Africa. *Alcoholism: Clinical and Experimental-Research* 25:557-562.

Ainsworth, M. S. D. 1967. *Infancy in Uganda: infant care and the growth of attachment.* Baltimore: Johns Hopkins University Press.

Ainsworth, M. D. S., M. Blehar, E. Waters and S. Wall. 1978. *Patterns of attachment: A psychological study of the Strange Situation*. New Jersey: Lawrence Erlbaum.

All, A. C. and L. Sullivan. 1997. The effects of an HIV/AIDS educational programme on the anxiety level of nursing students. *Journal of Advanced Nursing* 26:798-803.

Allan, M., D. M. Luiz and C. Foxcroft, C. 1992. The performance of South African normal preschool children on the Griffiths Scale of Mental Development: A comparative study. Paper presented at the Psychological Association of South Africa, at Stellenbosch, Cape Town.

Ansell, N. and L. Young. 2004. Enabling households to support successful migration of AIDS orphans in southern Africa. *AIDS Care* 16:3-10.

Antle, B., L. Wells, R. Goldie, D. DeMatteo and S. King. 2001. Challenges of parenting for families living with HIV/AIDS. *Social Work* 46:159-169.

Antoni, M. H., B. Esterling, S. Lutgendorf, M. A. Fletcher and N. Schneiderman. 1995. Psychosocial stressors, herpes virus reactivation, and HIV-1 infection. In *AIDS and oncology: Perspectives in behavioral medicine*, edited by M. Stein and A. Baum, 135-168. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

Antoni, M. H., K. Goodkin, D. Goldstein, A. LaPerriere, G. Ironson and M A. Fletcher. 1991. Coping responses to HIV-1 serostatus notification predict short-term and long-term affective distress and one-year immunologic status in HIV-1 seronegative and seropositive gay men [abstract]. *Psychosomatic Medicine* 53:227.

Armistead, L., K. Klein and R. Forehand. 1995. Parental physical illness and child functioning. *Clinical Psychology Review* 15:409-422.

Baer, M. R. and J. Roberts. 2002. Complex HIV treatment regimens and patient quality of life. *Canadian Psychology* 43:115-121.

Bauman, L., S. Camacho, E. Silver, J. Hudis and B. Draimin. 2002. Behavioral problems in school-aged children of mothers with HIV/AIDS. *Clinical Child Psychology and Psychiatry* 7:39-54.

Bavolek. S. J. 1984. Handbook for the Adult-Adolescent Parenting Inventory. Park City, Utah: Family Development Resources.

Bayley, N. 1993. *Bayley Scales of Infant Development*. 2nd ed. San Antonio, Texas: Psychological Corporation.

Beebe, B. and F. M. Lachmann. 2002. *Infant research and adult treatment: Co-constructing interactions*. Hillsdale, NJ: The Analytic Press.

Belsky, J. 1996. Parent, infant, and social-contextual antecedents of attachment security. *Developmental Psychology*, 32:905-913.

Bertucci, N. M. 2000. Responsiveness to relaxation for distress in HIV(+) patients. Postgraduate diss., New School for Social Research, United States.

Black, M. M., P. Nair and D. Harrington. 1994. Maternal HIV infection: Parenting and early child development. *Journal of Pediatric Psychology* 19:595-616.

Bogart, L. M., S. L. Catz, J. A. Kelly, M. L. Gray-Bernhardt, B. R. Hartmann, L. L. Otto-Salaj, et al. 2000. Psychosocial issues in the era of new AIDS treatments from the perspective of persons living with HIV. *Journal of Health Psychology* 5:500-516.

Bradley, R. H. 1994. The HOME inventory: Review and reflections. *Advances in Child Development and Behavior* 25:241-287.

Bradley, R. H. and B. M. Caldwell. 1979. Home Observation for Measurement of the Environment: A revision of the Preschool State. *American Journal of Mental Deficiency* 84, no. 3:235-244.

___. 1981. Home Environment and Infant Social Behavior. *Infant Mental Health Journal* 2, no.1:18-22.

Bradley, R. H., R. F. Corwyn and L. Whiteside-Mansell. 1996. Life at home: Same time, different places – An examination of the HOME Inventory in different cultures. *Early Development and Parenting* 5, no. 4:251-269.

Bradley, R. H., B. M. Caldwell, S. L. Rock, H. M. Hanrick and P. Harris. 1988. Home Observation for Measurement of the Environment: Development of a home inventory for use with families having children 6 to 10 years old. *Contemporary Educational Psychology* 13:58-71.

Bray, R. 2003a. Predicting the social consequences of orphanhood in South Africa. *African Journal of AIDS Research* 2, no. 1:39-55.

___. 2003b. Who does the housework? An examination of South African children's working roles. *Social Dynamics* 29:95-131.

Bromer, J and J. Henly. 2004. Childcare as family support: Caregiving practices across child care providers. *Children and Youth Services Review* 26:941-964.

Bronfenbrenner, U. 1995. Developmental ecology through space and time: a future perspective. In *Examining lives in context. Perspectives on the ecology of human development*, edited by P. Moen, G. H. Elder and K. Luscher, 619-647. Washington D.C.: American Psychological Association.

Broun, S. N. 1996. Clinical and psychosocial issues of women with HIV/AIDS. In *Women and AIDS: Coping and care*, edited by A. O'Leary and L. S. Jemmott, 151-166. New York: Plenum Press.

Burgoyne, R. and R. Renwick. 2004. Social Support and Quality of Life over Time among Adults Living with HIV in the HAART Era. *Social Science & Medicine* 58:1353-1366.

Byrne, M. 1998. Feeding interactions in a cross section of HIV-exposed infants. *Western Journal of Nursing Research* 20:409-425.

Carver, C. S. 1997. You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine* 4:92-100.

Carver, C. S., M. F. Scheier and J. K. Weintraub. 1989. Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology* 56:267-283.

Case, A. and C. Ardington. 2004. *The impact of parental death on school enrolment and achievement: Longitudinal evidence from South Africa.* CSSR Working Paper No. 97, University of Cape Town, Cape Town.

Ciambrone, D. 2003. *Women's experiences with HIV/AIDS: Mending fractured selves.* New York: The Haworth Press.

Collins-Jones, T. 1997. AIDS orphans: The psychological adjustment of children with multiple family members with a terminal illness. Postgraduate diss., University of Oklahoma, United States.

Cooper, P. J., M. Landman, M. Tomlinson, C. Molteno, L. Swartz and L. Murray. 2002. Impact of a mother-infant intervention in an indigent peri-urban South African context: a pilot study. *British Journal of Psychiatry* 180:76-81.

Cooper, P. J., M. Tomlinson, L. Swartz, M. Woolgar, L. Murray and C. Molteno. 1999. Postpartum depression and the mother-infant relationship in a South African peri-urban settlement. *British Journal of Psychiatry* 175:554-558.

Cooper, P. J., M. Tomlinson, L. Murray, L. Swartz, A. Stein and C. Molteno. Work in progress. A controlled trial of a community based mother-infant intervention in a South African peri-urban settlement. Cape Town, South Africa.

Crampin, A., S. Floyd, J. Glynn, N. Madise, A. Nyondo, M. Khondowe, et al. 2003. The long-term impact of HIV and orphanhood on the mortality and physical well-being of children in rural Malawi. *AIDS Care* 17:389-397.

Crossley, M. L. 2000. *Introducing narrative psychology: Self, trauma and the construction of meaning*. Buckingham: Open University Press.

Department of Health 2004. *Report. National HIV and syphilis antenatal sero-prevalence survey in South Africa* [On-line]. Available: www.doh.gov.za/docs/2003hiv-f.html.

DeMatteo, D., L. M. Wells, R. S. Goldie and S. M. King. 2002. The 'family' context of HIV: a need for comprehensive health and social policies. *AIDS Care* 14:261-278.

Dorsey, S., K. Klein and R. Forehand. 1999. Parenting self-efficacy of HIV-infected mothers: The role of social support. *Journal of Marriage and the Family* 61:295-305.

Duggan, D. 2000. *Out here by ourselves: The stories of young people whose mothers have AIDS*. New York: Garland Publishing, Inc.

Dutra, R., R. Forehand, L. Armistead, G. Brody, E. Morse, P. Morse, et al. 2000. Child resiliency in inner-city families affected by HIV: The role of family variables. *Behaviour Research and Therapy* 38:71-486.

Elkin, E., C. Mellins, A. Ehrhardt, W. Grant and A. DuBose. 1995. Stress and psychosocial functioning in HIV-infected mothers and their children. Paper presented at HIV Infected Women's Conference, at United States.

Fair, C., E. Spencer, L. Weiner and K. Riekert. 1995. Healthy children in families affected by AIDS: Epidemiological and psychosocial considerations. *Child and Adolescent Social Work Journal* 12:165-181.

Fogel, J., S. M. Albert, F. Schnabel, B. A. Ditkoff and A. I. Neugut. 2002. Internet use and social support in women with breast cancer. *Health Psychology* 21, no. 4:398-404.

Forehand, R., R. Steele, L. Armistead, E. Morse, P. Simon, L. Clark, et al. 1998a. The Family Health Project: Psychosocial adjustment of children whose mothers are HIV infected. *Journal of Consulting and Clinical Psychology* 66:513-520.

Forehand, R., L. Armistead, E. Morse, P. Simon, L. Clark, G. Brody et al. 1998b. The Family Health Project: A multidisciplinary longitudinal investigation of children whose mothers are HIV infected. *Clinical Psychology Review* 18:839-856.

Forehand, R., L. Armistead, E. Morse, P. Simon and L. Clark. 2001. The Family Health Project: An investigation of children whose mothers are HIV-infected [On-line]. Available: www.apa.org/pi/aids/forehand.html.

Forehand, R., D. Jones, B. Kotchick, L. Armistead, E. Morse, P. Morse, et al. 2002. Noninfected children of HIV-infected mothers: A 4-year longitudinal study of child psychosocial adjustment and parenting. *Behavior Therapy* 33:579-600.

Forsyth, B., L. Damour, S. Nagler and J. Adnopoz. 1996. The psychological effects of parental human immunodeficiency virus infection on uninfected children. *Archives of Pediatric and Adolescent Medicine* 150:1015-1020.

Foster, G. and J. Williamson. 2000. A review of current literature on the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS* 14:S275-S284.

Freeman, M. 2004. HIV/AIDS in developing countries: heading towards a mental health and consequent social disaster? *South African Journal of Psychology* 34:139-159.

Gauvain, M. 1992. Thinking in niches: socio-cultural influences on cognitive development. *Human Development* 38:25-45.

Geballe, S., J. Gruendel and W. Andiman, eds. 1995. *Forgotten children of the AIDS epidemic*. New Haven, CT, Yale University Press.

Gerstadt, C. 2003. Discrepancies in the reporting of the mental health of children who have mothers with HIV/AIDS. Postgraduate diss., New School for Social Research, United States.

Gopnik, A., A. Meltzoff and P. Kuhl. 1999. *How babies think: The science of childhood.* London: Weidenfeld & Nicolson.

Gordillo, V., J. del Amo, V. Soriano and J. Gonzalez-Lahoz. 1999. Sociodemographic and psychological variables influencing adherence to antiretroviral therapy. *AIDS* 13:1763-1769.

Greene, K., V. Derlega, G. Yep and S. Petronio. 2003. *Privacy and disclosure of HIV/AIDS in interpersonal relationships: a handbook for researchers and practitioners***.** Mahwah, NJ: LEA Publishers.

Griffiths, R. 1976. *The abilities of babies: A study in mental measurement*. Amersham: Association for Research in Infant and Child Development.

Gunning, M., S. Conroy, V. Valoriani, B. Figueiredo, M. H. Kammerer, M. Muzik, et al. 2004. Measurement of mother-infant interaction and the home environment in a European setting: preliminary results from a cross-cultural study. *British Journal of Psychiatry* 184:s38-s44.

Hackl, K. L., A. M. Somlai, J. A. Kelly and S. C. Kalichman. 1997. Women living with HIV/AIDS: The dual challenge of being a patient and caregiver. *Health and Social Work* 22:53-62.

Hale, A. K., D. Holditch-Davis, J. D'Auria and M. S. Miles. 1999. The usefulness of an assessment of emotional involvement of HIV-positive mothers and their infants. *Journal of Pediatric Health Care* 13:230-236.

Henderson, P. C. 1999. Living with fragility: children in New Crossroads. Ph.D. diss., University of Cape Town, Cape Town.

Holditch-Davis, D., M. S. Miles, M. Burchinal, K. O'Donnell, R. McKinney and W. Limm. 2001. Parental caregiving and developmental outcomes in infants of mothers with HIV. *Nursing Research* 50:5-14.

Hough, E. S., G. Brumitt, T. Templin, T. Saltz and D. Mood. 2003. A model of mother–child coping and adjustment to HIV. *Social Science and Medicine* 56:643-655.

Hudis, J. 1995. Adolescents living in families with AIDS. In *Forgotten Children of the AIDS Epidemic*, edited by S. Geballe, J. Gruendel and W. Andiman, 83-94. New Haven, CT: Yale University Press.

Hudson, A., K. Lee and C. Portillo. 2003. Symptom experience and functional status among HIV-infected women. *AIDS Care* 15:483-492.

Hundeide, K. 1990. Preparing for early psycho-social intervention in non-Western cultures: Mapping the child's "developmental niche". University of Bergen, Norway, unpublished paper.

___. n.d. The nature of empathic care: Care and abuse inside and outside the zone of intimacy. University of Oslo, Norway, unpublished.

Hunter, S. and J. Williamson. 2002. *Children on the brink. Strategies to support children isolated by HIV/AIDS.* Washington, DC: USAID.

Ironson, G., A. Friedman, N. Klimas, M. Antoni, M. A. Fletcher, A. LaPerriere, J. Simoneau and N. Schneiderman. 1994. Distress, denial, and low adherence to behavioural interventions predict faster disease progression in gay men infected with human immunodeficiency virus. *International Journal of Behavioral Medicine* 1:90-105.

Jaquess, D. L. 1994. Psychosocial variance in the outcomes of pediatric HIV. Postgraduate diss., Virginia Polytechnic Institute and State University, United States.

Jelsma, J., J. Hughes, E. Mclean and M. Darder. 2003. Health-related quality of life in PLWA receiving HAART - does gender make a difference. Paper presented at the Gender and HIV/AIDS Workshop, Women's Health Research Unit, May, at Cape Town.

Johnson, O. G. 1976. Qualities of caregiving and home environment. In *Tests and measurements in child development. Handbook II*. Vol. 2, 735-753. San Francisco: Jossey Bass.

Johnson, M. O. and M. L. Lobo. 2001. Mother-child interaction in the presence of maternal HIV infection. *Journal of Association of Nurses AIDS Care* 12:3-17.

Jones, D. J., S. R. H. Beach and R. Forehand. 2001a. HIV infection and depressive symptoms: An investigation of African American single mothers. *AIDS Care* 13:343-350.

___. 2001b. Disease status in African American single mothers with HIV: The role of depressive symptoms. *Health Psychology* 20:417-423.

Jones, D. J., R. Forehand, G. Brody and L. Armistead. 2002. Psychosocial adjustment of African American children in single-mother families: A test of three risk models. *Journal of Marriage and Family* 64:105-115.

Kalichman, S. C., K. Difonzo, J. Austin, W. Luke and D. Rompa. 2002. Prospective study of emotional reactions to changes in HIV viral load. *AIDS Patient Care and STDs* 16:113-120.

Judd, F. K., A. M. Cockram, A. Komiti, A. M. Mijch, ‚J. Hoy and R. Bell. 2000. Depressive symptoms reduced in individuals with HIV/AIDS treated with highly active antiretroviral therapy: A longitudinal study. *Australian & New Zealand Journal of Psychiatry* 34:1015-1021.

Khan, L. 2004. Experiences of HIV/AIDS diagnosis, diclosure and stigma in an urban informal settlement in the Cape Peninsula: A qualitative exploration. Centre for Social Science Research, Working paper, No 94.

Kirksey, K., M. Hamilton and M. Holt-Ashley. 2002. Correlates of perceived health in women diagnosed with HIV disease. *Internet Journal of Advanced Nursing Practice* 5:119-132.

Kirshenbaum, S. and J. Nevid. 2002. The specificity of maternal disclosure of HIV/AIDS in relation to children's adjustment. *AIDS Education and Prevention* 14:1-16.

Klein, K., L. Armistead, D. Devine, B. Kotchick, R. Forehand, E. Morse, et al. 2000. Socioemotional support in African American families coping with maternal HIV: An examination of mothers' and children's psychosocial adjustment. *Behavior Therapy* 31:1-26.

Koopman, C., C. Gore -Felton, F. Marouf, L. Butler, N. Field, M. Gill, et al. 2000. Relationships of perceived stress to coping, attachment and social support among HIV-positive persons. *AIDS Care* 12:663-672.

Kotchick, B., R. Forehand, G. Brody, L. Armistead, E. Morse, P. Simon, et al. 1997a. The impact of maternal HIV infection on parenting in inner-city African-American families. *Journal of Family Psychology* 11:447-461.

Kotchick, B., P. Summers, R. Forehand and R. Steele. 1997b. The role of parental and extrafamilial social support in the psychosocial adjustment of children with a chronically ill father. *Behavior Modification* 21:409-432.

Kotras, H. 2001. Exploring the developmental profiles of black South African HIV+ infants using the revised Griffiths Scales of Mental Development. Master diss., University of Port Elizabeth, Port Elizabeth.

Letteney, S. and H. LaPorte. 2004. Deconstructing stigma: Perceptions of HIV-seropositive mothers and their disclosure to children. *Social Work in Health Care* 38:105-123.

LeVine, R. A. 1990. Infant environments in psychoanalysis: A cross-cultural view. In *Cultural psychology: essays on comparative human development*, edited by J. W. Stigler, R. A. Shweder and G. Herdt, 454-474. Cambridge, Massachusetts: Harvard University Press.

LeVine, R. A. and P. M. Miller. 1990. Commentary. *Human Development* 33:73-80.

Lewis, M. 1995. The special case of the uninfected child in the HIV-affected family: Normal developmental tasks and the child's concerns about illness and death. In *Forgotten Children of the AIDS Epidemic*, edited by S. Geballe, J. Gruendel and W. Andiman, 50-63. New Haven, CT: Yale University Press.

Luiz, D. M. Ed.. 1988. *Griffiths scales of mental development: South African studies*. Port Elizabeth, South Africa: University of Port Elizabeth.

Luthar, S. S., D. Ciccheti and B. Becker. 2000. The construct of resilience: A critical evaluation and guidelines for future work. *Child Development* 71, no. 3:543-562.

Lyons-Ruth, K., B. Repacholi, S. McLeod and E. Silva. 1991. Disorganised attachment behaviour in infancy: Short-term stability maternal and infant correlates and risk-related subtypes. *Development and Psychopathology* 4:377-396.

Lyons-Ruth, K., M. A. Easterbrooks and C. D. Cibelli. 1997. Infant attachment strategies, infant mental lag, and maternal depressive symptoms: Predictors of internalizing and externalizing problems at age 7. *Developmental Psychology* 33:681-692.

Majumdar, B. 2004. An exploration of socioeconomic, spiritual, and family support among HIV-positive women in India. *The Journal of the Association of Nurses in AIDS Care* 15:37-46.

Mast, T., G. Kigozi, F. Wabwire-Mangen, R. Black, N. Sewankambo, D. Serwadda, et al. 2004. Measuring quality of life among HIV-infected women using a culturally adapted questionnaire in Rakai district, Uganda. *AIDS Care* 16:81-94.

Mbaye, I. and N. Mbaye. 1998. Management of children in families affected by HIV/AIDS: Community issues. Paper presented at International Conference on AIDS at Switzerland.

Mellins, C. A., A. A. Ehrhardt, L. Newman and M. Conard. 1996. "Selective kin": Defining the caregivers and families of children with HIV disease. In *Women and AIDS: Coping and care*, edited by A. O'Leary and L. S. Jemmott, 123-149. New York: Plenum Press.

Mens-Verhulst, J., and C. Spence. 2004. The private struggle of mothers with asthma: a gender perspective on illness management. *Patient Education and Counseling* 54:79-86.

Michaels, D. In progress. Factors influencing HAART adherence in HIV-infected children aged 0-6 years in a resource-poor setting, Cape Town, South Africa. Ph.D. diss., School of Public Health and Family Medicine, University of Cape Town, Cape Town.

Miles, M. S., J. V. Gillespie and D. Holditch-Davis. 2001. Physical and mental health in African American mothers with HIV. *Journal of the Association of Nurses in AIDS Care* 12:42-50.

Miles, M. S., P. Burchinal, D. Holditch-Davis, V. Wasilewski and B. Christian. 1997. Personal, family, and health related correlates of depressive symptoms in mothers with HIV. *Journal of Family Psychology* 11:23-34.

Moneyham, L., R. Sowell, B. Seals and A. Demi. 2000. Depressive symptoms among African American women with HIV disease. *Scholarly Inquiry for Nursing Practice* 14:9-39.

Morrison, M. F., J. M. Petitto, T. Ten Have, D. R. Gettes, M. S. Chiappini, A. L. Weber, et al. 2002. Depressive and anxiety disorders in women with HIV infection. *American Journal of Psychiatry* 159:789-796.

Murphy, D. A., W. D. Marelich, M. E. Dello Stritto, D. Swendeman and A. Witkin. 2002. Mothers living with HIV/AIDS: mental, physical, and family functioning. *AIDS Care* 14:633-644.

Murphy, D., W. Marelich and D. Hoffman. 2002. A longitudinal study of the impact on young children of maternal HIV serostatus disclosure. *Clinical Child Psychology and Psychiatry* 7:55-70.

Murray, L., A. Hipwell, R. Hooper, A. Stein and P. J. Cooper. 1996. The cognitive development of five year old children of postnatally depressed mothers. *Journal of Child Psychology and Psychiatry* 37:927-935.

Myers, J. K. and M. M. Weissman. 1980. Use of a self-report symptom scale to detect depression in a community sample. *American Journal of Psychiatry* 137:1081-1084.

Nagler, S., J. Adnopoz and B. Forsyth. 1995. Uncertainty, stigma and secrecy: Psychological aspects of AIDS for children and adolescents. In *Forgotten Children of the AIDS Epidemic*, edited by S. Geballe, J. Gruendel, & W. Andiman, 71-82. New Haven, CT: Yale University Press.

Newell, M., H. Coovadia, M. Cortina-Borja, N. Rollins, P. Giallard and F. Dabis. 2004. Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. *The Lancet* 364:1236-1243.

Olds, D., H. Kitzman, R. Cole and J. Robinson. 1997. Theoretical foundations of a program of home visitation for pregnant women and parents of young children. *Journal of Community Psychology* 25:9-25.

Olds, D., C. J. Henderson, H. Kitzman, J. Eckenrode, R. Cole and R. Tatelbaum. 1998. The promise of home visitation: Results of two randomized trials. *Journal of Community Psychology* 26:5-21.

Olley, B., F. Gxamza, S. Seedat, H. Theron, D. Stein, J. Taljaard, E. Reid and H. Reuter. 2004. Psychopathology and coping in recently diagnosed HIV/AIDS patients - the role of gender. *South African Journal of Psychiatry* 10:21-24 (Reprinted from the South African Medical Journal (2003), 93:928-931).

Orlando, M., J. Tucker, C. Sherbourne and M. Burnam. 2005. A cross-lagged model of psychiatric problems and health-related quality of life among a national sample of HIV-positive adults. *Medical Care* 43:21-27.

Owens, S. 2003. African American Women living with HIV/AIDS: Families as sources of support and of stress. *Social Work* 48:163-170.

Peterson, N. J., D. Drotar, K. Olness, L. Guay and R. Kiziri-Mayengo. 2001. The relationship of maternal and child HIV infection to security of attachment among Ugandan infants. *Child Psychiatry and Human Development* 32:3-17.

Pretorius, T. B. 1993. *Problem solving appraisal, stress, depression, social support*. Cape Town: University of the Western Cape.

Radloff, L. S. 1977. The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement* 1, no. 3:385-401.

Reissman, C. 1993. *Narrative analysis*. Newbury Park, California: Sage.

Reyland, S., A. Higgins-D'Alessandro and T. McMahon. 2002. Tell them you love them because you never know when things could change: voices of adolescents living with HIV-positive mothers. *AIDS Care* 14:285-294.

Reynolds, P. 1991. *Dance, civet cat: Child labour in the Zambezi Valley*. Harare, London, Athens, Ohio: Baobab, Zed Books, Ohio University Press.

Riccobono, A. 1995. Coping and depression in HIV+ mothers and development of the HIV+ child. Postgraduate diss., Yeshiva University, United States.

Richter, L. 2001. *Development and implementation of a primary care model to promote interactions between caregivers and young children in the Eastern and Western Cape Provinces*. Pretoria: Department of Health, Directorate for Mental Health and Substance Abuse.

Richter, L. and K. W. Grieve. 1991. Home environment and cognitive development of Black infants in impoverished South African families. *Infant Mental Health Journal* 12:88-102.

Richter, L., J. Manegold, J. and R. Pather. 2004. *Family and community interventions for children affected by AIDS*. Cape Town: HSRC Publishers.

Riordan, D., L. Appleby and B. Faragher. 1999. Mother-infant interaction in postpartum women with schizophrenia and affective disorders. *Psychological Medicine* 29:991-995.

Roberts, M. C., R. A. Emsley, W. P. Pienaar and D. J. Stein. 1999. Anxiety disorders among abstinent alcohol-dependent patients. *Psychiatric Services* 50:1359-1361.

Sambamoorti, U., S. Crystal and H. Dermatis. 1995. Who cares for the carers? Informal caregiving and use of health services among women with HIV disease. Paper presented at HIV Infected Women's Conference, at United States.

Sarason, B. R. and I. G. Sarason. 1994. Assessment of social support. In *Social support and cardiovascular disease*, edited by S. A. Shumaker and S. M. Czajkowski, 41-63. New York: Plenum Press.

Sarason, I. G., H. M. Levine, R. B. Basham and B. R. Sarason. 1983. Assessing social support: The Social Support Questionnaire. *Journal of Personality and Social Psychology* 44:127-139.

Shaffer, A., D. Jones, B. Kotchick and R. Forehand. 2001. Telling the children: Disclosure of maternal HIV infection and its effects on child psychosocial adjustment. *Journal of Child and Family Studies* 10:301-313.

Shelmerdine, S. 2004. Working document for Centre for Social Science Research, June at University of Cape Town, Cape Town.

Sherbourne, C. D. and A. L. Stewart. 1991. The MOS social support survey. *Social Science and Medicine* 32:705-714.

Siegel, K., D. Karus and L. Dean. 2004. Psychosocial characteristics of New York City HIV-infected women before and after the advent of HAART. *American Journal of Public Health* 94:1127-1132.

Siehnhold, S. 1999. Women and HIV: An exploratory study of psychosocial support in heterosexual and lesbian women with HIV/AIDS (immune deficiency). Postgraduate diss., California School of Professional Psychology, California.

Silver, E., L. Bauman, C. Camacho and J. Hudis. 2003. Factors associated with psychological distress in urban mothers with late-stage HIV/AIDS. *AIDS & Behavior* 7:421-431.

Solomon, J. and C. George. 1999. The measurement of attachment security in infancy and childhood. In *Handbook of attachment: theory, research and clinical applications*, edited by J. Cassidy and P. R. Shaver, 287-316. New York: Guilford Press.

Soskolne, T. 2003. Moving beyond the margins: A narrative analysis of the life stories of women living with HIV/AIDS in Khayelitsha. Cape Town, CSSR Working Paper No. 33.

Spangenberg, J. J. and J. C. Theron. 1999. Stress and coping strategies in spouses of depressed patients. *Journal of Psychology* 133:253-262.

___. 2001. Stress and coping in parents of children with Down syndrome. *Studia Psychologica* 43:41-48.

Spielberger, C. D. 1983. *Manual for the State-Trait Anxiety Inventory*. Palo Alto, California: Consulting Psychologists Press.

Srisurapanont, M., S. Sungworn and N. Jarusuraisin. 2002. HIV-Seropositive results, health related quality of life and social support: A 24-week prospective study in Thailand. *AIDS Patient Care and STDs* 15:211-215.

Steele, R. G., R. Forehand and L. Armistead. 1997. The role of family processes and coping strategy in the relationship between parental chronic illness and childhood internalizing problems. *Journal of Abnormal Child Psychology* 25:83-94.

Stein, A., L. Murray, P. Cooper and C. G. Fairburn. 1996. Infant growth in the context of maternal eating disorders and maternal depression: A comparative study. *Psychological Medicine* 26:569-574.

Steinberg, M., S. Johnson, G. Schierhout, D. Ndegwa, K. Hall, B. Russell, et al. 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*. Report compiled for the Henry J. Kaiser Family Foundation and the Health Systems Trust [On-line]. Available: www.hst.org.za/uploads/files/hittinghome.pdf.

Stewart, K., L. Cianfrini and J. Walker. 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* 17:350-358.

Stewart, R. 1997. The Griffiths scales of mental development: a South African pilot validity study. Master diss., University of Port Elizabeth, Port Elizabeth.

Tang, H. 2002. Impact of social support and stress on health-related quality of life among people living with HIV and AIDS. Postgraduate diss., University of Alabama, Birmingham, United States.

Teti, D. M. and M. Nakagawa. 1990. Assessing attachment in infancy: The Strange Situation and alternate systems. In *Interdisciplinary Assessment of Infants: A Guide for Early Intervention Professionals*, edited by E. Gibbs and D. M. Teti, 191-214. Baltimore: Paul H Brookes.

Tomlinson, M. 2003. Culture and infancy: a critical examination. *Journal of Child and Adolescent Mental Health* 15:45-48.

Tompkins, T. L. and A. Nelson. 2005. Parentification and maternal HIV infection: Beneficial role or pathological burden? Paper presented at the Society for Research in Child Development Biennial Meeting, 7-10 April, at Atlanta, Georgia.

Tostes, M., M. Chalub and N. Botega. 2004. The quality of life of HIV-infected women is associated with psychiatric morbidity. *AIDS Care* 16:177-186.

UNAIDS 2004. *Care, women and AIDS. UNAIDS media backgrounder* [On-line]. Available: http://www.unaids.org/html/pub/una-docs/gcwa_care_02feb04_en_pdf.pdf.

UNICEF 2003. *Africa's orphaned generations*. New York: UNICEF [On-line]. Available: www.unicef.org/media/files.orphans.pdf.

___ 2004. *The state of the world's children 2005: Childhood under threat*. Available: http://www.unicef.org/sowc05/english/fullreport.html.

USAID 2004. Understanding the needs of orphans and other children affected by HIV and AIDS in Africa: State of the Science. Working draft, April 2004.

Uthis, P. 2000. The effects of commitment to caregiving role, stressors, appraisal of stress, coping resources, and coping responses on emotional well-being among HIV/AIDS family caregivers in Thailand. Postgraduate diss., Case Western Reserve University, United States.

Van IJzendoorn, M. H. and A. Sagi. 1999. Cross-cultural patterns of attachment: Universal and contextual dimensions. In *Handbook of attachment: theory, research and clinical applications*, edited by J. Cassidy and P. R. Shaver, 713-734. New York: Guilford Press.

van Wijk, C. 2001. Submarine escape: The effect of training on anxiety. *Journal of Human Performance in Extreme Environments* 5:7-10.

Vincent, S. L. 1997. Illness-related stress, positive attitudes, and social support as predictors of psychological outcomes in HIV symptomatic patients. Postgraduate diss., California School of Professional Psychology, San Diego.

Weiner, A. P. and K. Lorber. 1998. Social supports for women who are HIV positive. Paper presented at International Conference on AIDS at Switzerland.

Weisner, T. S. 1989. Cultural and universal aspects of social support for children: Evidence from the Abaluyia of Kenya. In *Children's social networks and social supports*, edited by D. Belle. New York, John Wiley.

Weisner, T. S. and R. Gallimore. 1977. My brother's keeper: Child and sibling caretaking. *Current Anthropology* 18, no. 2:169-186.

Wild, L. 2001. Review: The psychosocial adjustment of children orphaned by AIDS. *Southern African Journal of Child and Adolescent Mental Health* 13:3-22.

Woodring, L. A. 2000. A qualitative investigation of adolescents' experiences with parental HIV/AIDS. Postgraduate diss., Fordham University.

Young, L. and N. Ansell. 2003. Fluid households, complex families: the impacts of children's migration as a response to HIV/AIDS in southern Africa. *The Professional Geographer* 55:464-479.

Ziehl, S. and A. Burns. 2004. *The impact of HIV/AIDS on household structures in South Africa*. Paper presented at the SASA Conference, 27-30 June, at Bloemfontein, South Africa.

APPENDIX A. QUESTIONNAIRE

PILOT STUDY:
MASIPHUMELELE RESEARCH PROJECT ON WOMEN CAREGIVERS

Research conducted by:
Child, Youth and Family Development,
Human Sciences Research Council

Respondent no: _____ Date of interview:_____

Respondent no:	Date of interview:

Background information

Demographic information

1. Uneminyaka emingaphi?
   How old are you (years)?

Nceda wenze uphawu ngoX kwimpendulo ekulungeleyo
Please mark the correct option with an X.

2. Loluphi ulwimi oluthethayo?
   What is your home language?

isiXhosa	
isiZulu	
isiSotho	
isiNgesi	
iAfrikaans	
Okunye	

3. Ugqibele okanye uphele kweliphi ibanga emfundweni?
   What is your highest level of education?

Lutho	
Umgangatho 1-7	
Umgangatho 8-11	
Umgangatho 12 / Matrik	
Emva kwe-Matrik *Post-matric*	

4. Uphangela kanjani okwangoku?
   How are you currently employed?

Awuphangeli *Unemployed*	
Uphangela ngokugcwele *Full-time*	
Awuphangeli ngokungcwele *Part-time*	
Ngamanye amaxesha (piece-job) *Piece-work*	
Okunye	

Xa kukho okunye, nceda uchaze *(If other, please specify):*

_____

Respondent no:	Date of interview:

5. Yimalini umyinge wemali ongena aph' endlini ngenyanga, xa udibanise nenkam nkam kanye noncedo olufumana kurhulumente?
What is your average monthly household income, including pensions or grants received from the state?

Ngaphantsi kwe R500	
R500-R1000	
R1000-R1500	
R1500-R3000	
Ngaphezu kwe R3000	

Medical and adherence data

(Not for self-report. To be collected from medical file.)

1. Date of diagnosis (month, year):
Inyanga yoxilongo okanye unyanga

2. Description of antiretroviral medication regimen:
Inkcazelo ngendlela elisebenza ngayo ngeciza leantiretroviral

_____

_____

3. CD4 count: _____

4. Viral load:_____

5. Pill count:_____

Household composition and caregiving history

1. Lomntwana (othatha inxaxheba koluphononongo) wazalwa phambi kwexesha na?
Was the child (participating in the study) born prematurely?

Ewe	Hayi

1.1 Xa usithi ewe, wazalwa ngaphambili kwexesha liphi na, kangeetsuku okanye iiveki ezingaphi?
If yes, by how many weeks/days?

Ngeviki	
Ngosuku	

(Ask the caregiver is she knows the child's due date and the actual date of birth. Can also ask for the Road to Health Card where information on the child will be recorded.)

Respondent no:	Date of interview:

2. Ubungumntu othenjiweyo na ekukhathaleleni lomntwana? (oku kuthetha ukuba, oyena na mntu ofanele amtyise, amhlambe, futhi amjonge oko)
   Have you always been the person responsible for the care of this child? (i.e. the person most responsible for feeding and bathing, and watching over the child)

3. Ukhona na omnye omhoyayo lomntwana ngaphandle kwakho, xa ekhona, ingaba kubanini apho?
   Has anyone else cared for this child and if so, when?

Ewe	Hayi

_____

_____

4. La abanye abantwana bakho bona, bayamkhathalele na umntwana? Xa kunjalo, nini?
   Do any of your other children care for the child and if so, when?

_____

5. Ubuhlala phi ukususela umntwana wazalwa na?
   Where have you lived since the child was born?

Indawo *Place*	Ukusukela phi *From*	De kube nini *Until*

6. Bangaphi abantwana (abangaphantsi kweminyaka engu18) abahlala kulendlu? (Ukuze ubalwe kumele umntu abesoludidini lweentsuku nobusuku obunge ngaphezu kwa4 elala aph' endlini.)
   How many children (under 18 years) live in the household? (To be counted, the person must spend at least 4 nights a week on average in the household.)

_____

7. Bangaphi abantu (abangaphezu kweminyaka engu18 ukunyukele kwabadala) abahlala kulendlu? (Ukuze ubalwe kumele umntu abesoludidini lwezintsuku nobusuku obunge ngaphezu kwa4 elala aph' endlini.)
   How many adults (18 years or older) live in the household? (To be counted, the person must spend at least 4 nights a week on average in the household.)

_____

Respondent no:	Date of interview:

Brief COPE

Kwezi zinto ezilandelayo zibonisa onokukwenza ukumelana nobunzima ebomini bakho, kususela ngexesha oweva ngalo ukuba unetsholongwane kagawulayo, uze ufumane ichiza lamayeza eARV's. Zininzi iindlela zokujongana neengxaki. Lomcimbi wethu uzakubuza ukuba intoni onokuyenza ukujongana neziigxaki. Kucacile ukuba ngokwesiqhelo, abantu banendlela, nge`ndlela zokwenza izinto. Ndinomdla wokuva ukuba ziziphi inzame ozenzileyo ukumelana nemeko yakho. Umbuzo ngamnye uchaza iindlela ethile yokuziphatha. Ndifuna ukwazi banzi kuluhlu ngalunye ukuba uzilandela kangakanani izinto ezibuzwayo ebomini bakho.Ungaphenduli phezu kwento yokuba iyakusebenzela okanye ayikusebenzeli. Phendula ukuba uyayenza okanye awuyenzi. Zama ukwehlula hlula iingcinga nganye. Nceda wenze iimpendulo zakho ezinyanisekileyo njengoko usazi.

These items deal with ways you've been coping with the stress in your life since you found out you were HIV+ OR began treatment on antiretroviral therapy. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not - just whether or not you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

Yenza isangqa kwinani ngalinye kula adwelisiweyo:
Circle one number on each line:

1 = Zange ndayenza lento *(I haven't been doing this at all)*
2 = Bendiyenza kancinci *(I've been doing this a little bit)*
3 = Bendiyenza ngeloxesha *(I've been doing this a medium amount)*
4 = Bendiyenza gqitha *(I've been doing this a lot)*

1.	Bendiphambukela emsebenzini ndiphangele okanye ndenze ezinye izinto ukuba ndingayicingi lento. *I've been turning to work or other activities to take my mind off things.*	1	2	3	4
2.	Ndiye ndazinikezela ngomdla wam wonke ukwenza endinako kwimeko yam. *I've been concentrating my efforts on doing something about the situation I'm in.*	1	2	3	4
3.	Bendizixelela ukuba 'ayikho lento'. *I've been saying to myself "this isn't real".*	1	2	3	4
4.	Bendisebenzisa utywala neziyobisi ukuze ndizive ndibetele. *I've been using alcohol or other drugs to make myself feel better.*	1	2	3	4

Respondent no:	Date of interview:

5.	Bendifumana uncedo novelwano kwabanye kwiimpembelelo. *I've been getting emotional support from others.*	1	2	3	4
6.	Ndiye ndanikezela ukumelana nemeko endikuyo *I've been giving up trying to deal with it.*	1	2	3	4
7.	Ndizame ukuzenzela imizamo yokujongana nokwenzabhetele imeko yam. *I've been taking action to try to make the situation better.*	1	2	3	4
8.	Bendisoloko ndisala ndingavumi ukuba ndiyikholelwe ukuba yenzekile. *I've been refusing to believe that it has happened.*	1	2	3	4
9.	Bendithetha izinto ezibangela imeko yam emaxongo ukuba idlule okanye ndizive ndiyilibele. *I've been saying things to let my unpleasant feelings escape.*	1	2	3	4
10.	Bendifumana uncedo neengcebiso kwabanye abantu. *I've been getting help and advice from other people.*	1	2	3	4
11.	Bendisebenzisa utywala neziyobisi ngenjongo zokudlula kwimeko endikuyo. *I've been using alcohol or other drugs to help me get through it.*	1	2	3	4
12.	Bendizama ukuyiqwalasela ngeliso elahlukileyo, ukuze ndiyijonge ngendlela enika ithemba. *I've been trying to see it in a different light, to make it seem more positive.*	1	2	3	4
13.	Bendizi gxeka mna. *I've been criticising myself.*	1	2	3	4
14.	Bendizama ukufumana icebo elinobuchule lokuba ndenze njani. *I've been trying to come up with a strategy about what to do.*	1	2	3	4
15.	Bendifumana ukuphathwa kakuhle kanye nolonwabo komnye umntu. *I've been getting comfort and understanding from someone.*	1	2	3	4
16.	Ndiye ndanikezela kwiinzame zokumelana nemeko. *I've been giving up the attempt to cope.*	1	2	3	4
17.	Bendikhangela into entle kulento yenzekayo. *I've been looking for something good in what is happening.*	1	2	3	4
18.	Bendisenza intlekisa ngayo. *I've been making jokes about it.*	1	2	3	4

Respondent no:	Date of interview:

19.	Bendenza izinto zokuba ndicinge kancinci ngalengxaki, njengokuya kwibhayisikobho, ndijonge umabonakude, ndifunde, ndibekumvandodwa, ndilale okanye ndiyokuthenga evenkilini. *I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.*	1	2	3	4
20.	Ndaye ndabamkela ubukho okanye ubunyani balento ndinayo okokubayenzeka. *I've been accepting the reality of the fact that it has happened.*	1	2	3	4
21.	Bendibonakalisa ukungaphatheki kakuhle. *I've been expressing my negative feelings.*	1	2	3	4
22.	Bendizama ukufumana ulonwabo enkolweni (umzekelo njengenkolo yezinyanya, masilamusi, amaRasta njll) okanye kwiinkolo yomphefumlo. *I've been trying to find comfort in my religion or spiritual beliefs.*	1	2	3	4
23.	Bendizama ukufumana uncedo kwabanye abantu ngezinto endingazenza. *I've been trying to get advice or help from other people about what to do.*	1	2	3	4
24.	Bendizama ukuphila nayo lemeko. *I've been learning to live with it.*	1	2	3	4
25.	Bendicinga nzulu ngezinyathelo ebendi ngazithatha. *I've been thinking hard about what steps to take.*	1	2	3	4
26.	Bendizisola mna ngendlela izinto zenzeka ngakhona. *I've been blaming myself for things that happened.*	1	2	3	4
27.	Bendithandaza okanye ndicinge nzulu entliziyweni yam. *I've been praying or meditating.*	1	2	3	4
28.	Bendihlekisa ngalemeko. *I've been making fun of the situation.*	1	2	3	4

Notes:_____

_____

_____

_____

Respondent no:	Date of interview:

CES-D Depression

Ngaphantsi koluluhlu kunemibuzo yokufumana iindlela zokuba ucacise ngokuba uzivanjani okanye uziphethe njani ngexesha lale viki elidluleyo. Nceda undixelele ukuba kukangaphi uziva njalo kwiviki elidluleyo.
Below is a list of ways that describe how you may have felt or behaved during the past week. Please tell me how often you have felt this way during the past week.

Yenza isangqa kwinani kumagama adwelisiweyo:
Circle one number on each line:

1 = Mankqapha-nkqapha okanye zangendayenza lonto (ngaphantsi kokuphela kosuku)
(*Rarely or none of the time (less than one day))*
2 = Intwan' encinci okanye ngamaxesha amancinane (1-2wezintsuku)
(Some or a little of the time (1-2 days))
3 = Ngamanye amaxesha okanye maphakathi nendawo ngamany' amaxesha
(Occasionally or a moderate amount of time (3-4 days))
4 = Kakhulu okanye'maxeshonke (5 kuya kwizintsuku ezingu7)
(Most or all of the time (5-7 days))

Ngexesha leveki ephelileyo:
During the past week:

1.	Bendikhathazwa zizinto ezingaqhelanga ukungandikhathazi. *I was bothered by things that usually don't bother me.*	1	2	3	4
2.	Andifunanga kwakudla, andaba namdla wokudla. *I did not feel like eating; my appetite was poor.*	1	2	3	4
3.	Ndizive kwanzima ukungatyhafi noba bezama ekhaya nabahlobo bami ukundonwabisa. *I felt that I could not shake off the blues even with help from my family or friends.*	1	2	3	4
4.	Ndizive ndilunge njengabanye abantu. *I felt that I was just as good as other people.*	1	2	3	4
5.	Ndibe negxaki yokunikela ingqondo yam kwinto endiyenzayo. *I had a problem keeping my mind in what I was doing.*	1	2	3	4
6.	Ndizive ndidakumbile. *I felt depressed.*	1	2	3	4
7.	Ndiye ndaziva yonke into endiyenzayo izinzame. *I felt that everything I did was an effort.*	1	2	3	4
8.	Ndizive ndinethemba ngekamva. *I felt hopeful about the future.*	1	2	3	4
9.	Ndicinge ukuba ubomi bam abuphumelelanga. *I thought my life had been a failure.*	1	2	3	4

Respondent no:	Date of interview:

10.	Ndizive ndisoyika. *I felt fearful.*	1	2	3	4
11.	Ukulala bekungekho kuphumla nakuzola. *My sleep was restless.*	1	2	3	4
12.	Bendonwabile. *I was happy.*	1	2	3	4
13.	Ndehlise nokuthetha ngokwesiqhelo. *I talked less than usual.*	1	2	3	4
14.	Ndizive ndindodwa. *I felt lonely.*	1	2	3	4
15.	Abantu bebengenabuhlobo kum. *People were unfriendly.*	1	2	3	4
16.	Ndibuvuyele ubomi. *I enjoyed life.*	1	2	3	4
17.	Ndibenento yoba ndivele ndilile. *I had crying spells.*	1	2	3	4
18.	Ndiye ndizive lusizi. *I felt sad.*	1	2	3	4
19.	Ndiye ndizive ngathi abantu abangithandi. *I felt that people dislike me*.	1	2	3	4
20.	Ndingakwazi nakuqalisa na ntoni na. *I could not get "going"*.	1	2	3	4

Notes:_____

_____

_____

_____

Respondent no:	Date of interview:

Spielberger State Anxiety Inventory

Zininzi iizindlela abantu abanokuzichaza ngayo, ezinye zazo zezi ezibhalwe ngezantsi. Funda uluhlu lwalengxelo, de wohlule evumelana nawe, ngendlela oziva ngayo, oku kukuthi, ngexesha langoku. Azikho iimpendulo ezilungileyo okanye ezingalunganga. Ungathathi ixesha elininzi kwintetho nganye kodwa sinike impendulo echaza ngendlela oziva ngayo okwangoku.
A number of statements which people have used to describe themselves are given below. Read each statement and then select the appropriate one to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

Yenza isangqa kwinani kwanga adwelisiweyo:
Circle one number on each line:

1 = Hayi nakancinci *(Not at all)*
2 = Noko *(Somewhat)*
3 = Ngokungagqithileyo *(Moderately so)*
4 = Kakhulu *(Very much so)*

1.	Ndiziva ndizolile. *I feel calm.*	1	2	3	4
2.	Ndiziva ndikhuselekile. *I feel secure.*	1	2	3	4
3.	Ndiziva ndixhalabile. *I am tense.*	1	2	3	4
4.	Ndiziva ndingamkelekanga. *I am regretful.*	1	2	3	4
5.	Ndiziva ndikhululekile. *I feel at ease.*	1	2	3	4
6.	Ndiziva ndiphazamisekile. *I feel upset.*	1	2	3	4
7.	Okwangoku ndiziva ndinexhala ngathi ndinamashwa. *I am presently worrying over possible misfortunes.*	1	2	3	4
8.	Ndiziva ndingadinwanga. *I feel rested.*	1	2	3	4
9.	Ndiziva ndixhalabile. *I feel anxious.*	1	2	3	4
10.	Ndiziva ndonwabile. *I feel comfortable.*	1	2	3	4

Respondent no:	Date of interview:

11.	Ndiziva ndizithembile siqusam. *I feel self-confident.*	1	2	3	4
12.	Ndiziva ndibuphazamisekile. *I feel nervous.*	1	2	3	4
13.	Ndiziva ndinophakuphaku. *I am jittery.*	1	2	3	4
14.	Ndiziva ndibucwangu ngcwangu. *I feel "high strung".*	1	2	3	4
15.	Ndiziva ndiphumle. *I am relaxed.*	1	2	3	4
16.	Ndiziva ndonelisekile. *I feel content.*	1	2	3	4
17.	Ndiziva ndikhathazekile. *I am worried.*	1	2	3	4
18.	Ndiziva ndonwabe kakhulu. *I feel overexcited.*	1	2	3	4
19.	Ndiziva ndinovuyo. *I feel joyful.*	1	2	3	4
20.	Ndiziva ndonwabile. *I feel pleasant.*	1	2	3	4

Notes:_____

_____

_____

_____

Respondent no:	Date of interview:

MOS Social Support Survey
(Inkxaso ephanda ngokuhlala)

Lemibuzo elandelayo yeyokufumana ukuba loluphina uncedo olufumanayo.
Next are some questions about the support that is available to you.

1. Bangaphi abahlobo nezalamane zakho onazo ovana nazo (abantu okhululekileyo ukuthetha nabo ngezinto ezisengqondweni yakho)? Bhala inani labahlobo nezalamane zakho.
   About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?
   Write in number of close friends and close relatives

Ngamanye amaxesha abantu banokujonga kubalingane babo, ukufumana uncediso okanye ezinye indlela zokuncedisana. Kukangakanani ufumana olunye loluncedo olufumanekayo kuwe xa uludinga?
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?

Yenza isangqa kwelinye lamanani adwelisiweyo:
Circle one number on each line:

1 = Alikho nalinye ixesha *(None of the time)*
2 = Ngexesha elincinci *(A little of the time)*
3 = Ngamanye amaxesha *(Some of the time)*
4 = Ngamaxesha amaninzi *(Most of the time)*
5 = Ngawowonke amaxesha *(All of the time)*

2.	Ukhona umntu onokukunceda xa ugula ungasakwazi ukuzenzela nto ulele ebhedini. *Someone to help you if you were confined to bed.*	1	2	3	4	5
3.	Ukhona umntu onokumamela xa ufuna ukuthetha maxesha wonke. *Someone you can count on to listen to you when you need to talk.*	1	2	3	4	5
4.	Ukhona umntu onokukucebisa ngokulungileyo xa usengxakini. *Someone to give you good advice about a crisis.*	1	2	3	4	5
5.	Ukhona umntu onokusa kugqirha xa udinga uncedo. *Someone to take you to the doctor if you needed it.*	1	2	3	4	5
6.	Ukhona umntu okunika uthando nobubele. *Someone who shows you love and affection.*	1	2	3	4	5
7.	Ukhona umntu onokonwaba naye. *Someone to have a good time with.*	1	2	3	4	5

Respondent no:	Date of interview:

8.	Ukhona umntu ongakunika iinkcukacha ngoncedo lwakho. *Someone to give you information to help you understand a situation.*	1	2	3	4	5
9.	Ukhona umntu omthembileyo ongathetha naye ngawe nangengxaki zakho. *Someone to confide in or talk to about yourself or your problems.*	1	2	3	4	5
10.	Ukhona umntu onokwanga *Is there someone to hug you*	1	2	3	4	5
11.	Ukhona umntu ongahlala naye nonwabe kunye. *Someone to get together with for relaxation.*	1	2	3	4	5
12.	Ukhona umntu onokukuphekela xa ungakwazi ukuzenzela ngokwakho. *Someone to prepare your meals if you were unable to do it yourself.*	1	2	3	4	5
13.	Ukhona umntu onengcebiso ozifunayo *Someone whose advice you really want.*	1	2	3	4	5
14.	Ukhona umlingane wakho onokususa ingcinga zakho ezinzima nezikuphazamisayo. *Someone to do things with to help you get your mind off things.*	1	2	3	4	5
15.	Ukhona umntu onokukunceda ngemisebenzi yemihla yonke xa ugula. *Someone to help with daily chores if you were sick.*	1	2	3	4	5
16.	Ukhona umntu onokumxelela imbilini yakho okanye uloyiko. *Someone to share your most private worries and fears with.*	1	2	3	4	5
17.	Ukhona umntu ongakumamela xa udinga ingcebiso zokujongana nengxaki omelene nazo. *Someone to turn to for suggestions about how to deal with a personal problem.*	1	2	3	4	5
18.	Ukhona umntu onokonwaba naye. *Someone to do something enjoyable with.*	1	2	3	4	5
19.	Ukhona umntu oziqondayo ingxaki zakho. *Someone who understands your problems.*	1	2	3	4	5
20.	Ukhona umntu okuthandayo nokwenza uthandeke. *Someone to love and make you feel wanted.*	1	2	3	4	5

Respondent no:	Date of interview:

21. Ukhona umntu onokwazi ukukujongela abantwana bakho xa unganakukwazi. *Someone to help take care of your children when you can't.*	1	2	3	4	5

Ngoku nceda usixelele ukuba uncedo olufumanayo luyakwanelisa na? (Nceda wenze isangqa kobubuso buncumileyo (☺) ukuba wonwabile ngoncedo olufumeneyo, okanye ukuba ulusizi yenza kobubuso buqumbileyo (☹).
Now we'd like to know whether or not you are satisfied with the different kinds of support you receive. (Please circle either the smiley face if you are happy (☺), or the sad face if you are not happy (☹)).

22.	Wonwabile a ngenkxaso oyifumeneyo, ephathekayo lube bubungqina bakho na?? (uhlu la 2, 5, 12, 15, 21) *Are you happy with the tangible support you receive? (items 2, 5, 12, 15, 21)?*	☺	☹
23.	Wonwabile ngobubele nothando loncedo olufumanayo? (uhlu 6, 10, 20) *Are you happy with the affectionate support you receive? (items 6, 10, 20)*	☺	☹
24.	Wonwabile okanye unalo na ithemba lemvisiswano ngentlalo-ntle ekuhlaleni na? (uhlu 7, 11, 14, 18) *Are you happy with the positive social interaction you receive? (items 7, 11, 14, 18)*	☺	☹
25.	Wonwabile ngochukumiseko/nangolwazi loncedo olufumanayo? (uhlu 3, 4, 8, 9, 13, 16, 17, 19) *Are you happy with the emotional/ informational support you receive? (items 3, 4, 8, 9, 13, 16, 17, 19)*	☺	☹

Notes:_____

_____

_____

_____

Respondent no:	Date of interview:

For the qualitative study:

These questions should be used as a guide for the interviewer to facilitate discussion. The questions have two key objectives:

- To find out how responsibility for childcare is shared across the HIV+ women's household and its support network. This means who shares the women's childcare role and also who provides other kinds of support to the women directly (thereby making her available for her caregiving role).

- To explore in some detail the women's history with HIV. This discussion will elicit a timeline of events and subjective states related to the women's personal experience of being HIV positive (in particular, diagnosis, disclosure, commencing treatment, and how sick and incapacitated she felt at these points during the course of her illness).

Some more specific prompts are provided below.

Household composition and the history of the caregiving network:

Draw a genogram with the woman and indicate the sex, age and relationship to the women of every person included in the genogram, as well as circling the child participating in the study. (Use the box on p. 27). The following questions can serve as a guide.

1. Ngobani izelamane zakho
   Who is in your family?

2. Ngubani ohlala endlwini yakho?
   Who lives in your house?

3. Unabo abantwana ngaphandle okanye ababhubhayo?
   Do you have children outside of your home or who have died?

4. Ngubani okubonelelayo nokukhathaleleyo ngoncedo olwahlukileyo xa udinga uncendo lokuqala?
   Who provides different types of care and who is available as a "backup" for the primary caregiver?

   (These "backup" caregivers can include people who assist in caring for the children in the household on a regular basis, even if they don't live in the household, as well as people who are considered family and who provide support on a semi-regular basis.)

Women's personal history of HIV/AIDS:

1. Uzive nini na ukuba uHIV positive?
   When did you first find out that you were HIV positive?

Respondent no:	Date of interview:

2. Uqale nini ukubhengeza ngalengxelo yemeko yokuba une HIV kwaye ngubani omxeleleyo?
   When did you first disclose your HIV status and who did you tell?

3. Uke waxelela abanye abantu ukuba uHIV positive?
   Have you told other people about your HIV status as well?

4. Baphendule njani abantu obaxelele ngesimo sakho?
   How have the people you disclosed your status to responded?

5. Uziva ukwazi ukuphila neHIV? Zintoni ezithe zatshintsha emva kokuva ukuba uneHIV. Ingabe ukuva ngemeko yokuba uneHIV, ingaba kukwenze ujonge ubomi bakho ngokwahlukileyo kunye nesiqu sakho. Bezikhona izinto obunexhala ngazo okanye ozoyikayo. Yintoni oyenzileyo ukujongana nemeko yakho okanye imvakalelo yayo kuwe. Yintoni eyenzeka kusukela ngoko?

   (Zama ukuveza ezakho imbono ngokufa nangokubhubha malungu nokungaqiniseki kukunika abantu uncedo. Ingaba lenkolelo ibangela amakhosikazi azive emadolo nzima okanye ecinga kancinane ngokwenza amacebo ekamva lomntwana).

   Do you feel you are coping with living with HIV? What things in your life changed after you found out you were HIV? Did finding out your status make you feel differently about life and yourself? Were there things that you were worried or scared about? What did you do to try and cope with your status and the way that it made you feel? And what has happened since then?

   (Try to probe perceptions of death and dying and implications for caregiving role, e.g. did this belief make the women more or less likely to think about making future plans for her child.)

6. Amava akho athini ngolunyango? Bakuxelele ukuba uzakuziva ugula njani na xa uqalisa amaARV's? Ukucinge ukuba xa ungumama/nomkhathaleli wabanye uye uzive ngathi unendlela thile ocinga ngayo njengoba unetsholongwane kagawulayo iHIV noba uyalisebenzisa iyeza na.
   What is your experience of being on treatment? How ill did you feel when you were told you would start ARVs? Do you think that being a mother/caregiver has any effect of how you think about your HIV status and whether you take your medication?

Respondent no:	Date of interview:

Intlalo nenani labantu endlwini:
Household composition:

APPENDIX B. HOUSEHOLD ROSTER

(To be counted as living in the household a person must spend at least 4 nights a week on average in the household)

No.	First name	Date of birth	Age (years)	Relationship to respondent	Nature of employment (incl. scholar or pensioner)[a]	Amount of employment or non employment-related income (e.g. grants) *contributed to the household* on average per month[b]
1						
2						
3						
4						

P.T.O.

No.	First name	Date of birth	Age (years)	Relationship to respondent	Nature of employment (incl. scholar or pensioner)[a]	Amount of employment or non employment-related income (e.g. grants) *contributed to the household* on average per month [b]
5						
6						
7						

Non-employment related income brought into household (please mark with an X if appropriate):

Food parcels	
Other	

If other, please specify:

_____

_____

A. To classify employment status:

Is the person:

1. Receiving an employment-related income for pay, profit, or family gain? (For example, formal work for a salary, wage or profit; informal work such as making things for sale, selling things to provide a service; work on a farm or land, whether for a wage or as part of the household's farming activities; or casual work)
2. Going to school/college/university?
3. Not working (but looking for work)?
4. Not working, not looking for work but available for work?
5. Full time househusband/housewife?
6. Retired (pensioner)?
7. Permanently unable to work?
8. Not working, not looking for work, not available for work?
9. Other (specify)

B. To quantify household income:

Sources of non-employment income to household:

1. Old age pension from the state/government
2. Pension from his/her specific work/retirement benefits
3. Disability grant
4. Worker's compensation
5. State maintenance grant (for parents or for children)
6. Private maintenance by father/former spouse (not living in the household)
7. Care dependency grant (single care grant)
8. Foster care grant
9. Unemployment fund/maternity benefit
10. Remittance/financial support from relatives/persons not in the household
11. Gratuities/other lump sums
12. Other sources

APPENDIX C. RECORD SHEET FOR OBSERVATION OF CHILDCARE IN THE HOME SETTING

Care prompt and action	**Child's response** Shuts down or seeks more interaction?	**Actions by other carer(s)**	**Simultaneous activities of carer(s)**	**Emotional climate of communica-tion** Any actions by carer expressing feelings toward child?	**Type of verbal interaction** (***)	**Evidence of 2-way relationship between child and carer?** Any intimate dialogue or emotional sharing?	**Factors in the home influencing care of child**	**Aspects of wider environment influencing care of child**
EXAMPLE: Child crying, Aunt picks her up	Stops crying, engages with aunt	Sister brings toy	Aunt: cooking Sister: doing homework	Calm Aunt: silent nods and smiles	Aunt: soothes Sister: talks to	Aunt + child: Take turns making eye contact	Stove keeps going out	Cold in shack.

*** Type of verbal interaction: Code as one of 11 categories: approves, disapproves, cautions, soothes, talks to, questions, labels, imitates, elaborates, sings, reads, shows pictures, directs (caregiver language observation instrument, Mary Knox Weir in Johnson, 1976)

APPENDIX D. HOME-BASED INTERVIEW GUIDE

INTERVIEW SCHEDULE FOR OBSERVATION OF CHILDCARE IN THE HOME SETTING

Note: These topics can be discussed in any order, and we should take our cue from points raised by our respondents.

A) General questions to ask before filling in the observation record sheet

Perceptions of children's needs and standards of child care

1) What do you think young children under 5 years need to do OK?
2) Do they need anything else to do really well? If so what?
3) Do you think your views differ from other moms/carers in this community?

4) How would you describe 'the best care' for children under 5 years?
5) How would you describe 'good enough care' for children under 5 years? (some examples)
6) How would you describe 'poor/bad care' of children under 5 years? (ask separately for age group of each of interviewee's children under 5).

7) Please describe a 'good child' (how do they behave, what do they do for you etc)
8) Please describe a 'bad child' (how do they behave, what do they do for you etc)
9) What can/should children under 5 years do for their parents? (for their mother, father, siblings etc?)
10) What do you think happens to children who are given lots of love?

B) For informal conversation during observation:

Motivation for carer's actions: only to get domestic tasks done or doing things specifically for the purpose of their child's development

1) When we observe carer doing something with or for the child (particularly if there does not seem to be a biological need being fulfilled), ask her: Why are you doing this?

Poverty/economic security level:

2) On the basis of what we see, make notes on household assets and evidence of economic security (*consider:* nature of house, number of rooms, sanitation facilities, TV/radio etc, white goods, how stocked is grocery cupboard?)

C) Informal conversation towards the end of observation

Perceptions of temperament, emotional needs and emotional expression

1) How would you describe your child's temperament (calm/noisy, shy/extrovert, active/passive etc.)
2) How do you show love to your child?
3) How does your child show love to you?
4) Does your child?

- Push you away when you get close?
- Try to show you his/ her skills/ what she can do?
- Like to sit close to you?
- Smiles at you when you show her affection?

Care strategies and discipline

5) What do you do when
   - Your child cries?
   - Your child hurts herself?
   - Your child does well at something (e.g. at school)?
6) You know that most parents have some problems in relation to their children, what are your problems, if any, with your child?
7) How do you cope with these problems?
8) And, if a child behaves badly, what would you do to stop him?
9) Who usually disciplines the child?
10) Does the child's father usually:
    - Contribute money to support the child?
    - Play and talk with child?
    - Feed and care for child?
    - Hold and carry child?
    - Teach things to child?

D) If time at end of observation (or in second observation visit):

1) Explore carer's current and previous relationships with / experiences of:
   - Male partners (find out marriage/relationship status)
   - Other kin
   - Neighbours, the wider community, services etc
2) Carer's employment situation and employment history.
3) Does carer receive any grants? If so which? Or does their child benefit from money coming from grants to others (e.g. pensions to carer's parent's generation)

APPENDIX E. DEVELOPMENTAL ASSESSMENT

PILOT STUDY: MASIPHUMELELE RESEARCH PROJECT ON WOMEN CAREGIVERS:

DEVELOPMENTAL ASSESSMENT OF CHILD

Child's date of birth: _____

Child age (years, months): _____

Was the child born premature? _____

If yes, by how many days or weeks? _____

Predominant language spoken in the home: _____

Were there any serious problems during the mother's pregnancy or during birth?

_____

_____

_____

Does the child have any known serious health or developmental problems which the examiner should know about?

_____

_____

Questions to be asked of the caregiver after the test session (circle the appropriate response):

Parental assessment of test session:

How typical was your child's behavior? Did (child's name) play the way she (or he) usually does? Was she (or he) as happy or upset as usual? As alert and active as usual?

Very atypical: caregiver never sees this type of behavior……	1
Mostly atypical…….	2
Somewhat typical: caregiver sees this type of behavior on some occasions…..	3
Typical…….	4
Very typical: caregiver always sees this type of behavior……..	5

Parental assessment of test adequacy:

Do you think (child's name) did as well as she (or he) could? Have you seen (child's name) do better or worse on the type of things we worked on?

Poor indicator of child's optimal performance; child always performs much better……	1
Barely adequate……	2
Adequate; child performs as well, on average……	3
Good……	4
Excellent; child never performs better……	5

Other notes or observations made by examiner:

APPENDIX F. EXAMPLE OF FULL CASE RECORD: CASE NO. R3

While there is some overlap in the methods used to collect the information summarised below, for the sake of clarity, it has been separated into sections reflecting the primary data collection method.

1. Interview part I: Questionnaire data

(refer to section 2.3.1)

Caregiver's identifying data	
Age and DOB	32 (23/06/72)
Home language	Xhosa
Education	Primary school (Grade 6)
Relationship status	Divorced; living with partner
Employment	Unemployed; used to do domestic work and run a small tuck-shop/ spaza store from home before became too ill and weak
Partner's HIV status	HIV+ (found out when treated for TB; not attending clinic regularly at present)

Household composition and resources	
Household size	4 (3 adults, 1 child)
Household composition	R3, C3, R3's boyfriend, R3's adult brother (head injury, on DG)
Income to household	R1650 + R2000 (R3 and R3's brother's DGs, C3's Child Support Grant, boyfriend's contract work of ±R2000 per month, but boyfriend does not contribute all of his income -has begun drinking, other girlfriends)
Other resources for household	Monthly food parcel from Living Hope. Two female neighbours sometimes bring C3 food during the day when R3 is away, and C3 sometimes eats at their homes as well. Another male neighbour and his girlfriend who are Mozambiquan sometimes also help out, and will feed C3 when R3 is away.
Major household expenses	Crèche for C3. No rent

Caregiver's medical data	
Date of diagnosis	2001 (after her boyfriend tested HIV positive while being treated for TB)
Date commenced ARVs	16/07/04
Duration on ARVs (at time administered scales)	4 months
Drug regimen	Stavudine 30mg twice daily (d4T 30 bd) Lamivudine 150mg twice daily (3TC 150 bd) Efavirenz 600mg daily (EFV 600 nocte)

CD4 count (at baseline)	10
Clinical stage (WHO)	III
Viral load	163076
Adherence (based on pill count)	Early on, missed 3 of 1 tablet and 2 of another; subsequently 100% adherent
Recent hospitalisations	September/October 2003 hospitalised for TB
Other medical history	Diagnosed with TB of collar bone Sept 2003; completed treatment 13/10/03 – 02/04/04; relapsed and began second line TB medication September/October 2004
HIV-related support group	Attends

Child's identifying data and medical history	
Study child's sex, age, DOB	F4.9 (5/03/00)
Child's birth	Delivered at 10 months (1mnth overdue) Tested HIV negative 2 years ago, will be re-tested No history of serious problems during pregnancy or birth reported.
Child's health and development	No history of serious health or developmental problems reported.
Child's schooling (if applicable)	Attends crèche (except recently when she had worms)

Childcare arrangements	
Child's place of residence	Born in Masi and never moved
Caregivers	R3 only
Childcare	Boyfriend helps with childcare (and also with domestic work) when he is at home or when R3 needs to care for her brother. Other individuals who play a supporting role are two mothers of small children who live nearby, as well as R3's boyfriend's Mozambiçan friend and his girlfriend.

Impressions	
Caregiver	R3 was tearful during interviews, especially when talking about her family of origin. She appeared to keep to herself, and to display limited energy and animation in her interaction with others, including C3. She feels helpless about her life and reported sleeping or avoiding contact with others in order to think less about her HIV status (and other problems).
Child (temperament)	C3 is a fairly precocious, outspoken child. She is not shy to challenge her parents, and was seen to boss other children around, including those who were older than her.

Caregiver standardised measures				
Scale	**Type of score**		**Range**	**Score**
Depression	Total depression		[0;60]	23
Anxiety	Total anxiety		[0;80]	38
Social support	Network size		[0;∞]	1
	Total support		[20;100]	50
	Tangible	Raw	[5;25]	10
		Standardised	[0;100]	40
	Affectionate	Raw	[3;15]	8
		Standardised	[0;100]	53
	Positive social interaction	Raw	[4;20]	12
		Standardised	[0;100]	**60**
	Emotional/informational	Raw	[8;40]	20
		Standardised	[0;100]	**50**
	Total satisfaction		[0;4]	**0**
Coping	Total coping		[1;112]	**76**
	Coping index†		[1;112]	**74**
	Adaptive coping	Raw	[18;72]	50
		Standardised	[0;100]	**78**
	Maladaptive coping	Raw	[10;40]	26
		Standardised	[0;100]	**73**
	Active coping		[2;8]	5
	Planning		[2;8]	8
	Positive reframing		[2;8]	7
	Acceptance		[2;8]	8
	Humor		[2;8]	2
	Religion		[2;8]	6
	Using emotional support		[2;8]	5
	Using instrumental support		[2;8]	5
	Venting		[2;8]	4
	Self-distraction*		[2;8]	5
	Denial*		[2;8]	8
	Substance*		[2;8]	2
	Behavioral disengagement*		[2;8]	6
	Self-blame*		[2;8]	5

† Reverse scored maladaptive coping items * Subscales classified as "maladaptive"

2. Interview part II: Semi-structured /exploratory interview
(refer to section 2.3.2)

Background information

R3 is a 32-year-old HIV positive woman who lives in a small shack in the wetlands area of Masiphumelele. She lives with her boyfriend (35 years), their 4-year-old daughter (C3), and R3's adult brother (29 years). R3 is Xhosa-speaking and has a grade 6 education. She is unemployed, but occasionally sells goods from her home when her health permits. She receives a Child Support Grant for C3 and a Disability Grant for herself. R3's brother also receives a Disability Grant due to the serious head injury which he sustained in 1998. R3's boyfriend is sometimes involved in contract work, part of which contributes to the running of the household. However, the fixed monthly household income is R1650. A monthly food parcel from Living Hope is a further resource to the household, and two female neighbours sometimes bring C3 food during the day when R3 is away. R3 was divorced from a previous partner in 1997. Neither R3 nor her boyfriend has any other family living either in Masiphumelele or in close proximity.

Personal history of HIV

R3 was diagnosed HIV positive in 2001 after her boyfriend tested positive while being treated for TB. Their daughter was tested the following year and found to be negative. Early on in R3's disease, when she was feeling very unwell, she reported feeling helpless and like her life was finished. Having felt quite free after her divorce in 1997, she felt dead inside when she tested positive, as if she was not alive in the way that those around her were. She was also frequently ill and in hospital, resulting in disruptions to her work. However, after the initially difficult period, R3 had an internal dialogue with herself and told herself that she had the disease and must live with it. She also tried to shut herself off from things which were difficult to cope with, such as her ill brother. In that way, she could be more at peace despite the sense of chaos around her.

R3 said that she did not care what people said about her or whether they knew that she was HIV positive. She had accepted that she was not well and that she could not stress too much about things. She knew that members of the community spoke and assumed that you were HIV infected if you were seen visiting the local clinic as she did. She believed that those who mock and point fingers at those infected with HIV may also be vulnerable because if you are sleeping with a man, you never know what he is doing when you are not around and you are therefore made vulnerable, too.

R3's main support was a single mother of three HIV negative children who attended the same support group as R3 (at Living Hope).According to R3, this woman also had a difficult history and they had a lot of pain in common, which made her someone that R3 could talk to and vent her frustrations with. She could understand what it was like to cope as a mother with her health being inconsistent. Three other neighbours also provided a source of support, two young women and one older woman.

Other than the members of the support group she had attended since 2003, R3 had disclosed her HIV status to her boyfriend and some of their Mozambiçan friends who live

in Masiphumelele. However, several of her neighbours also knew that she was unwell. One neighbour was told about R3's HIV status when she accompanied R3 to a doctor in Langa when R3 was experiencing difficulties breathing. The doctor was led to believe that R3 and the woman were sisters, and after pushing R3 to disclose, told the woman himself that R3 was HIV positive. In addition, after R3 was admitted to False Bay Hospital in June 2004, C3 asked her mother why she was in hospital and told her that someone had said to C3 that it was because R3 had AIDS. This discussion was, however, not continued and R3 reports not being ready to discuss her status with C3.

R3 began taking antiretroviral therapy in July 2004 and had been on treatment for 4 months at the time of the study. At the time she started treatment, her CD4 count was 10 and she had stage III HIV. The doctors told R3 that her condition was very serious and that she might not survive being on treatment. Early on she missed some of her tablets, but at the time of assessment, she was reported to be 100% adherent. After two months on ARVs, she also commenced daily TB treatment. She successfully completed a course of TB treatment in February of the same year, after being hospitalised in September 2003. She had to be treated for an abscess in her chest area, related to her TB, but, according to her medical file, was coping well with all the medication which she needed to take. R3 reported feeling quite weak at times and could no longer push a trolley from her house to a nearby venue where she usually collected goods to run a tuck-shop from home. Consequently, she had to stop her small business and was therefore financially dependant on her grant. However, she also reported feeling better compared with her weak state after first starting treatment, and said that her health had stabilised on treatment.

Other relevant personal history

When R3 was 14, her parents were divorced, apparently due to her father's mental illness. R3's mother got remarried and left both R3 and her brother in their father's care since her new family did not want anything to do with the children. R3's uncle provided some support in raising the children. Neither R3 nor her brother had had any subsequent contact with their mother. When the uncle died, R3 and her brother moved to Cape Town to look for work.

After moving to the Cape, in 1997, R3's brother sustained a serious head injury while fighting over a girlfriend. Since then he has been "mentally disturbed", suffers from epilepsy, and is in need of constant care. Initially the doctors did not think R3's brother would live for more than a few months. As a result of this injury and R3 wanting to care for her brother, she was divorced from her husband since his family would not have her brother live with them. In 1998, R3 and her brother, as well as her two children at the time, moved to Masiphumelele. Subsequently, at the insistence of the paternal grandparents, the children moved to the Eastern Cape to live with their grandparents in 2002. Although R3 sometimes sees her two eldest children, they mostly live and are supported financially by her ex-husband who also lives in the Eastern Cape. The children's grandmother will not even let them visit their mother (R3) in Masiphumelele as she thinks R3 will keep the children in Cape Town.

R3 reported finding living hard because of the many rejections she had experienced since she was a child. She cursed God for this and for giving her so much responsibility from the time she was young. She was waiting for her brother to die so that she could concentrate on her own health. She did not believe that there was anyone who could assist in caring for

her brother in order to provide her with relief. However, it was also reported that the couple's Mozambiçan friend's girlfriend was willing, and often did, assist in caring for R3's brother.

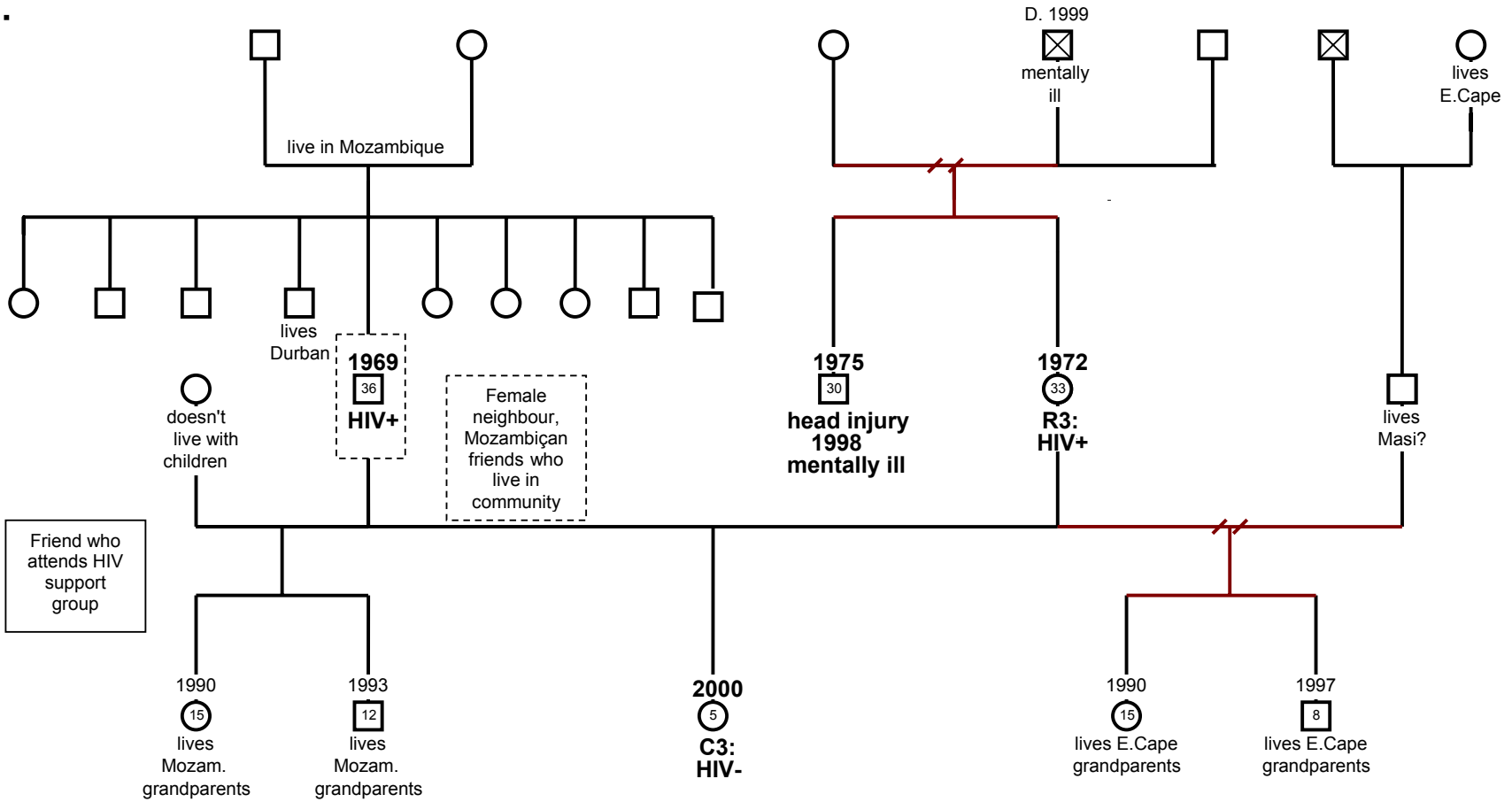
Childcare across the HIV infected household and its support network

R3 associated her HIV status with being a more "restless" parent because 'one doesn't know how long you will have to see your children grow up'. She said that that makes every moment with your child precious. Because R3 was often tired, she was aware that she had less energy to give to her child, and C3 was left to do things for herself earlier than she would otherwise be. R3 reported that before she was infected with HIV, she cared for her (older) children in a more relaxed manner and was less often worried. She felt very sad that she was not always able to provide for her children due to illness which sometimes meant that she was an unreliable employee.

R3 was the main caregiver for C3. She worried about C3, but knew that her boyfriend's family in Mozambique had offered to raise her should anything happen to R3. Her care responsibilities extended also to her brother who was in need of regular care and supervision. While R3's boyfriend provided some support with respect to both childcare and other domestic duties, at other times he was "reckless" and a source of stress to her. This was particularly due to the fact that he sometimes drunk alcohol excessively and slept with other women. According to R3, she left Masiphumelele for the Eastern Cape in December 2003, and their relationship was better after she had a break from him and his irresponsible behaviour. R3's boyfriend apparently used a condom when he had sex with R3, but the doctors have still warned her of the risk to her health, especially since her CD4 count was very low at one point.

R3's older two older children live in the Eastern Cape with their paternal grandmother. Originally, R3 was not happy with the arrangement, and the children were meant to return to Masiphumelele to live with their mother when she had a house. However, her mother-in law was opposed to the children returning and R3 felt that she did not have the energy to challenge the customary laws which were being used to keep her children in the Eastern Cape. She also realised that it was good for the children to live with their grandmother and that their being there was a source of some relief to her as she had less worries. Nonetheless, it still made her sad and it was painful for her when she was not able to go the Eastern Cape over the festive season and visit them.

Genogram



Key:

Circle:	Female	X	Deceased
Square:	Male	Bold typeface:	Household members
Number above circle/square:	Year of birth (or death)	Square with solid line	Closest friends and relatives

Number inside circle/square:	Age	Square with dotted line:	People to whom disclosed HIV status

3. Observation of childcare in the home setting part I: Observational tool (refer to section 3.3.1)

Care prompt and action	**Child's response** Shuts down or seeks more interaction?	**Action by other carer(s)**	**Simultaneous activities of carer(s)**	**Emotional climate of communication** Any intimate dialogue or emotional sharing?	**Type of verbal interaction**	**Evidence of 2-way relationship between child and carer?** Any intimate dialogue or emotional sharing?	**Factors in the home influencing care of child**	**Aspects of wider environment influencing care of child**
C3 picks up muffin (given by researchers) and looks at R3	R3 does not respond. C3 puts muffin back on table	R3's brother sits quietly in one corner looking at magazine pages on walls [R3 said he cannot care for C3]	R3 talking to researcher1	Calm	None, then C3 says 'I don't want it'. R3 says 'OK'	Eye contact	Shack is small and tidy. Few material goods in kitchen, no evidence of toys so far.	None, then C3 says 'I don't want it'. R3 says 'OK'
R3 looks at C3 and strokes her hair	C3 offers R3 the muffin,	None present	R3 talking to researcher1	Calm, friendly	Body language, C3 questions R3	R3 stroking hair; C3 offering R3 muffin	As above	Body language, C3 questions R3
R3 returns it to table and says 'no thanks'	C3 opens muffin bag making it go 'bang!', extracts muffin and hops towards front door	None present	R3 talking to researcher1	Calm, muted	R3 talks to C3. R3 says only the minimum in response to C3's question	C3 seeks attention then leaves with muffin	As above	R3 talks to C3. R3 says only the minimum in response to C3's question

[R3 remains in shack, researcher2 follows C3 outside]	C3 joins group of small children sitting in doorway of nearby shack. Shares her muffin with them	Other children happy to be given pieces of muffin	Two women sitting outside another nearby shack chatting, sewing and *seem to be* keeping an eye on children	Friendly, as if this is part of everyday life	Talks to: Light conversation between children, and between children and 2 women	Friendliness and familiarity amongst children and 2 women	Not relevant as C3 outside	Talks to: Light conversation between children, and between children and 2 women
R3 asks C3 to go and wash glass.	C3 brings clean glass and bike pump into house, gives glass to R3,	None present	R3 talking to researcher1	Calm, matter of fact	Calm, matter of fact	Directs	Eye contact, and C3 touches R3's knees after giving glass	R3's brother has gone outside
R3 says 'thanks'	C3 pumps handle of pump up and down making noise.	None present	R3 talking to researcher1	Calm, matter of fact	Calm, matter of fact	Talks to / responds to C3 fulfilling request	C3 seeking attention by creating noise with pump?	No change
R3 asks her to take it outside	C3 takes pump outside and joins friends	None present	R3 talking to researcher1 and putting water on to boil	R3 seems muted / weary	R3 seems muted / weary	R3 directs and cautions C3 'the pump is making a noise'	C3 seems to recognize need to leave (no protest)	No change

Researcher2 uses video camera to capture C3's movements for 20 minutes, and notes the following:
C3 spends most of this time outside with other small children. She returns to her family shack every five minutes or so, as if to check up on what is happening. She sits with five friends (all girls aged approximately 4 to 8 years) in doorway of nearby shacking putting stickers on their skin. A neighbour is keeping an eye on the girls. As researcher2 videos the scene, the children pose and get excited about the camera. The group breaks up and runs around. A girl approaches C3 showing her a cut on her hand, C3 wipes the blood off and asks her if she has any other cuts. The girl points to her foot, then turns and walks towards a shack where a woman stands (girl's home and mother/carer?).

4. Observation of childcare in the home setting part II: Informal interview guide (refer to section 3.3.2)

This data was generated both from home observations and interview material, and is structured in response to a set of guiding questions which informed the design of both tools (see section 8.3.1).

Who does the caring?
R3 has the heaviest care responsibility for C3, and of course her mentally disabled brother. During our second visit, before R3's boyfriend returned from work, we asked R3 about his role in the home. She said that he does an even share of domestic tasks (fetching water, cooking, cleaning) and will do all of it in the evening if she is not feeling well. When he is at home and not working, he cares for C3 to give R3 some time out. It was clear from C3's greeting of R3's boyfriend that she is very fond of him. When we asked about playing games with C3, R3 and boyfriend told us that he is the one who plays with her (substantiated by C3's cheeky playful reaction when he came through the door), whereas R3 rarely plays with C3, only to show C3 how to use a toy (she made a movement towards this when we gave C3 the posting box, but a very muted action and C3 got on with figuring it out herself)

It was evident during the first observation that the neighbours play a 'watching out' role but unclear as to whether they do more than this, or whether there is any particular neighbour who plays a greater role than others. We asked during our second visit and R3 and boyfriend told us that the two mothers of small children with whom C3 plays, and who living in joined shacks diagonally opposite R3's home are the ones who they trust and rely upon to look out for C3. They give C3 food during the day, and C3 will often take her bowl of food from her own home to eat in the neighbour's shack and share it with their children.

R3's boyfriend's 'friend/brother' from Mozambique and his girlfriend also play a key support role for R3 and boyfriend, that has involved some care of R3's brother and C3. For example, R3 said that if she, her boyfriend and C3 go to Mozambique for Christmas, the girlfriend will come and live in R3's shack and care for her brother. When C3 was little and before R3 was getting formula from the clinic, this couple used to bring them formula for C3. They also visited R3's boyfriend when he was in hospital for TB during 00/01 and brought him food. They do not offer cash support.

Do different people perform different care-related tasks?
See above, Also R3 and boyfriend said that R3 does the main care and the disciplining of C3 (when boyfriend tries, C3 does not take it seriously, she only listens to her mother and plays games with her father). The two female neighbours mentioned above keep an eye on, and give food to, C3 during the day when R3 is out (e.g. daily visit to clinic; R3 sometimes takes C3 but sometimes not) and evidently when she is at home also.

What sort of relationship exists between two or more people caring for a young child?
The relationship between R3 and her boyfriend seems stable (problems in the past relating to his drinking and sleeping around, R3 says he is less prone to binges partly through positive influence of the Mozambique 'friend/brother' mentioned above). She clearly trusts him and relies on him, and he seems to be happy in his partner and father roles. There was

no obvious intimate friendship between R3 and the female neighbours who look out for C3. No visits while we were there, unlike the neighbourly 'popping in' we have witnessed in other homes. I have the sense that R3 keeps herself to herself, especially when feeling unwell (and/or anxious?). She spoke of how handy it is that she can leave the main door of the shack open, and rest in her bedroom (owing to the hidden door) and anyone coming past can poke their head in, see no-one there, and leave.

What influence do fathers and other 'non-primary' carers have on children?
See info under Q2

What role do siblings play in performing or mediating care?
No siblings present. C3 has half siblings who live in Umtata. There are lots of small children in the neighbourhood who C3 plays with. The neighbours children and others living nearby are C3's main companions. She clearly takes on a leadership role in the group, organizing them into lines and distributing chips, carting them around from here to there, sorting out a cut finger etc. We asked if there were any older children who C3 looks to as big sister or big brother and R3 replied that C3 bosses the older ones (7-8 years) about to. When R3's 14 year old daughter was in CT and R3 was working, she would sometimes pick up C3 from crèche. This is the only person who seems to be 'older sisterly' to C3.

How is care given/displayed?
R3 is gentle and affectionate with C3, but her interactions observed thus far lack animation or energy. *What kind, and how much, stimulation does C3 get from R3?* We asked whether R3 and/or boyfriend tell stories to C3, they said no, or whether they do any special things together. R3 said that she sings to C3, usually church songs, at different times of the day, and often at bed time. During both visits, it is apparent that C3 seeks and receives most of her social interaction and stimulation from her friends in the neighbourhood.

Look at the balance between attending to physical needs, comforting, showing affection, teaching/assisting, accompanying etc. Does this balance change for different children?
There is only one child, C3, in this household set up. We saw very limited evidence of 'teaching/assisting' by R3 when we gave C3 the posting box. C3 glances at R3 for approval and 'permission' to open muffin bag, and when trying to get the lid off the box. R3 gives very muted signals to C3, hardly observable to us. Perhaps more muted by our presence and her sense of needing to focus on our conversation?

Are the care relationships characterized by dominance or exchange? (Scheinfeld parental interview in Johnson, 1976) How is the balance between the two maintained?
There is clearly an exchange element here as C3 is not shy to challenge her mother's responses. This is quite unusual in Xhosa families where young children especially are expected to 'respect' their seniors. During the second observation we asked R3 and her boyfriend about how they feel about this aspect of C3's nature. They smiled and recounted other stories of C3 keeping a check on both parents, for example, saying to her mother when father came back 'you haven't told him that we bought something today'. She likes to have everything out into the open. R3 said that most of the time they see it as quite amusing, and even helpful because if they start to argue, C3 will intervene and say 'no, you are lying' making sure that the truth is told, or will say 'don't argue because I don't like it'. Other times R3 said that C3's behaviour is 'not right', it is embarrassing because C3 does not know how to be discrete.

Where does care fit on the ladder of pressing household and family tasks? (What priority do carers give to their young children when there are other urgent chores to be done?)
We did not get the impression that there are many urgent household chores to be done. C3 was out of the home so much that R3 putting on the stove made no impression on her.

Are there observable patterns in care-related tasks? Does care seem to be more or less effective in households where there are observable patterns of care?
There were no observable patterns of care of C3 by R3 during either obs visit. The only 'pattern' we could see was C3 popping back into the shack every 10 mins or so to see what we were doing, and interact briefly with her mother. We asked R3 and her boyfriend whether they have regular times for anything, or whether things happen in a free flow way according to C3s needs etc. They said that they eat at around 7.30 in the evening (R3 had cooked in advance on our second visit as she knew we would be with her from 5-7pm). They tend to eat together.

What factors relating to the physical nature of the home influence care activities and potentially the quality of care provided?
Limited play space, no toys or other forms of stimulation in the home. C3 eager to draw on RB's paper using her pen (nothing like that around inside, so C3 goes outside). During the first observation, C3 came in with a bicycle pump that she was playing with, and when she started pumping it she was told by R3 to take it out as it makes a noise (could disturb her brother). It seemed that C3 is heavily discouraged from active/noisy play in the home. However during our second visit, C3 had brought 4 friends into the shack to play with the posting box, and they were chanting 'thank you', and singing 'Nkosi sikelela' in very loud voices, while R3's brother was around. R3 did not react.

What physical and social characteristics of the neighbourhood influence care activities (and potentially the quality of care provided)?
Shacks are dotted around a sandy environment, no sanitation immediately nearby, children play in lots of sand, full of rubbish, glass, nails. C3 spends a lot of time sitting outside neighbours doorsteps and playing in a group of 5 or 6 girls, and a few small boys. There are a few boys age about 6-8 years who play nearby, but not so much with the girls.

Is there evidence of difference in level or style ('quality') of care in situations where the carer is relatively new, and/or the child has experienced disruptions in their care (different carers, residential mobility)?
We are not aware of any 'disruptions' in this care relationship except R3's period in hospital. R3, boyfriend and C3 went to Mozambique together in April, and R3 loved the trip as she could relax and let her mind wander. She got on well with her boyfriend's family.

5. Developmental assessment
(refer to section 2.3.4)

Standardised measures			
Type of score		**Norm / range**	**Score**
Griffiths test:			
IQ		100	90.1
Intellectual range		-	Low end of average
CA (months)		-	57
MA (months)		-	51.4
Index scores	A. Locomotor	100	98.2
	B. Personal-social development	100	101.8
	C. Hearing and speech	100	101.8
	D. Eye and hand coordination	100	80.7
	E. Performance	100	77.2
	F. Practical reasoning	100	80.7

Other (taken from Bayley's Behavior Rating Scale – parent-report):		
Typicality of child's behavior during test session	[1;5]	2
Extent to which test results are an indicator of child's ability / usual performance	[1;5]	4