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SOCIAL SCIENCE RESEARCH

**COPING WITH HIV/AIDS:  
A CASE ANALYSIS OF THE  
PSYCHOLOGICAL EXPERIENCES  
OF POOR, HIV POSITIVE MOTHERS  
AND WOMEN CAREGIVERS ON HAART**

René Brandt

CSSR Working Paper No. 120



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# Coping with HIV/AIDS: A Case Analysis of the Psychological Experiences of Poor, HIV Positive Mothers and Women Caregivers on HAART<sup>1</sup>

## Abstract

*The primary objective of the current study is to investigate the psychological experiences of HIV positive mothers and women caregivers on antiretroviral therapy, and the strategies they employ to cope psychologically. It is also intended to inform both the content and method of ongoing work on maternal well-being and caregiving in HIV affected environments. Five HIV positive women caregivers were interviewed. They had been receiving antiretroviral therapy for less than six months and were the primary caregiver of at least one HIV negative child who was less than six years old. Each woman was administered a questionnaire and a semi-structured interview was conducted. The key issues which emerged were the complexity of women's psychological functioning, the fact that many women made strategic decisions about disclosure aimed at protecting important social networks, and that it was necessary to view well-being over time as a function of both situational and dynamic factors, such as changes in household composition. Women also spoke of consistent concerns about dying before their children were able to care for themselves. The study provides evidence for the value of adopting a contextual approach to investigating the psychological functioning of HIV positive mothers and women caregivers living in communities in which HIV is highly prevalent and poverty endemic.*

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<sup>1</sup> I would like to acknowledge and thank Lindiwe Mthembu-Salter who helped to conduct the interviews for the study. Thanks also to Nicoli Nattrass, Amelia van der Merwe and Lucie Cluver all of whom made useful comments on drafts of this paper, and to Rachel Bray and Andy Dawes who were willing to engage in thoughtful conversation during analysis. I must also acknowledge the women 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 R1 who sadly passed away shortly after the study's completion, under circumstances which have yet to be properly explained. This narrative is a testament to her strength and courage despite adversity.

## Background and significance

While HIV/AIDS was once viewed as a disease of homosexual men and intravenous drug users, the number of women with HIV has been increasing worldwide, particularly in areas where heterosexual sex is the dominant mode of HIV transmission (UNAIDS, 2004c). Globally, nearly half of all infected persons are women, with women in Africa representing nearly 60% of infected persons across all age groups, and 75% in the 15 to 24 year age band (UNAIDS, 2004b). Figures for South Africa show that more than a quarter of pregnant women in six of the nine provinces are HIV positive (Department of Health, 2004), with the projected national adult prevalence rate for 2005 at 25.6%<sup>2</sup> (ASSA, 2002).

Not only are women overrepresented by the numbers, it is now widely recognised that the epidemic has a disproportionate social and economic impact on women. The presence of AIDS in households and communities in South and southern Africa has resulted in an increase in both the number of female-headed households and the economic strain experienced by those households (UNAIDS, 2004b). Survey data indicates that between half and three-quarters of households in South Africa are female-headed, with only 12.5% of these women having a partner present in the home (UNICEF, 2003; Steinberg, *et al.* 2002; Ziehl & 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, and women are more likely than men to take in orphaned children (UNAIDS, 2004a). The large majority of these women will also continue to participate in the “care economy”, carrying out unpaid care and other domestic work in the household, even if they themselves are sick with AIDS (Steinberg *et al.*, 2002; UNAIDS, 2004a).

Consequently, a large number of women, many of them with young children, will have to negotiate the dual role of being HIV positive and being a caregiver in addition to the economic demands placed on them by virtue of living in poor communities in which they are often responsible for meeting the survival needs of their households.

While mental health has typically been neglected in developing countries (Desjarlais *et al.*, 1995), the multiple stressors associated with poverty, HIV/AIDS and caregiving quite clearly places these women at increased risk for mental health problems. Even in communities where multiple stressors are less

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<sup>2</sup> This figure is for the population between the ages of 15 and 59 years.

likely to be present, research has found elevated levels of depression and other mental health problems amongst HIV positive men and women (Freeman, 2004; Struthers, 2002 in Freeman, 2004). Further, several controlled studies have documented higher levels of depression amongst HIV positive than HIV negative women (Jones *et al.*, 2001a; 2001b; Miles *et al.*, 2001; Moneyham *et al.*, 2000; Morrison *et al.*, 2002).

Studies conducted both in South Africa and abroad have also found that HIV positive women have a particularly strong need to maintain their parental status, and that many will continue their role as mother and caregiver, even at the expense of their own physical and emotional well-being (Broun, 1996; Ciambrone, 2003; Freeman, 2004; Hackl *et al.*, 1997; Soskolne, 2003). The need to maintain this highly valued role is sometimes achieved through women's silence about their HIV status, potentially resulting in relative isolation and a lack of support (Freeman, 2004). This is likely to pose further challenges to the women's psychological well-being.

The implications for women's mental health have been documented in studies with asymptomatic and symptomatic women, as well as those on treatment. However, some studies fail to make the potentially differentiated experiences of these groups of women clear. Consequently, this remains an area for further research.

With the advent of highly active antiretroviral therapy (HAART), it has been fairly widely assumed that the psychological experiences of women living with HIV/AIDS would be significantly altered in a positive manner (Siegel *et al.*, 2004). However, the limited research available does not unequivocally support this contention (Bogart *et al.*, 2000). Amongst a sample of HIV infected women in New York, no significant differences in levels of psychological distress were reported before and after the advent of HAART (Siegel *et al.*, 2004). Rather, other 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). This might be particularly true for persons living with HIV/AIDS (PLWHA) who have been very ill and dysfunctional prior to commencing treatment (as opposed to relatively asymptomatic), and may therefore experience more real and perceived difficulties in managing their lives with the illness in the long-term (personal communication, Desireé Michaels, July 2004). Further, in addition to the changing nature of mental health problems, the treatment itself, with its numerous potential side-effects, can be a leading cause of psychological problems.

# **Aims and methods**

## **Study aims**

The primary objective of the current study was to investigate the psychological experiences of poor, HIV positive mothers and women caregivers who were sick with AIDS and on antiretroviral therapy, and to attempt to understand the strategies which they employ to cope psychologically. An important focus in this regard was the women's social networks and their coping strategies within families and neighbourhoods. This approach is different to many other studies in the area of mental health and HIV/AIDS which do not consider the role of contextual factors, including poverty, in promoting or undermining mental health outcomes. A related objective was therefore to examine the usefulness of the contextual approach in revealing issues which shed light on women's psychological experiences. The study also formed part of ongoing work on maternal mental health in the context of HIV/AIDS, and was intended to inform both the method and content of that work.

## **Sample and site selection**

The study sample comprised five HIV positive women caregivers who lived in the community of Masiphumelele, a low-income, peri-urban settlement in the Cape Peninsula.

Masiphumelele was chosen as an appropriate community for the study due to the fact that 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. In addition, the community has a range of HIV-related services, including an antiretroviral programme. It is also important to note that, in the context of endemic poverty and the high prevalence of HIV/AIDS in communities such as Masiphumelele, social security assistance from the South Africa government often forms a key component, if not the only source, of income available to both recipients and their household members whom the grants are typically used to support as well (see Simchowitz, 2004 for a discussion of social security and HIV/AIDS in the context of ARV treatment). Assistance includes the Disability Grant (for adults), the Care Dependency Grant (for children), the Child Grant and Old Age Pension.

The selection criteria for the study were that the women had been on antiretroviral therapy for not more than six months, and were the primary caregiver of at least one child who was HIV negative and less than six years old. 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, transporting and monitoring. While the six-month period on treatment was dictated partly by practical limitations since the antiretroviral programme was relatively new in Masiphumelele, research with HAART patients in South Africa has shown changes in quality of life within the first six months (Jelsma *et al.*, 2003). Further, follow-up data has shown that the most significant shifts in quality of life and well-being may occur during the first six months on treatment, thereby rendering it an interesting period for investigation (Jelsma *et al.*, in press). In addition, the criterion of the child's age was set at less than six years due to the fact that the care burden for younger children is likely to be higher and the challenges of negotiating multiple roles therefore greater for the caregiver. The child's negative status was specified due to the fact that the increasing success of Mother-to-Child-Transmission (MTCT) Programmes may give rise to an increasing number of HIV positive mothers caring for HIV negative children.

The participants were all Xhosa-speaking and ranged in age from 23 to 37 years. They were all the biological mothers of the child under six years living in the household, and were sick with AIDS at the time of the study (CD4 counts at the commencement of HAART ranged from 10 to 142). The women were identified randomly through the local HIV treatment centre with the help of medical staff, and informed consent was obtained for their participation in the study. One woman was excluded from the study due to difficulties scheduling appointments as well as concerns regarding her emotional vulnerability.

## Research procedure

Two meetings were held with each woman: the first to administer a questionnaire and the second to conduct a semi-structured interview. All material was translated into *isiXhosa*, the predominant language spoken in the community. The questionnaire collected individual and household-level demographic information, a history of caregiving, and information about the caregiver's functional health and adherence to treatment. In addition, it included four standardised scales which were selected in order to assess maternal psychological well-being, in particular, risk for depression (Centre for Epidemiologic Studies Depression Scale – see Appendix A; Radloff, 1977), levels of anxiety (Spielberger State Anxiety Scale – see Appendix B; Spielberger, 1983), coping strategies (Brief COPE – see Appendix C; Carver, 1997), and the availability of support as well as satisfaction with that support (Medical Outcome Study's Social Support Survey (MOS SSS) – Revised – see Appendix D; Sherbourne & Stewart, 1991)<sup>3</sup>. The semi-structured interview was

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<sup>3</sup> See Appendix E for further information regarding each scale.

intended to allow for further exploration of some of the issues covered in the questionnaire. For the purpose of this paper, data was analysed using a combination of thematic content analysis (Holsti, 1969) and a narrative approach (Crossley, 2000; Reissman, 1993).

## **Narrative presentation**

The following section presents a brief sketch of each of the five women participants. It should be noted that these narratives are not intended to be an exhaustive account of the data collected. Rather they include some of the more striking aspects of the women's lives which are useful for analysis as well as providing the reader with a picture of each of the women's contexts and experiences. The narratives also attempt to pose questions aimed at understanding the women's psychological lives in sufficiently subtle ways.<sup>4</sup> For further details regarding each case, see Table 1 below for a summary of the quantitative data and Table 2 for each participant's scale scores. Genograms<sup>5</sup> are also provided, including a key indicating which person(s) each participant had disclosed their HIV status to, and identified as their closest supporters (see Figures 1-4).

### **Respondent 1: Can she really be this resilient or is there a layer not yet seen?**

Respondent 1 (R1) is a 23-year-old single, HIV positive woman who lives alone with her five-year-old son (C1) in a small shack. She has a grade 11 education and was previously employed as a domestic worker. However, after losing that job during the course of the study, the only remaining income to the household was a Disability Grant and Child Support Grant which she and C1 received respectively. R1's brother (34 years) and his wife, who live in Khayelitsha (a large informal settlement on the Cape Flats approximately 50 km from Masiphumelele), also provide R1 and C1 with food when needed, and R1's brother put her on his life policy around the middle of 2004. Neither R1 nor C1 have any contact with C1's father and he does not provide either maintenance or emotional support to them. The people R1 experiences as most supportive are

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<sup>4</sup> Due to the fact that the primary purpose for data collection was piloting of the instruments, interviews were not transcribed and quotations cannot be provided. All material reported is a close account of the fieldworker's interviews, as well as impressions formed that were objectively assessed in light of other data available on each participant.

<sup>5</sup> Abbreviations used: E.Cape = Eastern Cape; Masi = Masiphumelele; C = children

Table 1. Summary data on women respondents (R1-R5)

Category		R1	R2	R3	R4	R5	
Identifying data	Age (years)	23	38	33	34	27	
	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	
	Partner's HIV status	N/A	Unknown (likely HIV+)	HIV+	HIV-	N/A	
	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	1650	1270	1970
		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 (incl. brother with head injury and epilepsy)	3 (incl. 20-year-old scholar)	5	
	Number of children	1	2 (incl. 17 year-old)	1	4 (incl. 16 & 17-year-old)	2 (both infants)	
	Sex and age of study child (M/F, years. months)	M 5.5	F 1.4	F 4.9	M 4.1	M 0.11	
Medical data	Years since diagnosis	2	1½	3	4½	1½	
	Weeks on treatment	16	2	16	4	7	
	Baseline CD4	36	129	10	142	73	
	Adherence	Good	Perfect	Perfect	No information available	No info. available	
	Attend support group	Yes	Yes	Yes	No	Yes	

Table 2. Summary of scale scores

Scale	Type of score	Range	R1	R2	R3	R4	R5 <sup>a</sup>		
Depression	Total depression	[0;60]	<b>7</b>	<b>9</b>	<b>23</b>	<b>28</b>	<b>36</b>	<b>35</b>	
Anxiety	Total anxiety	[0;80]	<b>40</b>	<b>30</b>	<b>38</b>	<b>43</b>	<b>22</b>		
Social support	Network size	[0;∞]	<b>8</b>	<b>10</b>	<b>1</b>	<b>2</b>	<b>6</b>		
	Total support	[20;100]	<b>100</b>	<b>90</b>	<b>50</b>	<b>86</b>	<b>90</b>		
	Tangible	Raw	[5;25]	25	24	10	19	21	
		Std	[0;100]	<b>100</b>	<b>96</b>	<b>40</b>	<b>76</b>	<b>84</b>	
	Affectionate	Raw	[3;15]	15	14	8	15	15	
		Std	[0;100]	<b>100</b>	<b>93</b>	<b>53</b>	<b>100</b>	<b>100</b>	
	Positive social interaction	Raw	[4;20]	15	16	12	20	16	
		Std	[0;100]	<b>75</b>	<b>80</b>	<b>60</b>	<b>100</b>	<b>80</b>	
	Emotional/informational	Raw	[8;40]	40	36	20	32	38	
		Std	[0;100]	<b>100</b>	<b>90</b>	<b>50</b>	<b>80</b>	<b>95</b>	
Total satisfaction		[0;4]	<b>4</b>	<b>4</b>	<b>0</b>	<b>3</b>	<b>4</b>		
Coping	Total coping	[1;112]	<b>86</b>	<b>70</b>	<b>76</b>	<b>71</b>	<b>87</b>		
	Coping index <sup>†</sup>	[1;112]	<b>98</b>	<b>80</b>	<b>74</b>	<b>73</b>	<b>77</b>		
	Adaptive coping	Raw	[18;72]	67	51	50	47	57	
		Std	[0;100]	<b>100</b>	<b>80</b>	<b>78</b>	<b>73</b>	<b>89</b>	
	Maladaptive coping	Raw	[10;40]	19	19	26	24	30	
		Std	[0;100]	<b>53</b>	<b>53</b>	<b>73</b>	<b>67</b>	<b>84</b>	
	Active coping		[2;8]	8	8	5	5	6	
	Planning		[2;8]	8	5	8	6	6	
	Positive reframing		[2;8]	8	6	7	8	7	
	Acceptance		[2;8]	8	7	8	4	8	
	Humor		[2;8]	8	2	2	2	2	
	Religion		[2;8]	5	6	6	6	8	
	Using emotional support		[2;8]	8	7	5	8	7	
	Using instrumental support		[2;8]	8	5	5	4	7	
	Venting		[2;8]	6	5	4	7	6	
	Self-distraction*		[2;8]	7	3	5	7	8	
Denial*		[2;8]	2	4	8	4	6		
Substance*		[2;8]	2	2	2	2	2		
Behavioral disengagement*		[2;8]	2	5	6	6	8		
Self-blame*		[2;8]	6	5	5	2	6		

<sup>a</sup> R5's CES-D was re-administered due to irregularities in her initial response which suggested that she may not have properly understood the questions and response options.

<sup>†</sup> Reverse scored maladaptive coping items

\* Subscales classified as "maladaptive" based on literature

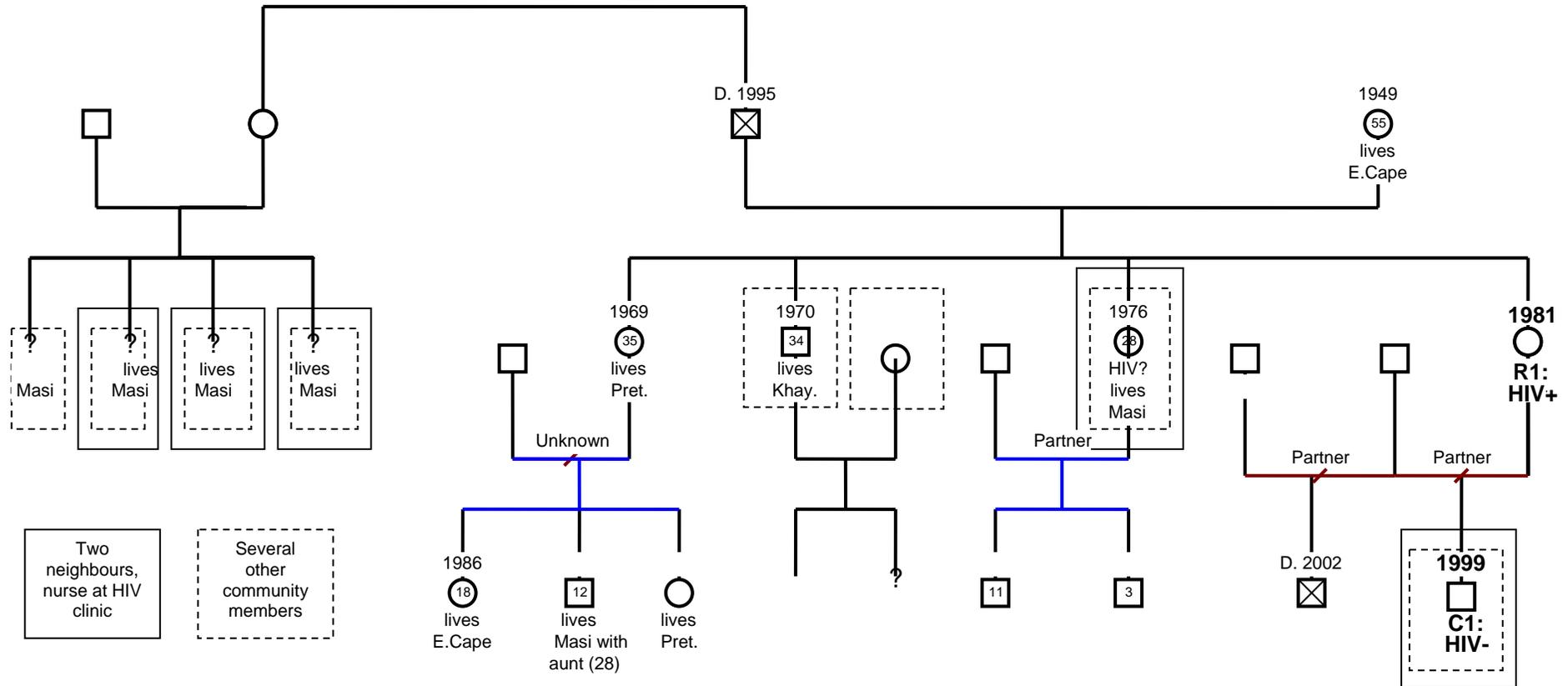
her sister, her son (C1), three cousins who also live in the community, two neighbours who provide some assistance with childcare, and a nursing sister at the local clinic with whom R1 has a good relationship.

For R1, HIV was something that had become interwoven into her life and she was very open about her positive status. She had even disclosed her status to her young son, resulting in him being very present in his awareness of her needs, and anticipating them at times. For example, after hearing about his mother's status, he told her that he wanted to take care of her and no longer wanted to return to the Eastern Cape to live with his grandmother.

R1 and C1 appeared to function as a "unit", and to have a caring relationship. They had support from R1's brother and his wife, while R1's relationship with her sister appeared more complicated. While R1 included her sister as one of the "close friends and relatives" who she 'felt at ease with and could talk to about what was on her mind', she also reported that her relationship with her sister had been strained for some time. Relations were better with R1's landlady who owned their plot and who R1 could at least talk to. Just after the study, R1 planned to disclose her HIV status to her mother in the Eastern Cape who was a potential alternate carer for C1.

Although R1 looked physically strong and healthy on treatment, she had several health problems in addition to her HIV status. She had been treated for depression and migraines previously and, at the time of the study, was awaiting a check-up regarding a growth on her ovaries which could be malignant. While scores on the scales administered reflected the strength of R1's support system (she achieved the maximum scores for all four types of support as well as satisfaction with support) and her low levels of depression (CES-D score of 7), her levels of anxiety were on the high end of the range for the sample as well as standardised cut-off scores for elevated symptoms of anxiety (Spielberger score of 40). Her son (C1) also had health problems and underwent follow-up surgery during the study for a congenital abnormality which had caused some problems with his gait.

Figure 1. R1's genogram



**Key:**

Circle:	Female	X	Deceased
Square:	Male	<b>Bold typeface:</b>	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

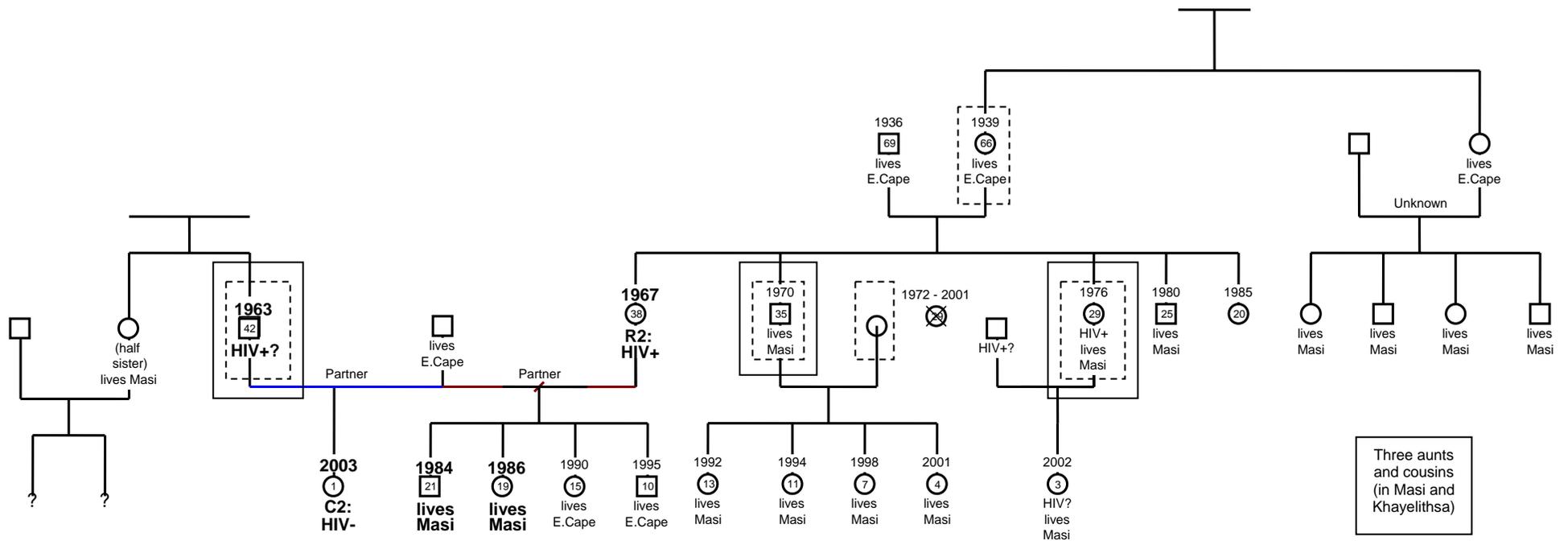
## **Respondent 2: An experienced coper or a system about to falter?**

Respondent 2 (R2) is a 38-year-old woman who lives with her boyfriend and their 16-month-old daughter (C2) in a yard consisting of several shacks. Two of R2's other four children from a previous partner, a girl of 18 and a boy of 20, also live in the same household. R2 has a primary school education and neither she nor her boyfriend was formally employed at the time of the study. The family's only stable source of income is C2's Child Support Grant and this is supplemented by the older children's occasional jobs, and by a small, irregular income which R2 receives from beadwork, sewing jobs, and the sale of loose cigarettes from the family's home. The household also receives a monthly food parcel from a local non-governmental organisation (Living Hope). R2's main support system is her boyfriend and father of her youngest child, her sister, brother, and other close relatives who live in the community or in Khayelitsha.

HIV was something secret and fearful in R2's household, and she had only disclosed her HIV status to her boyfriend. She had not disclosed to her teenage son and daughter who lived at home. During the course of the study, a shift occurred when R2's sister confronted her about seeing R2 travelling to the clinic, and it emerged that both sisters were HIV positive.

R2 was the eldest of six siblings and it appeared that she was accustomed to being the 'one who coped' and that she used self-distraction as a means to achieve this. This was reflected in several of her scale scores which indicated the strength of her support system (she achieved the maximum scores for satisfaction with support and reported receiving high levels of all forms of support), her low levels of depression (CES-D score of 9) and low to moderate levels of anxiety (Spielberger score of 30), and relatively high levels of adaptive coping (Coping index score of 80 on the Brief COPE). She was someone who attempted to cope through active strategies (active coping was her highest subscale score on the Brief COPE). She worked very hard at keeping some income of her own a secret and used it to provide her older son with a private room in the family house.

Figure 2. R2's genogram



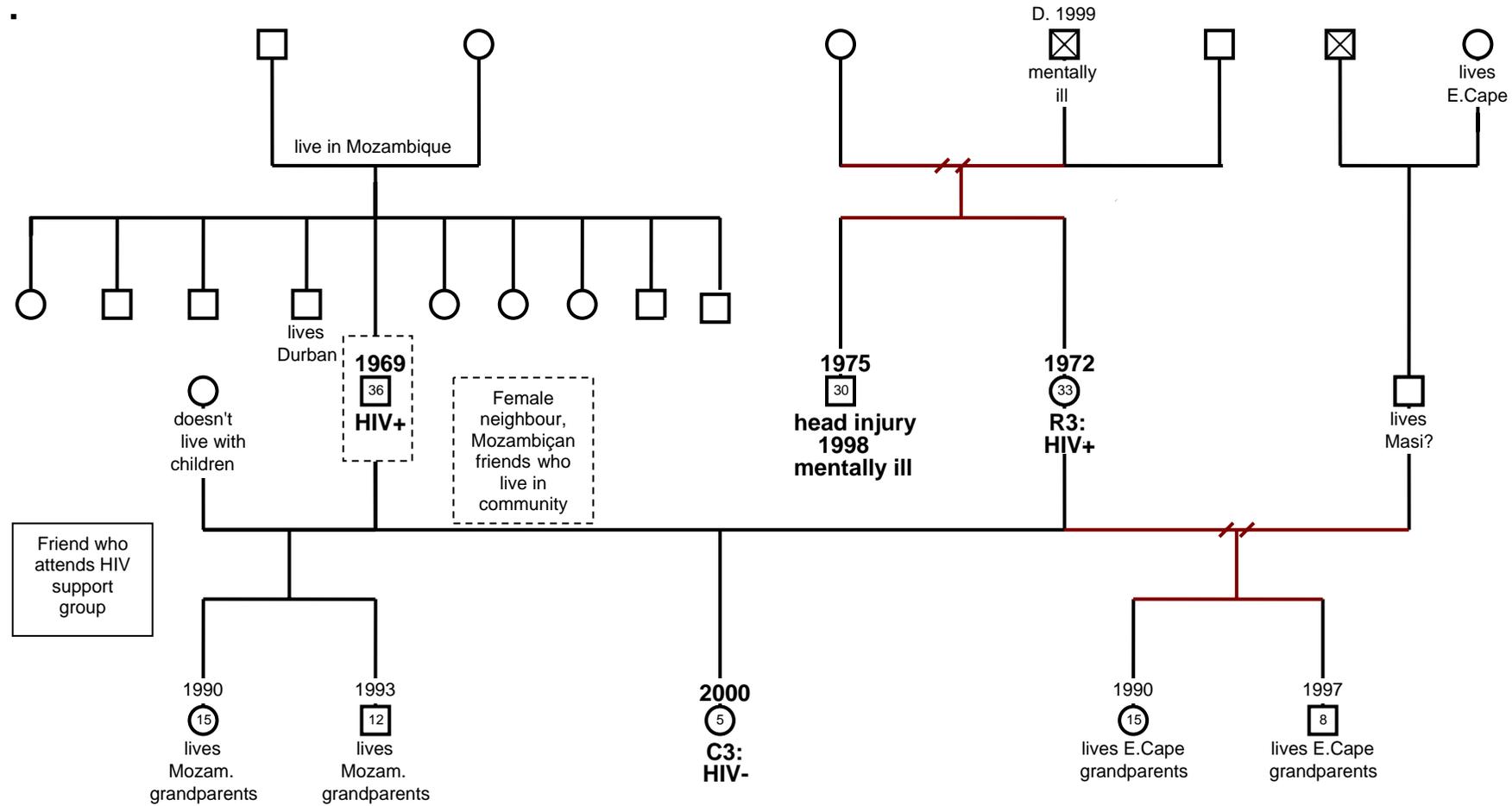
In some ways, living in a yard meant that there was support close by. This was confirmed by the fact that C2 spent most of the day playing with her cousins of similar age and slightly older in the compound created by the ring of shacks. However, it also appeared that R2 and C2's household and support system might be at risk in the longer term. Despite her small personal income, R2 was effectively financially dependant on her boyfriend, a precarious situation since he appeared very ill. (He refused to be tested for HIV).

### **Respondent 3: Vulnerable and isolated, but resourceful?**

Respondent 3 (R3) is 32 years old and lives with her boyfriend, their four-year-old daughter (C3) and her adult brother in a very poorly resourced, outlying wetlands area. She has a grade 6 education. Other than goods which R3 sells from home when her health permits, the household's source of income is a Child Support Grant, two Disability Grants which R3 and her brother receive, and some income that R3's boyfriend contributes to the running of the household. Neither R3 nor her boyfriend has any other family living either in Masiphumelele or in close proximity, and the only person which R3 experiences as genuinely supportive is a friend who attends her support group and, like R3, is the mother of HIV negative children. The impoverished nature of her support system was reflected in her scale scores which were very low, both in comparison with the other women in the sample and in general terms (she reported a score of 0 for satisfaction with support). She was also at risk for depression (CES-D score of 23) and used coping strategies which tend not to promote good mental health, in particular high levels of denial (she used several maladaptive coping strategies fairly often, with her highest subscale score on the Brief COPE being for denial).

For R3, living with HIV and caring for her young daughter was one of many challenges which she had faced in her life. She had a history of losses and rejections by family, and had to care for her young child (C3) as well as her mentally ill adult brother. She had no siblings or other family to support her; and said that her Mozambiquan boyfriend's family was her family and they would care for C3 should anything happen to her. C3 had confronted her mother about her HIV status after hearing rumours from neighbours, but R3 had denied the truth of the rumours. R3's boyfriend was the first person who she could be dependant on in any way. Her illness had made her financially dependant on him as well, as she was often too weak to collect the goods which she had previously sold from her home for extra money.

Figure 3. R3's 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

In addition to her HIV medication, R3 was taking daily tuberculosis (TB) treatment and had been very unwell after having a TB-related sore misdiagnosed initially. However, she continued to take both her TB and antiretroviral treatment and proved resourceful in dealing with her stressors. When there were tensions in her intimate relationship, she went away for a holiday, and created a concealed entrance to a private room within the house to give her some privacy and space away from her sick brother who she experienced as a considerable burden on her. She was also able to access grants for herself, her brother and C3, and used the support group and research interviews as an opportunity to unburden herself emotionally. R3 was even reaching out to identify need in others, seeking help for a family who lived near her.

## **Respondent 4: Isolated and at risk, or in control?**

Respondent 4 (R4) is 34 years old and lives with her boyfriend (37 years) and their two children (5 and 12 years), as well as a distant relative of her boyfriend (20 years). R4's two older children from her late ex-husband also moved from the Eastern Cape to join the household, her son (18 years) in January 2004 and her daughter (17 years) in January 2005. R4 has a Grade 5 education and runs a hair salon from the house where she lives. Additional sources of income to the household are a Child Support Grant for her youngest child (C4), her boyfriend's relative weekend job, and her boyfriend's regular income as a cleaner at a nearby shopping centre. Aside from her boyfriend, her youngest sister who also lives in Masiphumelele is her biggest source of support.

R4's life seemed to revolve around her household (from where she worked) and the fact that she was pregnant. Her boyfriend was supportive and involved as a partner and parent despite asking her to keep her status a secret. HIV could hardly be spoken about in the home due to the lack of disclosure, and appeared to be a 'hat' which R4 put on when she needed to go to the clinic for medication. Since no-one except her boyfriend knew about her status, household members believed that the antiretroviral medication which she took daily was due to her pregnancy. She chose not to attend a support group so as not to risk her HIV status being revealed, not least of which to her sister-in-law who owned the house in which they lived and with whom relations were very strained.



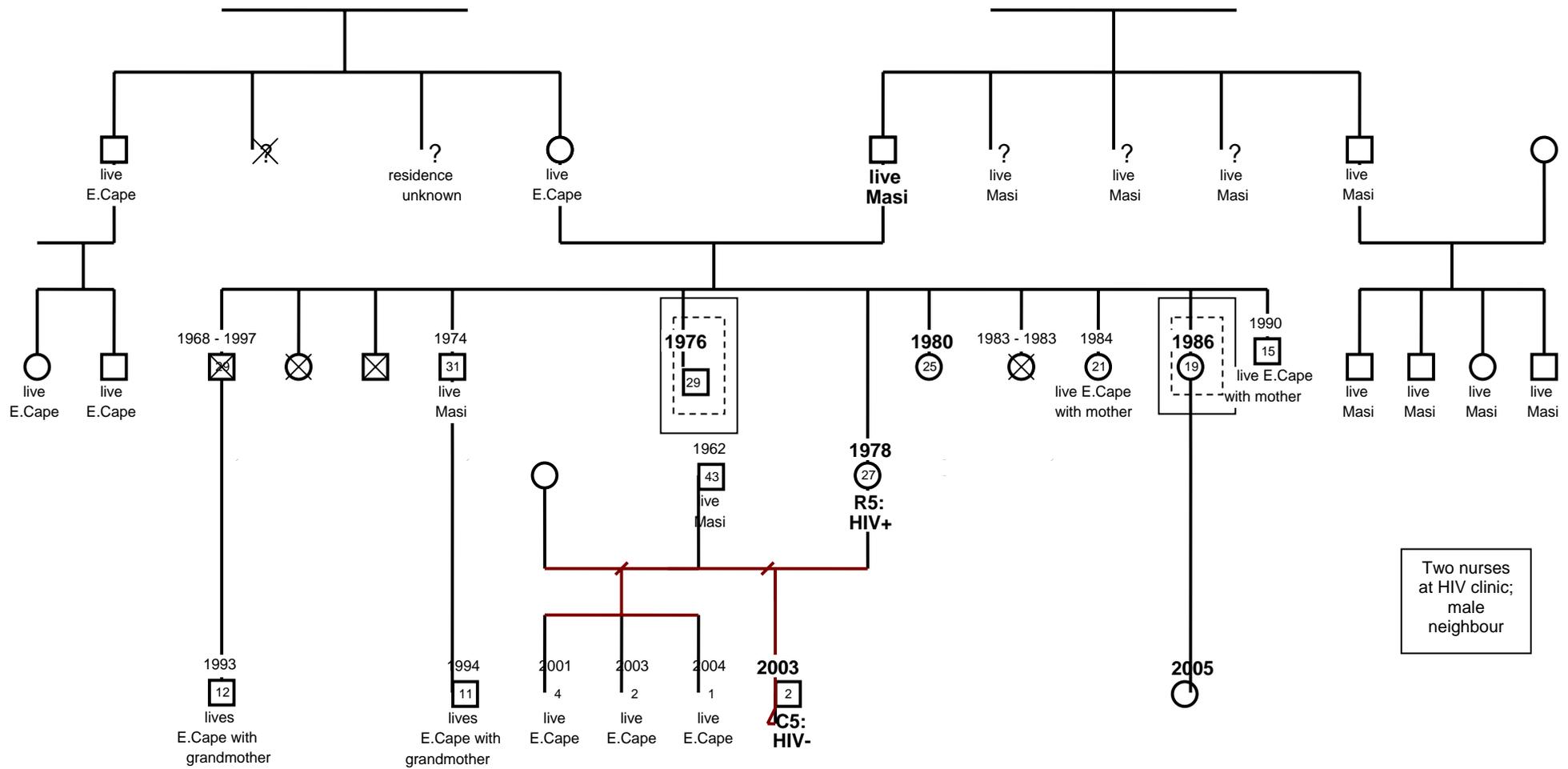
R4 was an independent woman, even aloof and insular. Both her self-report and scale scores suggested that she might be depressed (CES-D score of 28) and anxious (Spielberger score of 43) at times and that not attending a support group could be a contributing factor. Ironically, she was the one who seemed to be in control, as the household rallied around their very pregnant partner and mother by taking responsibility for most domestic and other tasks.

## **Respondent 5: ‘Well-supported’, but caring, sad and fragile?**

Respondent 5 (R5) is a single, 27-year-old mother of an 11-month-old boy (C5). She lives with several members of her family of origin, namely, her father, brother, two of her sisters, and her youngest sister’s one-month old baby. R5 has a grade 11 education and, other than occasional domestic work prior to the birth of her son (C5), has never been employed. R5’s brother’s monthly salary from his job at a concrete company is the household’s main source of income. In addition, C5 has a Child Support Grant, and R5’s father sometimes earns money selling wood on the side of the road or doing the occasional gardening job. R5’s youngest sister has attempted to obtain the Child Support Grant for her child, and R5’s father has attempted to go on pension, but both have been unsuccessful due to administrative problems within state services. If the family cannot come out on their money, the other brother who lives in Masiphumelele will help to buy groceries, but at times the family has to go without food for a few days. Along with her brother and sister with whom R5 has a close relationship, she experiences two of the clinic sisters and a (male) neighbour as very supportive. These generally high levels of support were corroborated by her scale scores (Total support score of 90 on the Social Support Survey).

R5 seemed a loving and caring mother, and a warm person who was struggling to live with her HIV status. She had periods of feeling depressed (CES-D scores of 35 and 36) and consciously used housework to try to avoid intrusive thoughts (self-distraction was one of her highest scores on the Brief COPE). These thoughts included being disappointed by her boyfriend who she felt had let her down, and seemed very unsupportive although she said he was never insulting towards her. He questioned whether he had infected her

Figure 5. R5's 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

despite the fact that she had been faithful and he was known to have had several other partners. At night, when R5 could neither work nor talk with people, her sleep was often disturbed by unpleasant thoughts.

R5 kept her HIV status a secret for several months before disclosing to her brother at the advice of clinic staff. She later disclosed to her younger sister as well. R5 and her sister were very close and were raising their young children (2 months and 11 months) together. R5 was observed to have a strong bond with C5 and was able to describe their relationship more articulately than the other mothers in the study. C5 engaged actively and affectionately with others in the household, particularly his young aunt and his grandfather.

## **Discussion**

The discussion which follows is an attempt to draw out some of the key issues which reflect on the women's psychological experiences, as well as their location within a social context. Despite the limited sample size, and its lack of representivity of HIV positive mothers in general, the narratives which emerged from the study were strikingly unique, and useful in generating hypotheses.

### **Understanding resilience and vulnerability**

A key issue which emerged from the data was the difficulty in making simplistic statements about the women's psychological well-being. Resilience is a useful construct in understanding well-being, but it must be understood as multidimensional and as a process rather than a personal trait (Luthar *et al.*, 2000). 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. This was evident in the finding that some of the women's experiences provided clear evidence of social competence and active attempts to live positively with the illness, as well as clear indications of vulnerability, although with differing degrees of salience.

R1, for example, showed resilience (as reflected by both her behaviour and scale scores) 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 when 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, namely, ovarian cancer).

Similarly, 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 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. While these behaviours could otherwise be construed, respectively, as escapist and inappropriate (particularly the extent to which she revealed highly personal information on first meeting the interviewer), in the context of her very limited support system, it is more appropriate to view her behaviour as a successful attempt to protect the support that was available to her in optimal ways. 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 and sister).

In R3's case, it is important to note that historical factors, namely the losses she had experienced in the past, were at least as central as current factors in understanding her vulnerability. Moreover, her present functioning reflected the fact that while she was often socially competent (for example, in accessing grants), she also experienced emotional distress. She was therefore both a vulnerable woman and a capable and resourceful woman who was able to negotiate difficult life circumstances at some points in time. In R3's case, the fact that she was sick with AIDS, and negotiating being on antiretroviral therapy, was clearly only one potential burden in an already high-risk situation. This is largely consistent with research in similar contexts which has found that parental HIV and AIDS usually serve as additive psychosocial stressors and must be understood with the context of a range of other existent

risk and protective factors (Black *et al.*, 1994; Forehand *et al.*, 1998; Wild, 2001).

In other cases, however, there was clearer evidence of mental health problems. R5's experience of her HIV status was different to that of R1 and R3. She was struggling to live with her HIV status and frequently used a variety of maladaptive coping strategies, in particular trying not to think about or deal with her situation (self-distraction and behavioural disengagement respectively; see Table 2 for scores on the Brief COPE). For example, during periods of feeling depressed, she consciously used housework to try to avoid intrusive thoughts. Moreover, at night, when R5 couldn't work or talk with people (to distract herself emotionally), her sleep was often disturbed by unpleasant thoughts. While not necessarily maladaptive if used intermittently together with other more adaptive strategies, R5's persistent use of avoidance is considered maladaptive and is likely to have contributed to her poor psychological functioning. As with R4, her scores on the social support and depression scales in particular supported other evidence (from the qualitative data) that her mental health was at risk. This is consistent with findings from other research that many HIV positive women do experience mental health problems, including those of a significant nature (Freeman, 2004; Jones *et al.*, 2001a; 2001b; Morrison *et al.*, 2002).

However, even R5's functioning appeared to have shifted over time and was therefore not necessarily a consistent picture of malfunction over time. This finding therefore lends further support to the process model of psychological resilience suggested earlier. Clearly, amongst the women in this study, a process approach was needed in order to capture the complexity of their emotional lives and its relationship to their HIV status.

## **The wisdom of disclosure**

A prominent coping strategy which emerged across all five of the narratives was a rational and strategic approach to the disclosure of HIV status in which women's behaviour was informed by information available to them at the time of disclosure, as well as their individual beliefs and perceptions. 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.

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, 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 HIV status could have been burdensome to C1, and while this was not apparent in the short-term, longer-term implications are possible (Tompkins & Nelson, 2005). However, R1 appeared to manage the disclosure and C1's resulting knowledge in a sensitive and developmentally appropriate manner. Further, it is important for the present analysis that 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 (Cooper *et al.*, 1999).

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 women 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. Regardless of whether their evaluations are objectively judged as correct or based on irrational beliefs regarding the outcome of disclosure (for example, R2's belief that her sister could not tolerate the burden of knowing her status when in fact she responded supportively when disclosure later occurred), both women's decision regarding disclosure represented an attempt to take control over their situations, whether consciously or not. The effect was to position them, in their own perception at least, as empowered and to minimise the

experience of the victim of a disease or diagnosis with all its negative social and cultural implications.

In one case, non-disclosure may have been both strategic and detrimental to the women's well-being (Luthar *et al.*, 1993). This was demonstrated by R4 who, at her partner's request, chose to keep her HIV status a secret from both her household and her community. Consequently she did not attend a support group for fear of being seen by community members and thereby inadvertently exposing her HIV status.

While this 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. Her approach to disclosure thereby minimised her vulnerability in one domain of her life, namely, her intimate relationship. However, it appeared to contribute to emotional distress as well as limited social interaction, both in and outside the household. Moreover, her situation was a tenuous one, as the entire household, including her teenage children, believed that her antiretroviral medication was medication she was taking as a result of her pregnancy. It was therefore likely that her HIV status would eventually emerge following the birth of the child. The combination of these factors could have served to further compromise her emotional well-being.

## **Concerns regarding children**

Aside from active attempts to live positively (such as with R1), concern regarding children was perhaps the issue which most compelled the women to confront the potential implications of their HIV status (Ciambrone, 2003; Hackl *et al.*, 1997; Soskolne, 2003). All of the women were also biological mothers, and each one expressed concern for their children's longer-term well-being and care arrangements. While many had difficulty articulating some of the more subtle emotional shifts which they experienced personally following their diagnoses, for example, grappling with feelings of anxiety, depression, guilt and fear, they were all able to speak easily about their emotional concerns for the children as a result of living with a mother with HIV/AIDS.

Commonly, the women spoke about fears that they would die before their children were old enough to look after themselves and live independently. R1 specifically said that she wanted to live until her son (C1) was at least 14 years old, the age at which she believed he could take care of himself. In

addition, R3 spoke about the impact on her current relationship with her young child. Since R3 was often tired, she was aware that she had less energy to give her child, and consequently her youngest child (C3) was left to do things for herself earlier than her older siblings had been. R3 also associated her HIV status with being a more “restless” parent than when caring for her older children before she became infected. She attributed this parenting style to the fact that ‘one doesn’t know how long you will have to see your children grow up’ and said that that made every moment with your child precious.

In addition to these weighty emotional concerns, the women’s HIV status also had some positive benefits, as noted above, where R1 reported a closer relationship with her son following her diagnosis and disclosure. Although this only emerged in one of the five cases, there is support for this finding in research on the caregiving environments of HIV affected children. Studies have found that some mothers become more tolerant and involved than previously (Black *et al.*, 1994), and attempt to compensate for their eventual absence (Johnson & Lobo, 2001). In addition, another study has shown that some infants attempt to compensate where HIV+ mothers have difficulty engaging with them (Byrne, 1998), thus highlighting the bi-directional nature of the caregiving process.

Further, where there is considerable assistance with childcare, concerns regarding present and future childcare arrangements are much less likely to be extreme. This was most evident in the case of R5 who lived with her family of origin, including her sister with whom she was raising their two infant children together. The burden of childcare was therefore very evenly shared, and R5’s sister was able to provide complete support for R5’s mothering role, including intervening where her HIV status interfered with her capacity to care for her young child. Further, in the event that her sister was unavailable, R5’s father or brother might be available to assist with childcare. Although this was the clearest case of shared caregiving, most of the other women had at least some assistance in the event that it was needed. For example, two of R3’s female neighbours also had small children and would sometimes monitor C3 while R3 went to the clinic for treatment. This is one way in which the contexts of childcare in the southern African contexts are likely to be quite different from more Western, middle-class societies where it is less common for children to be raised by a range of caregivers in addition to a biological parent (Bray, 2003; Henderson, 1999; Reynolds, 1991).

## The roles of household dynamics

While less prominent in the narratives, three other themes also emerged as potentially important mediating factors in understanding women's coping within the household context in particular. First, differences in household composition had some explanatory power. For, example, it might have been particularly important for R1 to disclose her status to her son since they lived alone and he was her most direct line of support, while the fact that R3 lived with a brother who was mentally unwell and dependant on her was key in understanding the stressors which contributed to her emotional vulnerability. This was in contrast to R5 who lived with her family of origin and R2 who lived in a yard with several shacks, both of whom who had considerable help with childcare, thereby reducing one of the potential burdens on their sense of well-being. Knowledge regarding household composition was therefore a key element of situating the women's psychological experiences within their broader social context.

Second, two of the women (R2 and R3) were financially dependant on their partners due to their illness, and R2 and R5 also had concerns about their capacity to provide food for their families. In these cases, finances were an important contextual variable influencing mental health, particularly in the case of R2 where she reported concerns about her children going hungry as something which troubled her and thereby compromised her sense of well-being.

Finally, situational factors such as that the fact that R1 lost her job during the course of the study, or the fact that R4 was pregnant, draw attention to coping and emotional well-being as a dynamic process rather than something inherent and stable. Both of these factors appeared to create instability in the functioning of the household, with likely impacts for the women concerned (as well as other household members). R1 suddenly felt threatened by the possibility that she could not continue to provide financial stability for herself and her young son (in particular sending him to crèche and paying off her house loan), while R4's well-being was maintained by her household's belief that her HAART medication was due to her pregnancy, information which would be more difficult to withhold following the birth of her child. For this reason, research which incorporates the use of longitudinal or retrospective methods, and can take account of changes over time, might be particularly useful. In addition, it was only through the use of a contextual approach which attempted to situate the women within their narrower household context, as well as their broader social networks, that many of these mediating and moderating factors emerged for analysis. The study therefore has

implications for the methods of further research on the same and related topics.

## **The role of men**

Finally, but not least important, the analysis unearthed some useful observations regarding the role of men in the lives of HIV positive mothers, whether in their capacities as fathers, grandfathers, partners, uncles, boyfriends or friends. Two of the women had been infected by partners who had subsequently left them and provided no financial or emotional support for their young children (R1 and R5), while two of the other women had no contact with the fathers (and ex-partners) of their older children (R2 and R3). However, in contrast to this predominantly negative role played by men, R1's brother was a key source of support to her and had placed her on his life policy; R3's live-in partner was very involved in both childcare and domestic duties; and R5's father (grandfather to C5) was a caring and involved male figure. While the study sample itself does not permit comment on the issue of loss for men living with women infected with HIV/AIDS, the neighbour of one of the women (R3) was grieving for his late wife following her death due to AIDS. It is worth noting that he had been left as the sole carer for their young baby.

Although limited in nature, the findings of the study therefore draw attention to the multiple roles which men can and do play in women's lives. While no definitive links can be drawn between the role of men and the women's well-being, it is evident in some cases (for example, R3 and R5) that men's involvement in HIV positive women's lives could serve a promotive factor for their well-being through the provision of support, both to them directly and to other members of the household, including children. The findings therefore provide a more multifaceted representation of men than the typically pejorative messages of men as either absent or doing harm, both in the context of HIV/AIDS and in poverty contexts more generally (Denis & Ntsimane, forthcoming; Montgomery, Hosegood *et al*, in press).

## Conclusions and recommendations

Despite the study's limitations, what emerged was a set of clear and interesting findings which have some support in the literature, and can serve as the basis for further research. Perhaps the key lesson of the study is the value of a holistic and contextual approach that locates women caregivers as individuals and as role-players within their households and broader social networks. Issues such as maternal mental health and disclosure in the context of HIV/AIDS have certainly received attention in the literature. However, the present study has further highlighted some of the complexities of these issues, and demonstrated how conceptualising women in the context of their families, households and broader support networks allowed these issues to emerge more fully through the narratives.

In examining women's approach to disclosure, for example, it was clear that their strategies and the implications for their emotional well-being differed over time as well as across contexts and domains. It was not possible to make global statements about women's resilience or lack thereof, rather more circumscribed statements had to be made about women's emotional distress, social competence, or social relatedness within a particular context and at a particular point in time (Luthar *et al.*, 2000). Some woman expressed their distress only when alone (R5), others in support groups and interviews (R3), and others not at all except as it was evident on assessment with self-report scales (R4). Women were different from each other, and there was difference within their own narratives, and examining different contexts over time allowed such differences to emerge. In addition to layers to their psychological functioning, there were layers to their stressors, particularly in the case of R3 where HIV/AIDS clearly needed to be viewed within a range of historical risk factors.

Context was also important in determining the extent of support for childcare (such as in the case of R5 where her sister played a key and equal role) and the availability of alternate caregivers (such as in the case of R1 where her child's grandmother had been a caregiver previously and could again be in the future). Men, whether as fathers, partners or brothers, also formed part of the context for understanding women's relationships and roles with important potential implications for how they coped with HIV. Finally, and perhaps the more obvious way in which researchers think about context in relation to HIV, household composition sometimes mattered; economic security clearly mattered; and marked life changes such as losing a job (R1) or being pregnant (R4) also played a role. An approach which had not explicitly focused on context may have missed some of the changes which the women experienced,

along with the fact that new and different strengths and vulnerabilities can emerge over time in response to such dynamic and situational factors.

In addition to directly assessing caregiver mental health at an individual level, a comprehensive approach, as the findings demonstrated, must therefore consider household- and community-level factors which impact on the individual (Bronfenbrenner, 1995). This approach is particularly important in developing contexts in which poverty is endemic and HIV prevalence is high, resulting in the mental health impact of the disease being felt even more by families, communities and society as a whole, as well as the infected individuals (Freeman, 2004; Mellins *et al.*, 1996). This is especially true for poor women, whose lives are often deeply embedded and who take on so many roles, of which living with HIV is very often only one.

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## Appendix A. Centre for Epidemiologic Studies Depression Scale (CES-D)

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.

Circle one number on each line:

- 1 = Rarely or none of the time (less than one day)
- 2 = Some or a little of the time (1-2 days)
- 3 = Occasionally or a moderate amount of time (3-4 days)
- 4 = Most or all of the time (5-7 days)

During the past week:

1.	I was bothered by things that usually don't bother me.	1	2	3	4
2.	I did not feel like eating; my appetite was poor.	1	2	3	4
3.	I felt that I could not shake off the blues even with help from my family or friends.	1	2	3	4
4.	I felt that I was just as good as other people.	1	2	3	4
5.	I had trouble keeping my mind on what I was doing.	1	2	3	4
6.	I felt depressed.	1	2	3	4
7.	I felt that everything I did was an effort.	1	2	3	4
8.	I felt hopeful about the future.	1	2	3	4
9.	I thought my life had been a failure.	1	2	3	4
10.	I felt fearful	1	2	3	4
11.	My sleep was restless.	1	2	3	4
12.	I was happy.	1	2	3	4
13.	I talked less than usual.	1	2	3	4
14.	I felt lonely.	1	2	3	4
15.	People were unfriendly.	1	2	3	4
16.	I enjoyed life.	1	2	3	4
17.	I had crying spells.	1	2	3	4
18.	I felt sad.	1	2	3	4
19.	I felt that people dislike me.	1	2	3	4
20.	I could not get "going".	1	2	3	4

## Appendix B. Spielberger State Anxiety Inventory

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.

Circle one number on each line:

1 = Not at all

2 = Somewhat

3 = Moderately so

4 = Very much so

1. I feel calm.	1	2	3	4
2. I feel secure.	1	2	3	4
3. I am tense.	1	2	3	4
4. I am regretful.	1	2	3	4
5. I feel at ease.	1	2	3	4
6. I feel upset.	1	2	3	4
7. I am presently worrying over possible misfortunes.	1	2	3	4
8. I feel rested.	1	2	3	4
9. I feel anxious.	1	2	3	4
10. I feel comfortable.	1	2	3	4
11. I feel self-confident.	1	2	3	4
12. I feel nervous.	1	2	3	4
13. I am jittery.	1	2	3	4
14. I feel "high strung".	1	2	3	4
15. I am relaxed.	1	2	3	4
16. I feel content.	1	2	3	4
17. I am worried.	1	2	3	4
18. I feel overexcited.	1	2	3	4
19. I feel joyful.	1	2	3	4
20. I feel pleasant.	1	2	3	4

## Appendix C. Brief COPE

These items deal with ways you've been coping with the stress in your life since you found out you were HIV+. 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. Circle one number on each line.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
2.	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3.	I've been saying to myself "this isn't real".	1	2	3	4
4.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5.	I've been getting emotional support from others.	1	2	3	4
6.	I've been giving up trying to deal with it.	1	2	3	4
7.	I've been taking action to try to make the situation better.	1	2	3	4
8.	I've been refusing to believe that it has happened.	1	2	3	4
9.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10.	I've been getting help and advice from other people.	1	2	3	4
11.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13.	I've been criticising myself.	1	2	3	4
14.	I've been trying to come up with a strategy about what to do.	1	2	3	4
15.	I've been getting comfort and understanding from someone.	1	2	3	4
16.	I've been giving up the attempt to cope.	1	2	3	4

17.	I've been looking for something good in what is happening.	1	2	3	4
18.	I've been making jokes about it.	1	2	3	4
19.	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.	I've been accepting the reality of the fact that it has happened.	1	2	3	4
21.	I've been expressing my negative feelings.	1	2	3	4
22.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23.	I've been trying to get advice or help from other people about what to do.	1	2	3	4
24.	I've been learning to live with it.	1	2	3	4
25.	I've been thinking hard about what steps to take.	1	2	3	4
26.	I've been blaming myself for things that happened.	1	2	3	4
27.	I've been praying or meditating.	1	2	3	4
28.	I've been making fun of the situation.	1	2	3	4

## Appendix D. Medical Outcome Study Social Support Survey (MOS SSS) – Revised

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

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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

1. Someone to help you if you were confined to bed.	1	2	3	4	5
2. Someone you can count on to listen to you when you need to talk.	1	2	3	4	5
3. Someone to give you good advice about a crisis.	1	2	3	4	5
4. Someone to take you to the doctor if you needed it.	1	2	3	4	5
5. Someone who shows you love and affection.	1	2	3	4	5
6. Someone to have a good time with.	1	2	3	4	5
7. Someone to give you information to help you understand a situation.	1	2	3	4	5
8. Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5
9. Is there someone to hug you	1	2	3	4	5
10. Someone to get together with for relaxation.	1	2	3	4	5
11. Someone to prepare your meals if you were unable to do it yourself.	1	2	3	4	5
12. Someone whose advice you really want.	1	2	3	4	5
13. Someone to do things with to help you get your mind off things.	1	2	3	4	5

14. Someone to help with daily chores if you were sick.	1	2	3	4	5
15. Someone to share your most private worries and fears with.	1	2	3	4	5
16. Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5
17. Someone to do something enjoyable with.	1	2	3	4	5
18. Someone who understands your problems.	1	2	3	4	5
19. Someone to love and make you feel wanted.	1	2	3	4	5
20. Someone to help take care of your children when you can't.	1	2	3	4	5

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 (☹)).

21. Are you happy with the tangible support you receive? (items 2, 5, 12, 15, 21)	☺	☹
22. Are you happy with the affectionate support you receive? (items 6, 10, 20)	☺	☹
23. Are you happy with the positive social interaction you receive? (items 7, 11, 18)	☺	☹
24. Are you happy with the emotional/ informational support you receive? (items 3, 4, 8, 9, 13, 16, 17, 19)	☺	☹

## **Appendix E. Summary of scales**

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

The Centre for Epidemiologic Studies Depression Scale (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 & Weissman, 1980). It has been used in South Africa with a sample of university students (Pretorius, 1993) and with HIV/AIDS home-based caregivers (South African Depression and Anxiety Group, n.d.). It is also currently being used in at least two ongoing studies with women affected or infected with HIV/AIDS (Forsyth *et al.*, 2005; Michaels, in progress).

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

### **(c) The 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 *et al.*, 1989) which has been used in several health-related studies, including studies with HIV+ 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 positive men and women attending an infectious diseases clinic at Tygerberg Hospital in Cape Town (Olley *et al.*, 2004). It is also being used in an ongoing study with HIV positive pregnant women in the Pretoria area (Forsyth *et al.*, 2005).

### **(d) The Medical Outcome Study Social Support Survey (MOS SSS) - Revised**

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 & Stewart, 1991). In addition to a question which elicits information regarding 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). The rationale for this inclusion is that in addition to perceived support, satisfaction with support was hypothesised to be more predictive than network size and received support of women's physical and psychological well-being (Sarason & 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 & 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 people living with HIV/AIDS (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).

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The **Social Surveys Unit** (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. Our core activities include the overlapping Cape Area Study and Cape Area Panel Study. The Cape Area Study comprises a series of surveys of social, economic and political aspects of life in Cape Town. The Cape Area Panel Study is an ongoing study of 4800 young adults in Cape Town as they move from school into the worlds of work, unemployment, adulthood and parenthood.

The **Southern Africa Labour and Development Research Unit** (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. In line with its historical contribution, SALDRU's researchers continue to conduct research detailing changing patterns of well-being in South Africa and assessing the impact of government policy on the poor. Current research work falls into the following research themes: post-apartheid poverty; employment and migration dynamics; family support structures in an era of rapid social change; the financial strategies of the poor; public works and public infrastructure programmes; common property resources and the poor.

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