

Risk and Protective Factors for the Psychological Well-being of Children Orphaned by AIDS in Cape Town, South Africa

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Abstract

Background: Orphanhood is a major consequence of the HIV/AIDS epidemic in sub-Saharan Africa. There is little evidence concerning psychological problems for AIDS-orphaned children. This thesis explores the relationship between orphanhood status and mental health. It also examines mediating influences of environmental risk and protective factors, and interactions between factors, on children's psychological problems.

Methods: 1200 isiXhosa-speaking children were interviewed, using standardised questionnaires, in deprived urban settlements of Cape Town. A qualitative stage with 60 AIDS-orphaned children, 42 caregivers and 20 professionals explored participant perceptions of risk and protective factors. A quantitative stage compared 1025 AIDS-orphaned children to control groups of other-orphans and non-orphans. Data were analysed with t-tests, chi-sq, anovas, regression and log-linear analyses. The study took place in collaboration with Cape Town Child Welfare.

Results: AIDS-orphaned children reported more depression ($p<.001$), peer relationship problems ($p<.001$), post-traumatic stress ($p<.001$), suicidal ideation ($p<.05$), delinquency ($p<.001$) and conduct problems ($p<.001$) than other-orphans and non-orphans. Anxiety showed no differences. Compared to Western norms, AIDS-orphaned children showed higher levels of internalising problems and delinquency, but lower levels of conduct problems. These differences remained when controlling for socio-demographic factors.

A number of factors strongly mediated the relationship between AIDS-orphanhood and mental health. These include poverty-related factors (food, education and social security, $p<.001$), caregiving-related factors (caregiver illness, $p<.001$, excessive housework $p<.001$, being a streetchild, $p<.001$) and AIDS-related stigma ($p<.001$). Cumulative effects were also found. Food insecurity and AIDS-related stigma interacted to raise likelihood of disorder from 19% to 83%, and orphanhood status and bullying interacted to raise likelihood from 12% to 76%.

Conclusions: This thesis shows clear evidence of heightened psychological problems amongst AIDS-orphaned children. It also indicates mediating factors and points to areas of possible intervention. The South African Ministry of Social Development plans to scale up the study to a national survey of AIDS-orphanhood.

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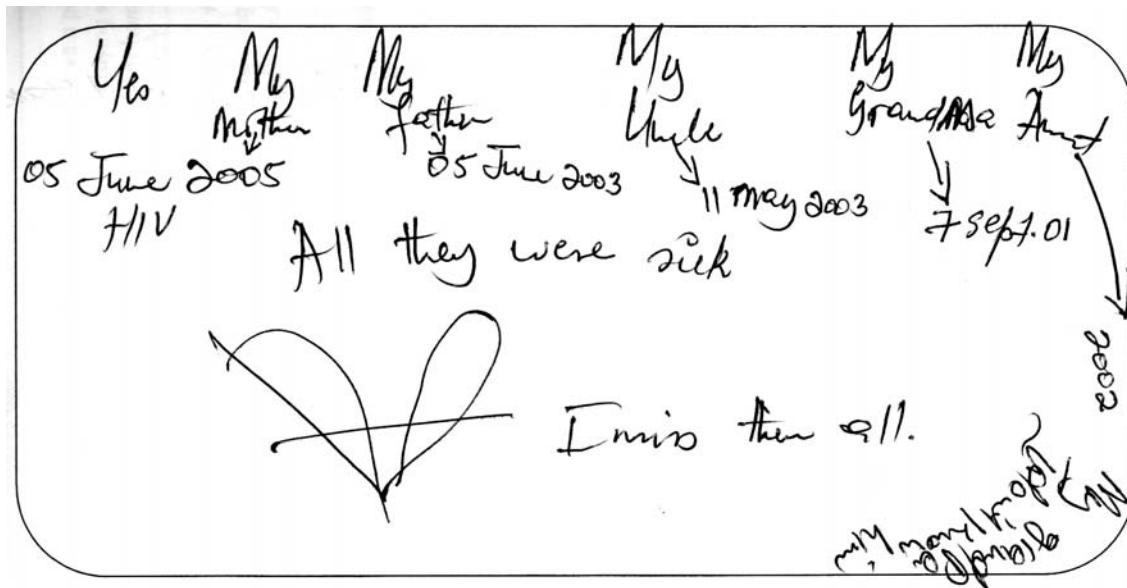


Figure 1: 'Has anyone close to you died? Could you tell us who they were?' Girl, aged 13, Macassar.

Publications and Presentations arising from this Thesis

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

Cluver, L, Gardner, F & Operario, D (2007) Psychological distress amongst AIDS-orphaned children in urban South Africa. *Journal of Child Psychiatry and Psychology and Allied Disciplines* 48(8) 755-763.

Cluver, L, Gardner, F & Operario, D (in press) AIDS-related stigma: Effects on mental health of AIDS-orphaned children. *Journal of Adolescent Health*.

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Cluver, L. & Gardner, F. (2007) Risk and protective factors for well-being of children orphaned by AIDS in Cape Town, South Africa: a qualitative study of children's views. *AIDS Care* 19(3) 318-325.

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Dowdney, L (ed) Adok, N, Arias, J, Castelli, L, Coulter, C, Cluver, L et al (2006) Trauma, Resilience and Cultural Healing: How do we move forward? Coalition to stop the use of child soldiers.

Goodman, R, Cluver, L, Tshandu, V & Vondani, P (2004) Xhosa version of the Strengths and Difficulties Questionnaire (Child and Parent report). Institute of Psychiatry, London.

The following papers arising from this thesis are currently under review

Cluver, L, Gardner, F and Operario, D (under review) Effects of poverty on the psychological health of AIDS-orphaned children.

Cluver, L and Orkin, M (under review) Cumulative risk and AIDS-orphanhood: Interactions of stigma, bullying and poverty on child mental health in South Africa.

The work in this thesis has been presented at the following international conferences:

Cluver, L, Gardner, F and Operario, D. Psychological distress amongst children orphaned by AIDS: Effects of stigma and other community factors in South Africa. Paper presented at: AIDS Impact Conference, 2007; Marseilles, France.

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Chapter 1: Introduction and Outline

Summary of findings

Chapter 1: Introduction and outline

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Figure 2: Interviewing a child in Langa

Summary of findings

Background:

Orphanhood is a major consequence of the HIV/AIDS¹ epidemic in sub-Saharan Africa. A predicted 2.2 million children in South Africa will be orphaned by AIDS in 2015: 86% of all orphans (ASSA, 2005). AIDS-orphanhood is at the centre of current debate: children orphaned by AIDS may be at particular risk for psychological problems, compared to both children who are not orphaned, and children who are orphaned by causes other than AIDS. Current available evidence is very limited, and does not adequately test this hypothesis.

Theoretical background

Theory and evidence suggest that environmental influences may have mediating effects on mental health of children exposed to stressful situations (Rutter, 2005). Thus, environmental factors may function as risk or protective factors, and these may combine to produce effects of cumulative disadvantage (Sampson & Laub, 1997). Amongst children more generally, a range of risk and protective factors have been identified in various spheres of an ecological framework, such as family, community and school (Bronfenbrenner, 1979).

However, few risk and protective factors have been tested with AIDS-orphaned children. This study focuses on three areas of risk and protective factors amongst isiXhosa-speaking children in Cape Town: i) poverty-related factors, ii) community factors, and iii) caregiving factors. The study also explores interactions between risk factors.

Questions this study examines:

¹ HIV/AIDS refers to Human Immunodeficiency Virus /Acquired Immunodeficiency Syndrome. Henceforth, for brevity, AIDS will be used to refer to HIV/AIDS.

- a) Whether orphanhood by AIDS is independently associated with higher risk of mental health problems of depression, anxiety, post-traumatic stress, peer problems, delinquency and conduct problems, when controlling for socio-demographic factors:
- b) Whether there are associations between orphanhood status (comparing AIDS orphans, non-AIDS orphans and non-orphans), psychological outcomes and a range of potential risk and protective factors, including poverty, community factors and caregiving arrangements. Whether these risk and protective factors mediate the relationship between orphanhood status and mental health.
- c) Whether there are interactions between risk factors which may contribute to cumulative effects on mental health of children in this sample.

Method:

The research took place in five stages:

- 1) Systematic review of mental health research with AIDS-orphaned children. Review of research on risk and protective factors amongst AIDS-orphaned children and other vulnerable groups.
- 2) Pilot Quantitative stage: 60 AIDS-orphaned children and matched, non-orphaned controls in Cape Town were interviewed using standardised questionnaires. This pilot comprised a prior MSc thesis, and is reported briefly in this chapter.
- 3) Qualitative stage: 125 isiXhosa-speaking AIDS-orphaned children, their caregivers, and professionals were interviewed regarding potential risk and protective factors
- 4) Quantitative stage: 1025 isiXhosa-speaking children and adolescents (aged 10-19) in deprived urban areas of Cape Town were interviewed using standardised psychological scales. Children orphaned by AIDS were compared with children orphaned by other causes, and non-orphaned children. Information on socio-demographic factors and potential risk and protective factors was also collected.

5) Dissemination stage: Research findings were disseminated to all participating schools and organisations, national and international NGOs, and the Ministry of Social Development.

Results:

Qualitative Stage: Participants suggested a range of potential risk and protective factors, which were included in the quantitative questionnaire.

Quantitative Stage: Controlling for socio-demographic factors such as age, gender, formal/informal dwelling and age at orphanhood, children orphaned by AIDS reported more symptoms of depression, peer relationship problems, post-traumatic stress, delinquency and conduct problems than both children orphaned by other causes and non-orphaned children ($p < .001$). Anxiety showed no differences. AIDS-orphaned children were more likely to report suicidal ideation. Compared to Western norms, AIDS-orphaned children showed higher levels of internalising problems and delinquency, but lower levels of conduct problems.

i) Poverty-related factors: Children orphaned by AIDS lived in poorer households, were less likely to be accessing social security and less likely to be enrolled in school than other groups ($p < .001$). Multivariate analyses, controlling for socio-demographic factors, were conducted. These showed that greater food security, access to social security grants, employment in the household and access to school were associated with better psychological health, and eliminated differences between groups on outcomes of depression, conduct and delinquency problems. Effects of AIDS-orphanhood on post-traumatic stress and peer problems were reduced, but group differences remained. Mediation analyses show that poverty factors strongly mediated associations between AIDS-orphanhood on all psychological distress scales.

ii) Community factors: AIDS-orphaned children reported higher levels of stigma and fewer positive activities than other groups ($p < .001$). There were no reported differences on bullying or community violence. All community-level risk factors were associated with poorer psychological outcomes. Multivariate and mediation analyses, controlling for age and gender, were conducted. These showed that experiences of stigma strongly mediated associations between AIDS

orphanhood and poor psychological outcomes. Controlling for stigma eliminated associations of AIDS-orphanhood with depression, post-traumatic stress, delinquency and conduct problems.

iii) Caregiving arrangements: Living on the streets was associated with heightened psychological distress for AIDS-orphaned children, independent of age, gender and poverty. Living with grandparents was associated with less anxiety, independent of age, gender and poverty. Overall quality of care was good in all groups, although AIDS-orphaned children reported more caregiver illness and excessive housework ($p < .001$). Poor quality of care, abuse, domestic violence, separation from siblings and changes of caregiver were associated with poorer outcomes for all orphaned children. Multivariate and mediational analyses showed that caregiver illness and duration of child housework strongly mediated associations between AIDS-orphanhood on all psychological distress scales. Controlling for these factors eliminated associations of AIDS-orphanhood with anxiety, delinquency and conduct problems.

iv) Interactions between risk factors: Multivariate logistic regressions and log-linear analyses were used to identify interactive relationships between risk factors and likelihood of children having a clinical-level internalising disorder. Two three-way effects were identified. Firstly, food insecurity and AIDS-related stigma interacted to increase likelihood of disorder from 19% to 83%. Secondly, high levels of bullying² interacted with AIDS-orphanhood status to raise likelihood of disorder from 37% to 76% amongst AIDS-orphaned children.

Conclusions:

AIDS-orphaned children are at high risk for psychological distress. This distress is strongly associated with a range of social and economic circumstances which are particularly severe for this group. These findings further provide evidence of cumulative effects of risk factors associated with AIDS-orphanhood. It is important that effective interventions are implemented to reduce relevant socio-economic risk factors.

² For differentiation between bullying and stigma measurements, please see Chapter 5. Broadly, bullying took place exclusively amongst children, and was not focused on HIV/AIDS status of parents. Stigma was experienced from any community member, and was focused on the illness of a family member.

This study shows key areas for possible intervention to reduce psychological distress. It focuses on policy-relevant and practicable factors. Programmes which reduce risk factors and promote protective factors have the potential to improve emotional and behavioural outcomes for AIDS-orphaned children. These include reduction of poverty, provision of social security, access to education, reduction in AIDS-related stigma, reductions in bullying, and reduction of illness amongst caregivers. It is essential that such programmes reach AIDS-orphaned children.

Future research:

This study has been identified by the Minister of Social Development (South Africa) for replication as a nationally-representative survey. This is currently in the planning stages with the Department of Social Development.

Future research is needed to examine mental health for AIDS-orphaned children longitudinally, in rural areas, in provinces other than the Western Cape, and amongst cultural groups other than amaXhosa. It is also necessary to examine the most effective means of reducing risk factors for AIDS-orphaned children. This may include universal provision, area-targeted services, and family-level provision. Any interventions must be rigorously evaluated.

1.1 Preface

The current study began as a problem and a puzzle. The problem was the increasing numbers of AIDS-orphaned children coming to the attention of social work services in Cape Town. In the year 2000 in the Western Cape, numbers of children maternally orphaned by AIDS were estimated to be 3000 (out of 49,000 total orphans). By 2005, maternally AIDS-orphaned children were 24,000 out of 72,000 total orphans. At the time of writing in 2007, 37,000 of 84,000 orphans in Cape Town are estimated to be maternally orphaned by AIDS (Dorrington, Johnson, Bradshaw, & Daniel, 2005). The puzzle was whether this particular group of children required a different set of responses to those needed for orphaned or poor children generally. This study looks at one area of child well-being: mental health. It examines whether, and how, AIDS-orphaned children differ from other vulnerable children in regard to psychological problems.

This study was undertaken by the author, working with both the Department of Social Policy and Social Work at Oxford University, and Cape Town Child Welfare Society. Cape Town Child Welfare is a non-profit organisation founded in 1908, providing social work and community work services to children in 108 areas of Cape Town. Psychological questionnaires were chosen in collaboration with the Department of Psychology in the University of Cape Town, and the Medical Research Council Trauma Research Unit in the University of Stellenbosch.

1.2 Definitions

AIDS-orphaned children: This study uses the UN definition of a child orphaned by AIDS as “a child who has at least one parent dead from AIDS” (UNAIDS, 2004, p. 33). AIDS-orphanhood is used to refer only to children who have experienced parental bereavement by HIV/AIDS, and does not include children who fall into the wider definition of ‘orphans and vulnerable children’ (Varrall & Sherr, 2007). The study uses the most recent age limit for orphanhood as 18 (UNAIDS, 2004), in concurrence with S.28.3 of the South African Constitution (Republic of South Africa, 1996b).

Richter, Foster and Sherr (2006) highlight the confusing and stigmatising use of the term ‘AIDS orphan’. Children whose parents have died of HIV/AIDS are often presumed to be HIV+ themselves, and thus stigmatised and denied services. In an attempt to avoid this confusion, the thesis will refer to ‘AIDS-orphaned children’ or to ‘children orphaned by AIDS’. In doing so, the study aims to differentiate the sample from ‘other-orphaned’ and ‘non-orphaned’ children, whilst avoiding a stigmatising term and recognising the fact that parental death by AIDS does not reflect children’s HIV status.

Children: ‘Children’ are defined as all those under the age of 18, following the UNICEF definition of childhood (UNICEF, 1989) and the South African Constitution (Bill of Rights, s.28).

Adolescents: ‘Adolescents’ are defined, following the World Health Organisation of adolescence as 10-19 years (WHO 2003, p. 1).

Child-headed households and youth-headed households: Child-headed and youth-headed households were defined as those headed by a sibling under 18 and 25 respectively (WHO, 2005a, p. 1).

Mental Health outcomes: For the purposes of this study, the term ‘mental health outcomes’ is used to identify children’s scores on standardised scales. These include both continuous scores, and proportions of children scoring above cut-offs for clinical-level disorder (please see chapter 5 for a fuller discussion of the use of clinical cut-offs).

Mediation: Mediation describes a putative causal chain in which one variable affects a second variable that, in turn, affects a third variable. It typically refers to explanatory variables which explain a main effect. The intervening variable is the mediating variable which mediates the main effect of a relationship between a predictor and an outcome. In this study, risk and protective factors are examined as potential mediating variables between the predictor (orphanhood status) and outcome (mental health) variables.

1.3 HIV/AIDS and orphan prevalence in South Africa

Estimates and projections of numbers of AIDS-orphaned children in South Africa are based on a number of different survey and models. These include Census 2001 (Statistics South Africa, 2003), the General Household Survey (Statistics SA, 2006a), the Demographic and Health Survey (Department of Health, 1998), the National HIV and Syphilis Antenatal Sero-prevalence Survey (Department of Health, 2005) and the HSRC South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey (Shisana et al., 2005). The current study largely uses the ASSA2003 AIDS and Demographic Model (Dorrington et al., 2005). This is the most recent version of the ASSA model released by the Actuarial Society of South Africa, and models the HIV/AIDS epidemic and its demographic impact at a provincial level. However, due to lack of available data, the ASSA model only estimates maternal AIDS-orphanhood.

Estimates of HIV prevalence: The different surveys give differing estimations of the extent of the AIDS epidemic and orphanhood, due largely to differing sampling strategies. For example, the Department of Health National HIV and Syphilis Antenatal Sero-prevalence Survey found that 30.2% of pregnant women were living with HIV in 2005 (15.7% in the Western Cape). From this, they extrapolate HIV prevalence in the general population of 18.8%. In contrast, the HSRC National HIV study estimates HIV prevalence in the general population as 10.8% in 2005 (1.9% in the Western Cape). There are biases inherent in both studies. Antenatal testing generally provides a representative estimate of the general population, although risks both overestimation of prevalence (antenatal attendees are by definition engaging in unprotected sex, which raises HIV risk) and underestimation (HIV reduces fertility). Antenatal surveys may also show bias towards African women, who are more likely to attend public ante-natal clinics than other, wealthier groups. The HSRC National survey has the advantage of giving an idea of prevalence levels amongst children, men and non-sexually active women. However, only 55% of those surveyed agreed to have an HIV test, reducing the reliability of the sample. As a household survey, it excludes homeless people, and people living in institutions such as police and army barracks, hospitals and prisons. In the case of HIV, this probably resulted in underestimation of prevalence. Children under 2 were also not tested, thus excluding many perinatally infected children from the sample.

Estimates of orphanhood and AIDS-orphanhood: The following section uses estimates from the most reliable available sources and only uses sources which provide, to some extent, descriptions of the data and estimation techniques used. However, estimates of numbers and projections of AIDS-orphaned children in South Africa show wide discrepancies, and probably are to be approached as no more than broad indications. Unlike HIV-prevalence, there is no national administrative database which reliably records presence of AIDS-orphanhood. Furthermore, different models of AIDS-orphanhood frequently vary in terms of definition of ‘orphan’, or estimate only a sub-group within orphans. For example, the most recent Statistics SA report on orphanhood only includes children under the age of 15 (Anderson & Phillips, 2006), stating that this is ‘standard practice’ (p2), despite contradicting South African and international legislation. The ASSA2003 model (Dorrington et al., 2005) only includes maternal orphans within ‘AIDS orphans’ (thus excluding paternal and double orphans), due to limitations of survey data. The report states that data available on paternal and double orphans does not allow reliable split of mortality between AIDS- and non-AIDS causes. Thus, the data presented below is to be read as indicative, rather than reliable. Both of the models used below must be viewed as under-estimates of the total number and proportion of AIDS-orphaned children in South Africa. However, consistent trends are noticeable regarding steep rises in both numbers of AIDS-orphaned children, and proportions of orphans who are parentally bereaved by AIDS.

HIV/AIDS estimates:

In 2006, the South African population was estimated at 47.4 million, of which 79.4% were classified as Black African. Of the total population, 42.6% were aged 0-19 (a total of 20.2 million) (Statistics SA, 2006b). Whilst HIV prevalence estimates vary (see table below), 18.2% of 15-49 year olds in South Africa were estimated to be HIV+ in 2006 (Statistics SA, 2006b) or 18.8% in 2005 (UNAIDS, 2006). Amongst African women aged 15-49 years, 27-30% are estimated to be living with HIV.

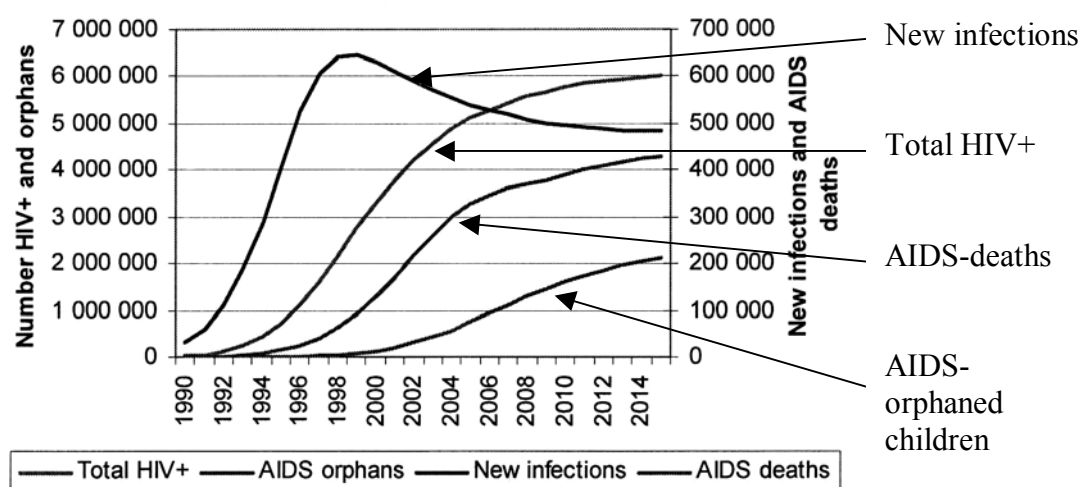
Table 1: Selected HIV/AIDS estimates for South Africa

NATIONAL		Year	Source
Total Population	47.4 million	2006	Statistics SA ³
% of 15-49 year olds HIV+	18.2%	2006	Statistics SA
	18.8%	2005	UNAIDS/WHO
% of 20-64% HIV+	19.2%	2006	ASSA2003
Number of HIV+ people	5.5 million	2005	UNAIDS/WHO
	5.2 million	2006	Statistics SA
	5.4 million	2006	ASSA2003
% of African women aged 15-49 who are HIV+	26.8%	2005	HSRC
	30.2%	2005	Department of Health

Waves of HIV, AIDS and orphanhood

As the HIV epidemic matures in South Africa, the number of new HIV infections is expected to slow (‘first wave: new infections’) (Dorrington et al., 2005). The number of HIV-infected people is estimated to stabilise at about 6 million, reflecting the rising number of AIDS-deaths from HIV-infection in prior years (‘second wave: HIV+ people’). So, whilst HIV-infections slow, AIDS-deaths will be likely to continue to increase rapidly and to plateau around 2015 (‘third wave: AIDS-deaths’). The lag of AIDS-deaths after the wave of HIV-prevalence is expected to result in a ‘fourth wave’ of AIDS-orphaned children. Numbers of orphans are expected to peak around 2015.

Figure 3: Waves of the AIDS epidemic (Dorrington et al, 2005)



³ (Statistics SA, 2006b)

The General Household Survey (2005) reported that South Africa has 20.2 million children under age 18, of whom around 19% (3.9 million) are orphaned (Statistics SA, 2006a). In 2006, it is estimated that two thirds of maternally orphaned children are bereaved by HIV/AIDS (Dorrington et al., 2005). The ASSA2003 model predicts that by 2015, there will be 2.5 million orphaned children in South Africa. 2.2 million of these will be maternally AIDS-orphaned: 86% of all orphans (Dorrington et al., 2005).

Table 2: proportions of orphans in South Africa

NATIONAL		Year	Source
Children as proportion of total population	42.6%	2006	Statistics SA
Number of children	20.2 million	2006	Statistics SA
Number of orphaned children (all causes)	3.9 million (1.1 million: maternal orphans 2.4 million paternal orphans 0.4 million double orphans)	2006	ASSA2003
Number of children orphaned by AIDS	1.02 million (maternal orphans) 1.2 million (all orphans)	2006 2005	ASSA2003 UNAIDS 2006
Orphans as proportion of all children	16% (aged 0-14 only) 13% (maternal) 25.9% (paternal) 4.3% (double)	2005 2006	Statistics SA ASSA2003
Proportion of orphaned children due to HIV/AIDS (maternal or double)	66%		ASSA2003

Figure 4: Projected number of maternal orphans under the age of 18 years, due to AIDS and other causes of death for 1990-2015 (Dorrington et al, 2005)

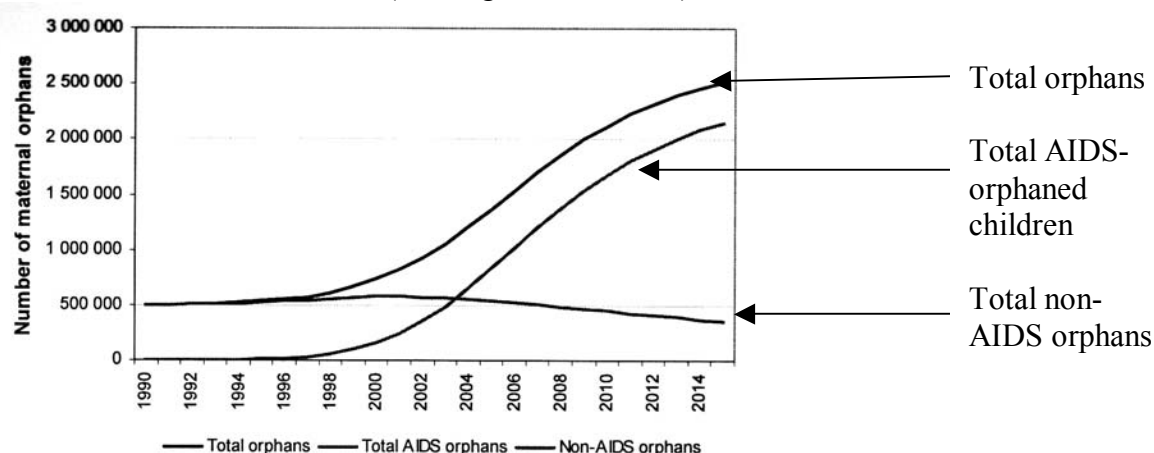


Table 3: Predictions of orphan numbers in South Africa

South Africa			
Year	Total orphans (either parent)	AIDS-orphaned children (maternal)	Non-AIDS orphans (either parent)
1990	495 176	100	495 077
1995	534 697	8 232	526 465
2000	739 054	158 073	580 981
2005	1 371 626	832 246	539 380
2010	2 123 286	1 674 359	448 927
2015	2 513 100	2 151 616	361 484

(Dorrington *et al*, 2006)

The Western Cape: The Western Cape has the lowest HIV prevalence of all South Africa's provinces. In 2006, adult prevalence (15-49 yr olds) was estimated at 8.6%. Prevalence amongst antenatal attendees was around 15%, with a projected plateau of 18% in 2015 (Dorrington *et al*, 2005). A total of 78,000 children in the province were estimated to be maternally orphaned in 2006, with 30,000 of these orphaned by AIDS.

However, the low prevalence and orphanhood rates for the Western Cape are misleading in terms of the effect of the epidemic on different population groups. The Western Cape has high population proportions of Coloured (54%), White (18%) and Asian (1%) inhabitants: groups with far lower HIV-prevalence than Black Africans. For example, in 2005 the Coloured area of Mitchell's Plain had a prevalence rate of 5.1%. The neighbouring Black African area of Khayelitsha had a prevalence rate of 33%. Another Black African area, Gugulethu/Nyanga, had a prevalence rate of 29% (Shaikh & Smith, 2006). Thus in terms of HIV prevalence and orphanhood, Black African areas of Cape Town probably reflect patterns in South Africa more widely, rather than patterns in the Western Cape.

Table 4: Estimates and predictions of orphan numbers in the Western Cape

Western Cape			
Year	Total orphans	AIDS-orphaned children (maternal)	Non-AIDS orphans
1990	37 400	1	37 399

1995	40 449	101	40 348
2000	48 617	3 086	45 531
2005	71 561	23 555	58 006
2010	105 694	59 926	45 768
2015	137 176	96 080	41 096

(Dorrington et al, 2006)

1.4 Research location

Fieldwork took place in deprived urban areas of Cape Town, designated as ‘Black African’ under the apartheid government. The study area spanned 1470 km² of the Cape Flats. Study areas were characterized by high population density, for example 67 people/hectare in Khayelitsha (Winter, Armitage, Caden, Rivett, & Sichone, 2006). Rates of internal migration are high, with continual urbanisation from the largely rural Eastern Cape province. The Cape Flats experience extreme levels of property crime, rape and violent crime (South African Police Services, 2004). Unemployment in Khayelitsha was 51% at the 2001 Census (Statistics South Africa, 2003). Data collection took place in both informal and formal settlements. Formal settlements are largely Reconstruction and Development Programme housing, consisting of one- or two-room houses with electricity and sanitation (City of Cape Town, 2004). Informal settlements vary in terms of service provision, but shacks rarely have inside sanitation or adequate refuse collection. However, urban renewal strategies since 2001 have had positive impacts, with improved provision of basic services such as electricity, piped water and shared outside toilets (N. Graham, 2006).

The choices of research location and sample group lead to limitations of scope in this study. The sample is restricted to Black African, isiXhosa-speaking children, who live in urban areas of the Cape Flats. Thus, this study cannot claim to be generalisable to other areas, to non-urban populations of the Western Cape, or to ethnic groups other than the amaXhosa. Further discussion of the limitations of this study is given in Chapter 7.

1.5 Theoretical Framework

This thesis aims to identify risk and protective factors which mediate the mental health outcomes of a group of children exposed to severe stressors. Whilst the study methodology focuses on

environmental factors, it uses an overarching theoretical framework which recognises the mediating effects of both biological/genetic and environmental influences on child mental health (Rutter, 1981, 2005).

Within a theoretical model of risk and protective factors, the current study uses an ecological framework (Bronfenbrenner, 1979; Richter et al., 2006) to guide the exploration of potential mediating factors in child mental health. It is recognised that these risk and protective factors may function in different spheres or levels of a child's life, such as family, home, school and community. It is further recognised that factors may interact between and across levels.

Environmental influences on child mental health

Research has shown that children who are exposed to particular highly stressful situations may be at heightened risk of experiencing mental health problems (Rutter, 2000). Different risk situations may influence different types of psychological problems (Hoge, Andrews, & Leschied, 1996). This study aims to identify a) factors which, when present, increase the likelihood of poor mental health ('risk' factors) and b) factors which, when present, decrease the likelihood of poor mental health outcomes ('protective' factors).

However, psychological literature has moved away from a focus on 'risk' or 'vulnerability' alone, to more complex models of childhood 'resilience' or 'positive pathways' (Rutter, 1989). There is an extensive literature on childhood resilience (Boyden & Mann, 2000): of all children who grow up in difficult situations, only some develop mental health problems (Radke-Yarrow & Sherman, 1992). The concept of resilience is an attempt to understand the mechanisms by which some children *do not* develop such problems, despite exposure to traumatic or challenging events (Clarke & Clarke, 2000), or to understand the *process* of negotiating risk situations (Snider & Dawes, 2006).

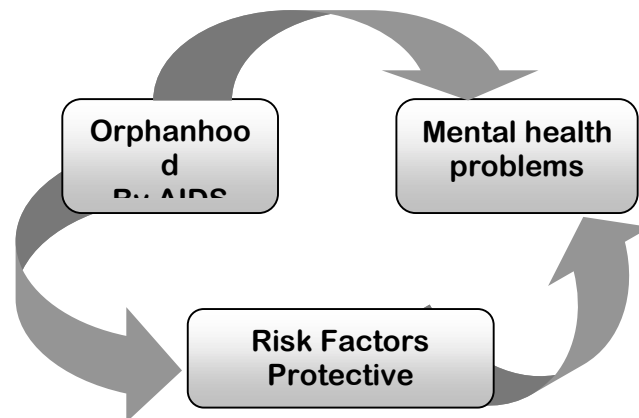
Early research on resilience focused on personal characteristics of 'resilient children' (Luthar, Cicchetti, & Becker, 2000). Personal resilience factors include self-confidence and problem-solving approaches (Rutter, 1985) and qualities such as resourcefulness and intelligence (Apfel &

Simon, 1995). Masten & Coatsworth define resilience as: “manifested competence in the context of significant challenges to adaptation or development” (Masten & Coatsworth, 1998).

But the concept of ‘resilience’ alone has little empirical evidence to support it (Boyden & Mann, 2000). Rutter (2000) finds no conclusive evidence for the exclusion of environmental factors in determining child outcomes. Thus, resilient qualities at an individual level must be combined with supportive features within the child’s environment, in order to challenge adverse outcomes associated with stressful situations (Masten, 2001; Masten & Coatsworth, 1998). It is perhaps most helpfully understood that personal resilience factors are insufficient in isolation: they need to be combined with ‘protective factors’ in the environment, in order that children can utilize available resources (Rutter, 1999). Furthermore, ‘personal resilience’ factors are partly created by positive aspects of a child’s environment. For example, problem-solving approaches can be encouraged by education.

These models of child resilience demand that we take a more nuanced approach to exploration of risk and traumatic situations on child outcomes. Rutter argues that risk literature overestimates the “universality and irreversibility” of trauma-related psychological damage (Rutter, 1985) (p.598). Although child mental health may be detrimentally affected by exposure to particular life circumstances, child outcomes may equally be mediated or moderated by interaction with protective factors, which operate in different spheres of children’s lives (Bronfenbrenner, 1979). In the context of a putative environmental risk such as AIDS-orphanhood, protective factors improve a child’s response to the environmental risk, resulting in a more adaptive outcome (Rutter, 1979).

Figure 5: A model of the mediating effects of risk and protective factors.



It is crucial, then, to explore not only the presence of ‘risk factors’, which exacerbate the effects of an environmental hazard, but also the mediating value of ‘protective factors’. These are conceptualized as reducing risk by compensating, challenging or ‘immunizing’ children’s adjustment (Werner, 2000). Risk and protective factors may, in practical terms, be ‘two sides of the same coin’. For example, low levels of food security may be seen as a risk, and high levels as a protective factor. The identification of a risk factor suggests that the removal or compensation of that risk factor has the potential to function as a protective factor.

There is another way to understand the functioning of risk and protective factors, or mediating factors, in the relationship between AIDS-orphanhood and child mental health. These factors can be seen as *mechanisms* by which AIDS-orphanhood impacts on psychological well-being. Much of the available theoretical and empirical work which looks at mechanisms, focuses on the distal mechanisms by which poverty impacts on mental health, such as discrimination (Richter, 2003) and education (Lipman, Offord, & Boyle, 1996). In this context, poverty itself may be seen as a potential mechanism by which AIDS-orphanhood can have effect: parental death by AIDS increases the likelihood of family poverty (Booyesen, 2002), which (perhaps through other mechanisms of its own) negatively impacts on child well-being.

Thus, the theoretical framework for this study emphasises the importance of identifying environmental risk and protective factors in informing the provision of services for children. If we can identify factors which both mediate mental health problems and are viable areas of

intervention, there is potential to increase and support resilience amongst children (Masten et al., 1999), even in the ongoing context of other stressors (Bronfenbrenner, 1979).

Cumulative effects of risk and protective factors

The risk of psychological problems increases for children who experience multiple stressors (Sameroff & Seifer, 1992; Werner & Smith, 1989). As risk factors increase, or multiple risk factors operate simultaneously, it may be necessary to have a proportionate increase in protective factors (Werner & Smith, 1989). It may be further necessary that these protective factors (or removal of risk factors) operate on more than one ecological level (Masten & Coatsworth, 1998).

Rutter's review of risks in child psychopathology (Rutter, 2000), concludes that the effects of a single stressful experience on children, 'if occurring in isolation from other adversities, were quite small' (p392). He states that real risks arise from cumulative combinations of stressful or negative experiences (Fergusson & Lynskey, 1996; Kolvin, Miller, Scott, Gatzanis, & Fleeting, 1990; Sameroff, Seifer, & Bartko, 1997). Rutter (1985) argues that risk and protective processes should be seen as chronologically sequential and cumulative in structure. These build on each other over time, and interact with one another forming a 'chain' of linkages (Rutter, 1999).

Cumulative risk has been explored in the delinquency field, and provides a useful example. Interactional theories in criminology see causal influences in delinquency as reciprocal and interactive over the life course (Thornberry, 1987). Sampson and Laub identified the term 'cumulative disadvantage' to developmental processes which result in stable poor outcomes such as delinquency (Laub & Sampson, 1993; Sampson & Laub, 1997). Using sociological theories of contingency and path-dependency (Aminzade, 1992), they argue that the stigmatizing effects of labelling delinquency 'act as intervening variables in the escalation to secondary deviance' (Paternoster & Iovanni, 1989, p. 384)⁴. Another example given of risk factor interaction is that of weak social bonding, which 'serves as a mediating and hence causal sequential link in a chain of

⁴ There may be direct parallels between this example and the cumulative effects of stigma and poverty shown in Chapter 6.

adversity between childhood delinquency and adult criminal behaviour' (Sampson & Laub, 1997, p. 13)

Longitudinal criminological evidence supports interactional theory (Farrington, 1977; R. Freeman, 1991; Loeber & Farrington, 2000), and suggests that cumulative effects may be most salient in explaining the structurally constrained lives of the urban poor. Increasingly, evidence supports the relevance of cumulative disadvantage theory in the area of child outcomes (Rutter, 1979a; Sameroff, 2000). Appleyard et al (2004) found evidence of cumulative risk effects in early childhood (i.e abuse, domestic violence, family disruption and low socio-economic status) on behaviour problems in adolescence. Analyses determined a linear (rather than threshold) model of cumulative risk, as did the findings of Atzaba-Poria et al (2004) on ethnic minority and majority children in the UK. Other research emphasises the importance of interactions between genetic risk factors and additive environmental factors (O'Keane, 2000).

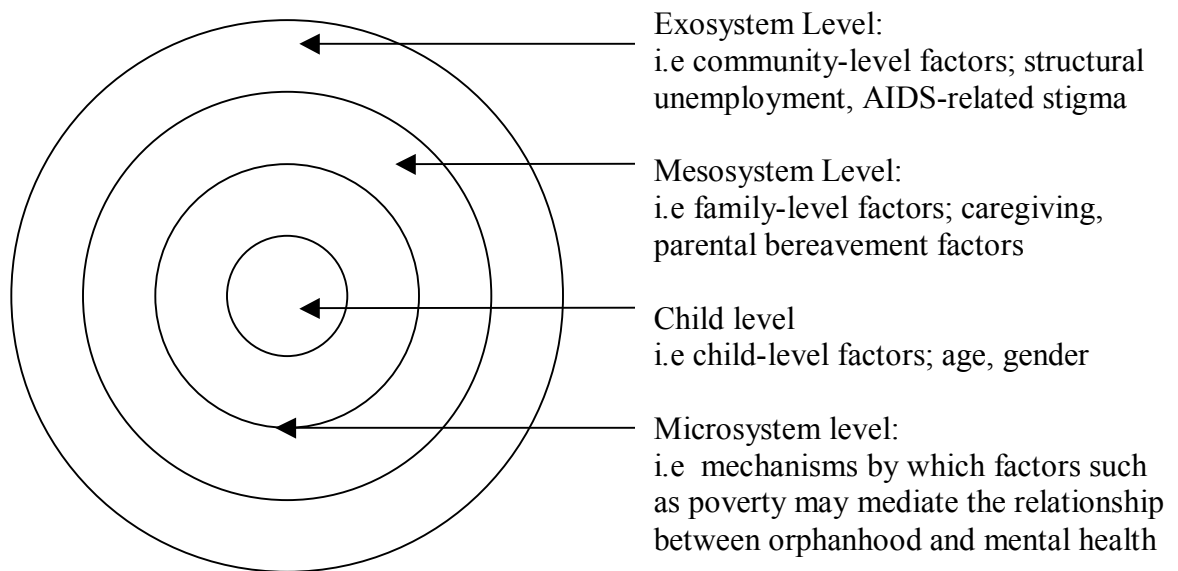
Is orphanhood by AIDS such a risk to children's mental health because of the cumulative negative effects which result from an AIDS-death in the family? Following Rutter (1985), this study will explore the possibility that risk factors for children may be interacting with one another, and contributing to a cumulative experience of disadvantage. This theory may be especially appropriate to the experience of AIDS-orphanhood. There is good evidence to show that a familial HIV/AIDS diagnosis leads to a set of connected disadvantages, such as increased poverty and AIDS-related stigma (Richter et al., 2006). Thus it may be that the cumulative nature of risk factors supports a multi-level (ecological) approach to investigating the determinants of child adjustment.

An ecological framework of risk and protective factors

Within an overall model of risk and protective factors, ecological frameworks provide a structure by which to understand better the relationships between individuals and their environments. Bronfenbrenner's ecological framework (Bronfenbrenner, 1979) identifies multiple levels of influence on child mental health, and sees development as produced by increasingly complex reciprocal interactions between the child and the objects, events and persons in his/her

environment. The current study focuses on risk and protective factors at Bronfenbrenner's microsystem, mesosystem and exosystem levels.

Figure 6: Bronfenbrenner's ecological framework



The microsystem level is the pattern of activities, roles and interactions experienced by the child in their immediate environment, for instance, familial or school settings, which restrict or invite the child's development (Bronfenbrenner, 1979/1997). For orphaned and vulnerable children in Cape Town, these may include family-level factors such as abuse, caregiving arrangement, and many of the poverty-related consequences of orphanhood. Supportive microsystem environments are fostered by the availability of a network of enduring and reciprocal relationships (Garbarino & Ganzel, 2000). Conversely, high-risk microsystems are characterised by a scarcity of mutually rewarding relationships, and/or the presence of destructive patterns of interaction.

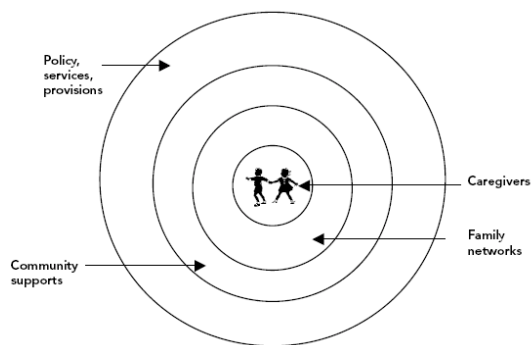
The mesosystem level comprises linkages and relationships between two or more (microsystem) settings (Bronfenbrenner, 1979). A protective mesosystem is one with sufficient strong, positive connections between microsystem settings. Conversely, high-risk mesosystems are characterised by inadequate or destructive connections between microsystem contexts. This may be a helpful framework through which to explore mechanisms by which factors could be affecting the relationship between orphanhood and mental health mechanisms. For example, heightened poverty amongst households in which AIDS-orphaned children live, may contribute to increased illness

amongst caregivers who cannot afford medical care, which may in turn impact on child mental health.

The exosystem includes institutions, organisations and neighbourhoods: contexts which impact on the development of children, but in which children are not directly involved (Garbarino & Ganzel, 2000). This may include factors such as community violence, AIDS-related community stigma, and wider influences of poverty within neighbourhoods, such as poor access to services. The macrosystem level is defined by Bronfenbrenner as the cultural ‘blueprint’ within society. It is the ideologies and institutions of a particular culture. Finally, chronosystems are defined as constituting changes over time in the individual’s life and in his/her environment (Bronfenbrenner, 1979).

Richter, Foster and Sherr (2006) have adapted Bronfenbrenner’s framework to approach the specific context of orphaned and vulnerable children, and this framework, alongside Bronfenbrenner’s original framework, will guide the literature review of risk and protective factors presented in Chapter 3.

Figure 7: ‘Circles of care’ – an adaptation of Bronfenbrenner 1979.



(Richter, Foster and Sherr, 2006)

Further theoretical sources: HIV/AIDS, bereavement and orphanhood

In determining a theoretical framework for this study, it was also useful to examine theories which may possibly aid understanding of the experiences of having HIV/AIDS, and the experiences of

other types of orphanhood. There seems to be little social theory which readily supports analysis of AIDS-orphanhood. However, there is an increasing body of work regarding the experiences of being HIV-positive and of having AIDS, which may have relevance to understanding the context which distinguishes AIDS-orphanhood. Theoretical approaches to the AIDS epidemic highlight its multifaceted and interactive aspects: AIDS is understood as not only a medical disease, but also as a social, political, economic and highly stigmatised affliction (Booyesen, 2002; Nattrass, 2005; Van Dyk, 2001). In this sense, theoretical frameworks can be utilised from studies such as Marks's explorations of stigmatised responses to syphilis (Marks, 2002), which emphasises high-risk situations for African poor, and persistent societal responses of blaming victims for disease. Increasingly, literature around HIV/AIDS requires a recognition that both causes and responses to the disease must be approached on multiple levels: social, economic, gender-sensitive and biomedical (Campbell, Nair, & Maimane, 2007).

The bereavement literature provides a useful background to understanding processes and mechanisms by which familial bereavement may impact on mental health of surviving relatives (Bonanno & Kaltman, 1999). However, it is to be noted that both this and the orphanhood literature discussed below, are based almost exclusively on developed-world samples, where consequences of parental loss (such as poverty) may be very much less extreme. Bereaved individuals consistently show elevated symptoms of depression and physical health problems (Stroebe, Stroebe, Abakoumkin, & Schut, 1996). The 'grief work' theory, originating in the Freudian psychotherapeutic model, identified a need to relinquish the attachment bond to the deceased person, but lacks support of empirical evidence (Wortman & Silver, 1989). Alternative theories, such as cognitive stress theory and trauma theory have greater evidential support, and may provide more valuable models through which to consider the context of AIDS-orphanhood.

Cognitive stress theory identifies the importance of the bereaved person's subjective evaluation of the difficulties associated with bereavement (N. Stein, Folkman, Trabasso, & Christopher-Richards, 1997). The trauma perspective sees bereavement (particularly complicated or violent bereavement) as potentially resulting in post-traumatic stress as well as depression (Zisook, Chentsova-Dutton, & Shuchter, 1998). Trauma theory emphasises the importance of distinguishing between different types of bereavement, and that some causes of death may be more distressing

than others. This perspective also focuses on the importance of disclosure; talking about the loss, although evidence suggests that this may be dependent on having a social environment which is sympathetic and supportive (A. Kelly & McKillop, 1996). The presumption that sudden or unexpected death produces more severe grief reactions than long illness has some limited empirical support, but has been found to have no effect in a number of studies (Fulton & Gottesman, 1980).

Children may experience some aspects of bereavement differently from adults. Orphanhood has a theoretical tradition which identifies experiences of loss, trauma and reduced care for children. Bowlby initially identified adverse mental health consequences of maternal deprivation, in relation to lost parental attachment and caregiving (Bowlby, 1951). Later, Parkes and others continued to conceptualise parental bereavement as a major cause of child mental health problems (Meyers, 1986; Parkes, 2001). Parkes and later Bowlby both understood death as the most extreme form of relationship deprivation.

Theory on the bereavement effects on family members of a prolonged death such as cancer, has identified different 'stages' in the mourning process, such as denial, numbing and acceptance (Kubler-Ross, 1969). Much bereavement literature has focused on the differential impacts (or manifestations of impact) of parental bereavement for children at different ages (Tremblay & Israel, 1998). Children's understanding of the meaning of death may be partial or inconsistent until adolescence (Christ, 2000), although this is mediated by adult explanations to children, as well as adult approaches towards the bereaved child. Bereavement theory largely focuses on emotional impacts of bereavement, and there is little evidence of different degrees of disturbance according to children's age. However, that disturbance may be expressed differently according to the child's developmental stage. For example, younger children may be more likely to show separation anxiety, bedwetting (Dowdney et al., 1999b) and night-time fears (Kaffman & Elizur, 1979). Adolescents may show more depression and guilt than those in middle childhood (Weller, Weller, Fristad, & Bowes, 1991).

Further work highlights the importance of family interactions and shifting family relationships in responding to parental death (Bowen, 1976). The impacts of such family processes on children's

mental health has been demonstrated through randomised controlled trials of interventions targeting such processes (I. N. Sandler et al., 1992). Factors which may be particularly important for bereaved children include children's exposure to subsequent negative events, such as financial difficulties following parental death (Silverman, 2000)

AIDS is certainly not the first example of mass orphanhood which is concentrated on a geographical region or particular population group. But many other pandemics, such as Spanish flu, predate psychological approaches to children's bereavement. Other explorations of mental health effects of mass parental bereavement include studies of war (i.e Barenbaum, Ruchkin, & Schwab-Stone, 2004) and genocide. These emphasise a 'lifelong sense of bereavement' amongst child holocaust survivors (Mazor & Mendelsohn, 1998), although a recent meta-analysis has shown that this is not transmitted to subsequent generations (van Ijzendoorn, Bakermans-Kranenburg, & Sagi-Schwartz, 2003). Holocaust literature introduced the idea of 'sequential traumatisation' for an accumulation of traumatic experiences associated with death and multiple bereavement (Keilson 1979) However, other studies suggest that child holocaust survivors may function normally, but be particularly vulnerable to subsequent stressors which recall events, such as Gulf War attacks on Israel (Solomon & Prager, 1992). This concurs with studies of Vietnamese and Korean war veterans, and may have parallels with experiences of AIDS-orphaned children who are exposed to subsequent sequential deaths of HIV-infected parents, siblings or family members. In the developing world, studies have found group responses of post-traumatic stress amongst Rwandan orphans (Perrier & Nsengiyumva, 2003). There is little available evidence of the differential impacts on children of single parental death, double bereavement or multiple bereavement. Prior studies of children who have experienced the death of both parents have largely been in circumstances of war, terrorism or disaster, and thus the particularly traumatic causes of parental death may have confounded the generalisability of findings to parental death by illness. However, studies of adult bereavement as a result of HIV/AIDS does suggest distress related to multiple bereavement (Sherr, Hedge, Steinhart, Davey, & Petrack, 1992).

There were pre-existing causes of mass orphanhood in Cape Town, before the HIV/AIDS epidemic. For example, tuberculosis has been prevalent for at least a century (Mizrahi, 2006) and is now the opportunistic proximate cause of death of many AIDS-victims (Lawn, Bekker,

Middelkoop, Myer, & Wood, 2006). Alcohol-related deaths are common in a wine and spirit-producing region (Parry et al., 2005). However, there seems to be little or no empirical research, linked to the cause of orphanhood, on the mental health of orphans in South Africa. Nor has much theory been developed with regard to these children.

This thesis combines theories which approached childhood bereavement more generally, with approaches to other forms of mass bereavement, and has attempted to view these within the context of the multiple impacts of HIV/AIDS on African families. Such an approach suggests that a nuanced view of the potential effects of AIDS-orphanhood is necessary. For AIDS-orphaned children in South Africa, the effects of parental bereavement must be seen in the context of community and personal responses to a highly stigmatised, impoverishing and politicised disease.

Summary

The current study uses a broad theoretical framework which recognises the importance of environmental influences on child mental health. These influences take place in a range of areas of children's lives, and may interact to produce cumulative effects on psychological well-being. These environmental influences may be specific to aspects of the experience of AIDS-orphaned children: i.e parental bereavement, stigma surrounding HIV/AIDS, and poverty.

1.6 The policy debate

The current study takes place not only within theoretical frameworks, but also within the context of an ongoing and emotive policy debate around provision of services to AIDS-orphaned children. The policy debate is discussed in greater detail in Chapter 7, in the context of the policy recommendations presented by this study, and government responses to the study findings. In Chapter 1, I will briefly outline relevant international and national policy and summarise the focus of debate.

There are a number of international policy commitments to the psychosocial support of children orphaned or made vulnerable by AIDS (Snider & Dawes, 2006). These include the United Nations Declaration of Commitment on HIV/AIDS (United Nations, 2001, p. 13), to:

“...implement national policies and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including by providing appropriate counselling and psycho-social support’.

In addition, the declaration (p.10) requires that signatory states will:

“By 2003, develop and by 2005 implement national policies and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including by providing appropriate counselling and psychosocial support, ensuring their enrolment in school and access to shelter, good nutrition and health and social services on an equal basis with other children”.

The South African Children’s Act (2007) does not mention orphanhood by AIDS. It defines an orphan as a child who ‘has no surviving parent caring for him/her’ (Section 24.15). This excludes children who are parentally bereaved but live with a surviving parent. The Children Act only mentions orphanhood in two further contexts: firstly in relation to eligibility for adoption, and secondly in distinguishing children in need of care and protection. This requires that the child is completely without ‘support’:

‘abandoned or orphaned and is without any visible means of support’ (Section 150.1.a).

However, the revised National Action Plan for orphans and other children made vulnerable by HIV and AIDS (Department of Social Development, 2006) includes psychosocial support as a primary requirement. Indicators in the plan require that psychosocial support is incorporated into all training programmes to address the holistic needs of orphans and vulnerable children (OVC) and their caregivers. Responsibility for this is taken by the National Action Committee for Children Affected by HIV & AIDS (NACCA).

The new National HIV and AIDS Strategic Plan for South Africa (Department of Health, 2007) states a commitment to challenge discrimination against orphans and vulnerable children (p.55), and broadly identifies the need for intersectoral collaboration for social protection of orphans (p.128). However, psychological support is not directly mentioned.

In South Africa, current policy and policy rhetoric are divided between two polar views. The first is that AIDS-orphaned or AIDS-affected children should not be prioritized or selected for support in preference to other vulnerable children, or to other children living in poverty. Targeted services are seen as both unnecessary and stigmatizing. The second view is that AIDS-orphaned children are in need of special care and support, over and above the needs of other vulnerable children. A policy ‘middle-road’ refers to increased needs amongst ‘OVC’ or ‘orphans and vulnerable children’, but this term lacks clear definition and is likely to confuse the determination of appropriate services.

There is clear validity in arguments for provision which does not further isolate an already-stigmatised group. However, the present thesis argues that before making decisions about allocation of services, it is important to have a secure evidence base for understanding the effects of different factors on child outcomes. Before determining whether all ‘OVC’ should be treated as a single risk group in regards to psychological intervention, research is needed to compare psychological difficulties amongst different sub-groups within the broad grouping of ‘orphans and vulnerable children’.

This study aims to inform the current debate on the desirability of prioritizing AIDS-orphaned children in South Africa. It provides evidence regarding the specific and differing needs of AIDS-orphaned children, in one particular sphere of child deprivation: mental health.

1.7 Overview of research questions

The study has two main research questions, each with sub-questions:

1) Do children orphaned by AIDS experience more mental health problems than children orphaned by non-AIDS causes, or than non-orphaned children?

1a) Are different types of mental health problems experienced more than others?

1b) How do AIDS-orphaned, other-orphaned and non-orphaned children compare to (Western-established) norms of proportions of children in the clinical range for psychological problems?

2) What risk and protective factors are mediating any differences in mental health problems experienced by different groups of children?

2a) What poverty-related factors mediate any differences in mental health problems?

2b) What caregiving-related factors mediate any differences in mental health problems?

2c) What community-level factors (including AIDS-related stigma) mediate any differences in mental health problems?

2d) Are there any interactions between risk factors, which may be combining to produce a cumulative effect on mental health problems amongst children?

1.8 Overview of methodology

Methodological requirements

Rutter (2000) identifies key methodological requirements for research which aims to identify specific risk and protective mechanisms. Firstly, he specifies that studies must use designs that ‘pull apart’ variables that ordinarily go together. This particularly applies to the current study in terms of the importance of separating the impacts of orphanhood by AIDS and orphanhood itself. In addition to a non-orphaned control group, the study used a second control group of children ‘orphaned by non-AIDS causes’. The study also aimed to isolate individual mediating factors such as poverty, education and stigma, within the complex and multi-risk experience of AIDS-orphanhood.

Secondly, Rutter states that the testing of causal hypotheses would be strengthened if the impact of factors on child mental health could be examined longitudinally (thus testing within-individual

changes over time, rather than relying on case-control comparisons). This would clearly be a preferential study design to the cross-sectional design used. However, the use of a prospective longitudinal design, starting pre-orphanhood, would have required an extremely large initial cohort of children, in order to produce sufficient sample sizes of AIDS-orphaned and other-orphaned children. This would have had large budget and time implications.

Thirdly, Rutter requires the use of well-validated, sensitive and differentiating measures of both potential risk and protective factors, and of psychological outcomes. This study used standardised, validated questionnaires for all psychological outcomes, and used established scales or items wherever available to measure risk and protective factors.

Fourthly, Rutter states that the sample size must be large enough to provide adequate power to test hypotheses. Before commencing fieldwork, power calculations estimated a minimum power of 115 children in each group (345 in total) in order to distinguish between clinical and non-clinical levels of mental health problems. The final sample size (1025) was well above this minimum.

Fifthly, Rutter states that research design must allow that ‘competing explanatory hypotheses can be pitted against each other, rather than simply seeking to gain support for the investigator’s preferred hypothesis. Appropriate statistical methods must also be geared to the same purpose’ (Rutter, 2000, p381). In order to allow competing hypotheses in this study, a wide range of potential risk and protective factors were measured, and were tested against each other using backwards elimination in multivariate regressions (see Chapter 6). Log-linear analyses also allowed exploration of interactive effects between all relevant variables, and were thus chosen in preference over path-analysis models which allowed the testing of only pre-hypothesised interactions.

Finally, Rutter requires that research articulates carefully and fully the assumptions upon which the chosen research design rests, and makes explicit the extent to which problems and limitations have been dealt with. This thesis explores assumptions such as the use of Western standardised questionnaires in Chapter 5, and details study limitations in Chapters 5 and 7.

1.9 Overview of Chapter contents

The study design included five stages:

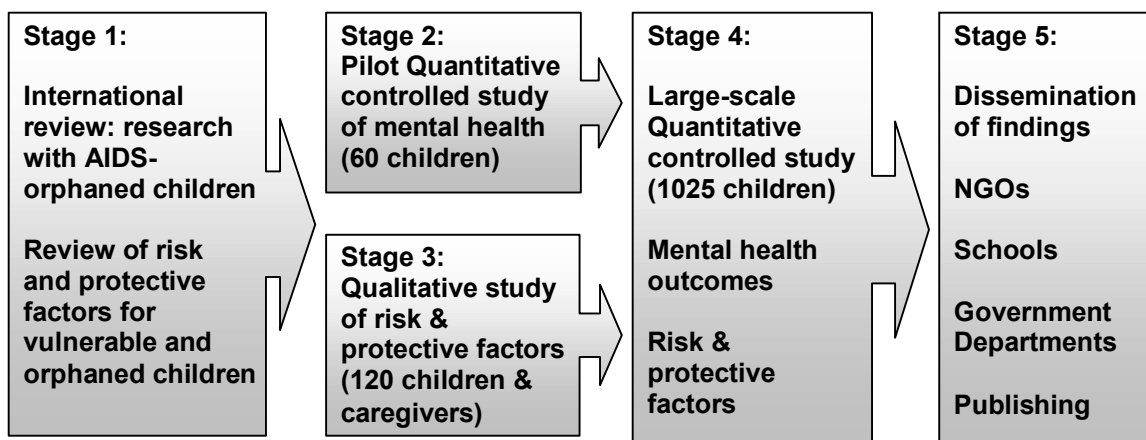


Figure 8: Overview of study design

Chapters 2 and 3: Stage 1 is reported in Chapters 2 and 3. An international review was made of all studies exploring mental health outcomes amongst children orphaned by AIDS. This included both published and unpublished studies. The review provided indications of mental health problems which may be important to investigate amongst orphans. However, it provided only a very limited indication of potential risk and protective factors in orphan mental health, as very few studies explored such factors. In order to determine potential risk and protective factors for AIDS-orphaned children, reviews were made of the risk and resilience literature, and of quantitative studies of risk and resilience amongst children more generally. Studies were also reviewed which examined risk and protective factors amongst children who may share some similar life circumstances to AIDS-orphaned children in our sample group. These included studies on parental bereavement, studies with refugee children, studies of homeless children, and studies of children who live in the geographical areas included in this study.

The pilot stage (Stage 2) for this study will not be described here, as it formed a thesis for the MSc in Applied Social Studies/Diploma in Social Work (Oxford University, July 2003), and has been published in the *Annals of General Psychiatry* (Cluver & Gardner, 2006). This stage was a small-scale, pilot quantitative study of mental health outcomes amongst children orphaned by AIDS, compared to non-orphaned children.

Chapter 4: Stage 3 is reported in Chapter 4. Due to the paucity of research concerning risk and protective factors for AIDS-orphaned children, a qualitative study was conducted prior to designing the quantitative questionnaire (Cluver & Gardner, 2007b). A total of 120 orphaned children, caregivers and professionals working with orphans, were interviewed. This stage allowed identification of risk and protective factors which had not been raised by literature review. The qualitative stage also introduced a participatory element to the wider study, by allowing participants to influence the study design.

Chapters 5 and 6: Stage 4 is reported in Chapters 5 and 6. A large-scale, quantitative controlled study was conducted, using standardised mental health questionnaires and measuring potential risk and protective factors in children's mental health. 1025 children were interviewed, comparing children orphaned by AIDS, children orphaned by other causes and non-orphaned children.

Chapter 7: Stage 5 is reported in Chapter 7. An essential part of this study was the feedback of study findings to relevant agencies. These included all schools and NGOs who had participated in the research, and a range of international and local NGOs working with AIDS-orphaned children. It also included reporting of findings to the South African Department of Social Development, and the subsequent planning of a national survey of AIDS-orphanhood. Findings of this study have been published in peer-reviewed journals.

In summary, this thesis presents a research project which involved both qualitative and quantitative methodologies. The research also includes dissemination of findings, and potential implications of findings for policy, as an integral part of the research design. The research design aimed to fulfil, as far as possible, Rutter's requirements for rigorous examination of environmental influences on child mental health.

1.10 Conclusion

Chapter 1 has aimed to outline the epidemiological, theoretical, geographical, and political contexts in which the research study has taken place. There is little reliable data on prevalence and proportion of AIDS-orphaned children in South Africa. Estimates and projections, whilst differing,

agree that numbers are large and increasing rapidly. It is clear that the next decade will produce millions of AIDS-orphaned children. As yet, we have little empirical knowledge regarding the vulnerability of this group within the child population. Existing theories of child mental health suggest that AIDS-orphaned children are potentially exposed to a range of risk factors which may negatively affect their psychological outcomes. These risk factors may be cumulative, and may be present in multiple ecological levels of children's lives. Theories of HIV/AIDS suggest potentially AIDS-specific risks which merit further exploration.

This research has also taken place within a highly-charged geographical and political context. The townships in which the fieldwork took place were exemplars of post-apartheid South Africa's struggles with poverty, HIV/AIDS and a continuing racial divide. On a national (and international) level, policy-makers are in a hotly-debated process of developing a response to the issue of AIDS-orphanhood. Chapter 7 will show the contribution which the current study makes to ongoing debate.

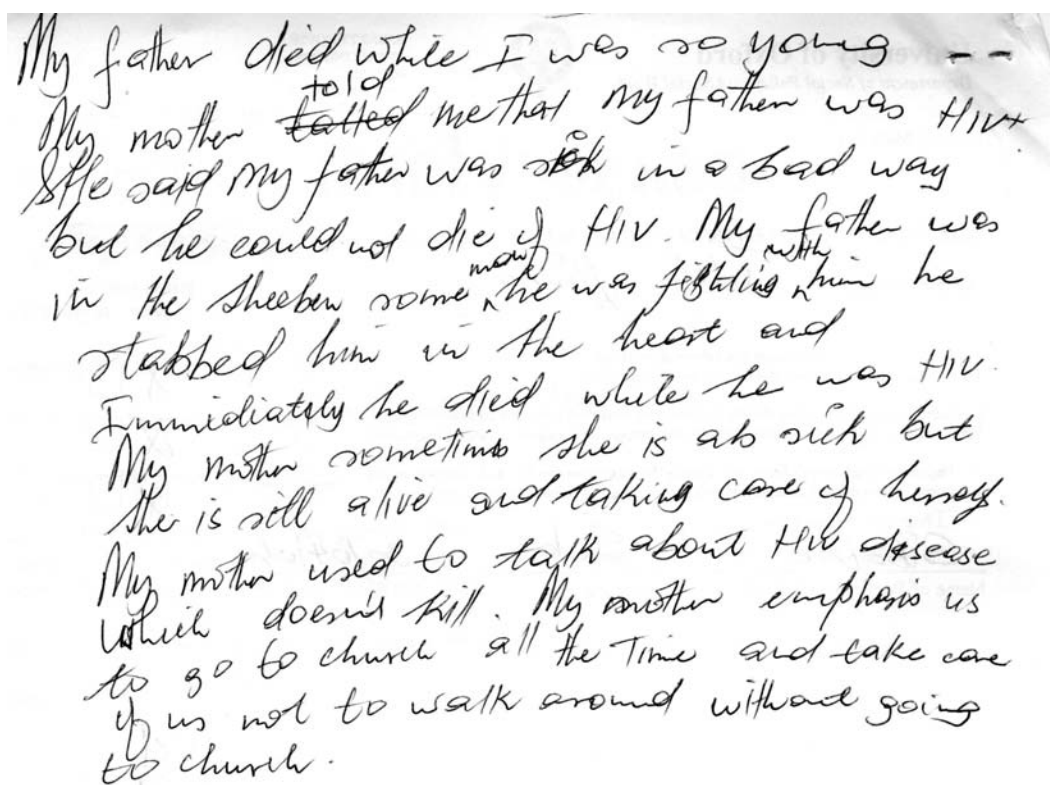
The research methodology had three aims. Firstly, it aimed to rigorously examine a new phenomenon. Secondly, it aimed to conduct highly ethical research in a particularly challenging context (see Chapter 5). Finally, it aimed to actively disseminate research findings, and to ensure that this study has an impact on the development of evidence-based policy.



Figure 9: Intshinga school, Guguletu

Chapter 2: Literature review 1: AIDS-orphaned children and mental health

- 2.1 Introduction
- 2.2 Definitions and parameters of the review
- 2.3 Reviewing and search strategy
- 2.4 Results: Review of studies
 - Controlled studies in Africa
 - Controlled studies in the US
 - Descriptive studies in Africa
 - Descriptive studies in the US
 - Non-quantitative literature
 - Distress prior to parental death
- 2.5 Discussion
- 2.6 Summary and conclusions

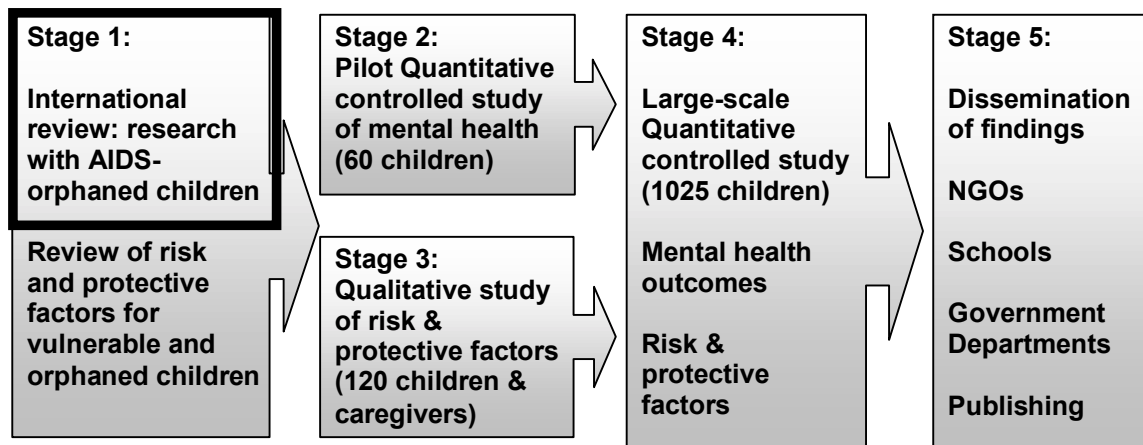


My father died while I was so young --
My mother ^{told} ~~tatted~~ me that my father was HIV+
She said my father was ~~sick~~ in a bad way
but he could not die of HIV. My father was
in the shebeen some ^{man} he was fighting with him he
stabbed him in the heart and
Immediately he died while he was HIV.
My mother sometimes she is a bit sick but
she is still alive and taking care of herself.
My mother used to talk about HIV disease
which doesn't kill. My mother emphasises us
to go to church all the time and take care
of us not to walk around without going
to church.

Figure 10. Boy, 12, Browns Farm.

‘My father died while I was so young. My mother told me that my father was HIV. She said that my father was sick in a bad way but he could not die of HIV. My father was in the shebeen [bar] and some man was fighting with him he stabbed him in the heart and immediately he died while he was HIV. My mother sometimes she is sick but she is still alive and taking care of herself. My mother used to talk about HIV disease which doesn’t kill. My mother emphasises us to go to church all the time and take care of us not to walk around without going to church’.

2.1 Introduction



Chapter 1 presented an outline of the study's methodology, and of the five stages of the research design. The present chapter addresses the first part of Stage 1. It outlines the methodology and findings of a review of international research on mental health and AIDS-orphaned children.

The focus was primarily to inform the design of Question 1: 'Do AIDS-orphaned children have more mental health problems than other children?' Firstly, the review aimed to establish whether this was a question worth asking; secondly, whether it was a question which had already been answered; and thirdly, whether the design of other studies could inform the choices of outcomes measured, sample groups and quantitative design.

There is limited available research, but increasing concern, regarding the psychological well-being of children orphaned by AIDS. These children are exposed to multiple stressors which may compound and complicate the grieving process. Children may have cared for and witnessed the death of parent/s with a debilitating illness, loss of bodily functions, and possibly AIDS-related mental illness (Olley et al., 2003; Tedstone & Tarrier, 2003). Children may experience multiple losses, for example of mother, father and peri-natally infected younger siblings. Caregivers of orphans have been found to experience poorer psychological health than other caregivers (Ferreira, Keikelame, & Mosaval, 2001; Manuel, 2002), and research suggests a correlation between caregiver and child distress. South African orphans report experience of stigma and secrecy surrounding AIDS, leading to social isolation, bullying and reduced opportunity to discuss grief (Bray, 2003a; Cluver & Gardner, 2007b; Giese, Meintjies, Croke, & Chamberlain, 2003). Poor

communication can lead to children's ignorance of causes of parental death, or fearing that they will also be infected (Marcus, 1999b).

This literature review focuses firstly, on research which is quantitative and explores psychological outcomes amongst uninfected children orphaned by AIDS. Both controlled and uncontrolled studies are included. Secondly, selected qualitative research, survey data and other helpful literature, with a focus on the Southern African context, are also reviewed.

2.2 Definitions and parameters of the review

UNAIDS definitions of 'children orphaned by AIDS' include distinctions between maternal, paternal and 'double' orphans (where both parents have died). All of these groups are included under the definition of 'total orphans' (UNAIDS & UNICEF, 2002).

Whilst recognising that the both death and illness of parental and non-parental caregivers may have important effects on children, this review focuses on children who have been parentally bereaved (one or both parents). However, some of the research studies included in this review have used a wider definition of orphanhood, such as Wild et al., (2006, July), which includes children bereaved by any primary caregiver.

There is also debate around the age range of 'orphanhood'. The UN definition has moved from an upper limit of 15 years (UNAIDS & UNICEF, 2002) to 18 years (UNAIDS, 2004), in concurrence with both the UNICEF definition of childhood (UNICEF, 1989), and the South African Constitution (Republic of South Africa, 1996b). This review uses the current definition of 18 years, but some (especially earlier) studies follow the previous limit of 15 years. A detailed discussion of the definitions of orphanhood used in the present study is given in Chapter 5.3.

This review does not focus on orphaned children who are also HIV+, as HIV infection has multiple effects which may confound or exacerbate the effects of orphanhood on child mental health. Whilst recognising the importance of further research on this vulnerable group, this review does

not include studies which are limited to clinical samples of HIV+ children. Further discussion of the exclusion of HIV+ children is given in Chapter 5.

2.3 Reviewing and search strategy

This review draws on both published and unpublished empirical studies. Keyword searches were made of: *Electronic databases*: PsycINFO, Medline, and the Index to South African Periodicals (ISAP), BMJ, TDNet, the British Library database, Zetoc, Cambridge Scientific Abstracts, Web of Science. *Online publications*: UNAIDS, UNESCO, UNICEF, World Health Organisation (WHO), Department of Health and government publications in South Africa, Botswana, Mozambique, Uganda, Lesotho, Tanzania, Zambia and Zimbabwe. *Handsearched*: AIDS Bulletin, ChildrenFIRST (SA), Children's Institute publications, *HIV/AIDS conference websites*: Beijing 2004, Barcelona 2002, Durban 2000, Gauteng 2000, specific conferences such as AIDS Impact 2005 (Cape Town), the National Conferences on Orphans and Vulnerable Children (Namibia) and others. *Thesis searches*: SABINET (1995-2005), SilverPlatter, Dissertation Abstracts International. Studies were also found through personal recommendations, emailed requests to academics, and web searches (google, google scholar, yahoo, altavista, findarticles.com). Reviews of psychosocial literature used, include Siegal and Gorey (1994), Wild (2001), and Stein (2003). Finally, information was shared with UNICEF and HSRC (Snider & Dawes, 2006).

2.4 Results: Review of studies

There have been relatively few published empirical studies on the psychological well-being of children orphaned by AIDS. Thorough searching revealed 23 studies worldwide of which five were conducted in the USA and eighteen in Africa. Thirteen of the studies are currently unpublished. Of the unpublished studies identified, one was only available as a conference abstract (Makaya et al., 2002) and two were thesis abstracts which were unable to be accessed (Gelman, 2003) or unable to be accessed in full (Hirsch, 2001).

Of the 22 studies (both ongoing and completed) with sampling information available, seven are descriptive and lack control groups. Fifteen studies compare orphaned children with some kind of control group. All of the Africa-based studies, and all but two of the US studies, are cross-sectional. Seventeen of the studies interview children directly, whilst 4 rely on caregiver report. Of the three ongoing studies, one in Rwanda (L. Brown, Thurman, & Snider, 2005) has published interim findings.

We must be cautious in assuming generalisability between studies conducted in diverse parts of Africa, due to variations in social, cultural and economic circumstances. It should also be noted that there may be difficulties translating US studies to an African context, due to differences in support systems and characteristics of HIV-infected groups. Samples in the US, often recruited through services, may also reflect a support system with superior resources concentrated on far fewer children than in African contexts.

Controlled Studies in Africa:

Poulter (1996), in Zambia, interviewed carers in 22 households with orphans, 66 with HIV+ parents, and 75 control families. However, as controls were randomly selected from the community, this group may have included HIV-affected families. They used the Rutter Scales (Rutter, Tizard, & Whitmore, 1970) with caregivers. Caregivers reported that orphans were significantly more likely to be unhappy or worried than children with HIV+ parents, and both groups were significantly more likely to be unhappy, worried, fearful, solitary and fearful of new situations than children in non-affected families (no p values reported). The study found no clear link between psychological disturbance and economic stress. They also found no evidence of conduct disorders or anti-social behaviour.

Sengendo & Nambi (1997) interviewed 169 orphans under the education sponsorship of World Vision in Uganda, and a comparison group of 24 non-orphans (using systematic random sampling from all eligible sponsored youth). They used a non-standardised 25-item depression scale,

interviews with orphans, teachers and some guardians. They found orphans had significantly higher depression scores ($p < .05$), and lower optimism about the future than non-orphans ($p < .05$).

Makame, Ani and McGregor (2002) in urban Tanzania, interviewed 41 orphans and 41 non-orphaned controls, using a non-standardised internalising problems scale based on the Rand Mental Health Inventory (Veit-Wilson, 1998) and items from the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). They found that orphans had increased internalising problems compared with non-orphans ($p < .0001$), and 34% reported that they had contemplated suicide in the past year, compared to 12% of non-orphans ($p < .016$).

Manuel (2002, unpublished thesis), in rural Mozambique, used a non-standardised internalising problems questionnaire adapted from the instrument used by Makame et al (2002). They interviewed 76 orphans, 74 non-orphaned controls from the area, and their carers. Orphans had higher depression scores ($p < .001$), were more likely to be bullied ($p < .001$), and were less likely to have a trusted adult or friends ($p < .001$). Caregivers of orphans reported more depression ($p < .001$) and less social support than controls.

Atwine et al (2005) in rural Uganda, interviewed 123 orphaned children and 110 matched, non-orphaned controls aged 11-15. Using the Beck Youth Inventory (BYI) (Beck et al., 1961), orphans were more likely to be anxious (OR = 6.4), depressed (OR=6.6) and to display anger (OR=5.1), and showed significantly higher scores for feelings of hopelessness and suicidal ideation. A range of questions were asked concerning current and past living conditions, and a multivariate analysis of factors with possible relevance for BYI outcomes found that orphan status was the only significant predictor of outcomes.

In Rwanda and Zambia, Chatterji et al (2005) compared orphans, children with chronically ill caregivers, and non-affected children. Children aged 6-12 ($n=1160$) completed a 7-item unstandardised 'worry/stress' scale developed from existing instruments. On this scale, Zambian orphans scored higher (i.e. with more mental health problems) than children with ill caregivers, who scored higher than other children ($p < .04$). In Rwanda, there were no differences between orphans and children with ill caregivers, but both groups scored higher than other children ($p < .03$).

In Rwanda, worry/stress was correlated with socio-economic status ($p < .03$) and community cohesion ($p < .001$).

In Ethiopia, Bhargava (2005) analysed data from a survey of 479 children who had been maternally orphaned by AIDS, with a control group of 574 children orphaned by other causes. Children completed 60 items from the 657-item Minnesota Multiphasic Personality Inventory 2 (MMPI) (Hathaway & McKinley, 1989), with subscales of social adjustment ($\alpha = .80$), and emotional adjustment ($\alpha = .86$). Children orphaned by AIDS showed more emotional and social adjustment problems, and girls reported higher levels of difficulties than boys. Significant predictors of higher scores in both groups included presence of the father, school attendance, household income, clothing conditions, distribution of food and emotional support within the fostering family.

Cluver and Gardner (2006) interviewed 30 children orphaned by AIDS, and 30 matched, non-orphaned controls, in Cape Town, South Africa. Standardised questionnaires were used; the Strengths and Difficulties Questionnaire (Goodman, 1997) and Impacts of Events Scale (Dyregrov & Yule, 1995). Both groups scored highly for peer problems, emotional problems and total scores. However, orphans were more likely to view themselves as having no good friends ($p = .002$), to have marked concentration difficulties ($p = .03$), and to report frequent somatic symptoms ($p = .05$), but were less likely to display anger through loss of temper ($p = .03$). Orphans were more likely to have constant nightmares ($p = .01$), and 73% scored above the cut-off for post-traumatic stress disorder. However, the PTSD scale was not administered to the non-orphaned control group.

A national survey in Zimbabwe (Nyamukapa et al., 2006) applied factor analysis to compare orphans and non-orphaned children aged 12-17 years ($n = 5321$). Psychosocial disorders were measured using a 16-item unstandardised scale, with items from the Child Behaviour Checklist, Rand Mental Health and Beck Depression Inventories. Findings showed more psychosocial disorders amongst orphans ($p < .05$), which remained when controlling for poverty, gender, age of household head, school enrolment and adult support. Depression showed group differences, but anxiety did not.

Also in Zimbabwe, Gilborn et al (2006) interviewed 1258 orphans and vulnerable children, comparing groups by exposure to various psychosocial support programmes. An unstandardised instrument was developed from formative qualitative research, and included 6 items suggestive of depression and 2 items suggestive of poor psychosocial well-being. Orphans reported higher stress ($p<.05$) and more psychosocial distress ($p<.05$).

Wild, Flisher, Laas and Robertson (2006, July: conference paper), have recently completed a study with adolescents (10-19 years old) in the Eastern Cape of South Africa. They compared 81 AIDS-orphaned children, 78 orphaned by non-AIDS causes, and 43 non-orphans. AIDS-orphaned children were recruited through NGOs. They used the Revised Children's Manifest Anxiety Scale (R-CMAS) (Reynolds & Richmond, 1978), the 10-item Child Depression Inventory (CDI) (Kovacs, 1992), items from the Child Behavior Checklist (CBCL-YSR) (Achenbach, 1991), and items from the Self-Esteem Questionnaire (DuBois, Felner, Brand, Phillips, & Leas, 1996). The study also looked at potential moderating factors of adult, peer and neighbourhood connection and regulation, and psychological autonomy. Findings showed that adolescents orphaned by non-AIDS causes reported more depression ($p<.05$) and anxiety ($p<.05$) than non-orphans, with scores for AIDS-orphaned children falling between the two groups and not differing significantly from either. There were no group differences in externalising problems. 'Other' orphans showed lower self-esteem than both non-orphans and AIDS-orphaned children. Of the potential protective factors for all orphans, greater autonomy from caregiver and greater neighbourhood regulation were significantly associated with lower anxiety ($p<.001$). Greater connection with caregiver and greater peer regulation were associated with lower depression ($p<.001$) (Wild, Flisher, Laas, & Robertson, 2006, July).

In Kenya, Elmore-Meegan et al (ongoing, data collection in progress) initially used the Achenbach Child Behaviour Checklist with orphaned and vulnerable children, but found the schedule over-long (Conroy, R, 2007 personal communication). They are currently developing a short, problem behaviour scale based on caregiver report, and gathering data on 400 children.

An ongoing study in Uganda (Lamphear & Jones, ongoing, data in analysis) compares levels of PTSD in AIDS-orphaned children (137) with matched control groups of orphans by non-AIDS

causes (98) and non-orphans (99). No information is as yet available regarding this study, but the authors supplied the following: Children (aged 8-18) completed the Child's Reaction to Traumatic Events Scale (Jones, Fletcher, & Ribbe, 2002), which measures PTSD arousal, avoidance and intrusive symptoms. Teachers completed the 'parent report of post-traumatic symptoms' (PROPS, Greenwald, 1997 – full reference unable to be found). An unstandardised semi-structured interview questionnaire measured exposure to current and past traumatic events, in order to identify risk and protective factors that might moderate children's PTSD and psychosocial adjustment.

Controlled studies in the USA:

The Family Health Services Research Unit in New Orleans, have conducted a series of cross-sectional and longitudinal studies with children of HIV-infected parents (Armistead & Forehand, 1995; Armistead et al., 1999; Brody & Forehand, 1986; Dutra et al., 2000; Forehand, Armistead, Mose, Simon, & Clarl, 1998; Forehand et al., 2002; Forehand et al., 1999; Pelton & Forehand, 2005; Shaffer, Jones, Kotchick, Forehand, & The Family Health Project Research Group, 2001). In 1999, Forehand et al interviewed 20 maternal orphans recruited from a primary public HIV clinic, and 40 non-orphaned children, recruited from public schools near the clinic. This longitudinal study measured symptoms amongst children whilst their parents were HIV+ and alive, and then 6 months after parental death. They used the Child Behaviour Checklist (Achenbach & Edelbrock, 1987) and the Child Depression Index (Kovacs, 1992). Children of HIV+ mothers showed more emotional and behavioural problems, lower cognitive and social competence than the control group ($p < .05$). 6 months after the death of their parents, there were non-significant improvements in orphans' psychosocial adjustment.

The most recent paper within this longitudinal study (Pelton & Forehand 2005) compared the same group of orphaned children before and 2 years after maternal death from AIDS, with two comparison groups of children with living, HIV+ mothers, and children with living, non-infected mothers. Caregivers completed Child Behaviour Checklists on 105 6-11 year olds (all African-American). Findings indicated that, relative to those in one of the two control groups, more orphans had clinical levels of emotional and behavioural problems, both before parental death and

at 2 years after parental death. Thus the 6-month finding of non-significant improvements (described above) may not indicate long-term effects of orphanhood.

Hirsch (2001, unpublished thesis abstract), compared 16 children (under age 12) whose mothers had died of AIDS, with 18 children whose mother had died due to other causes. Some children were HIV+ (number not given). Attachment security was measured using the Attachment Q-Set (Van Dam & Van Ijzendoorn, 1988), and anxiety, depression and conduct were measured using scales from the Behaviour Assessment System for Children (BASC-PRS) (Reynolds & Kamphaus, 1992). Results found no significant differences between groups for attachment security. Children orphaned by causes other than AIDS showed higher depression, anxiety and conduct problems than AIDS-orphaned children, although neither group's mean scores were generally within the clinical range. Recruitment method was not stated (this is an abstract for an unpublished thesis), but a reference to the AIDS-orphaned children receiving social services suggests that participants were recruited through services.

In New York, an intervention-based study (Rotheram-Borus, Lee, Lin, & Lester, 2004; Rotheram-Borus, Stein, & Lin, 2001), used longitudinal assessments with standardised instruments. The study compared adolescents orphaned by AIDS (73) with adolescents whose parents were alive and HIV+ (138). At 2 years after parental death, they found that bereaved children reported more emotional distress on the Brief Symptom Inventory (Derogatis & Melisaratos, 1983), and more problem behaviours (smoking, alcohol, crime and aggressive behaviour) than children whose parents were still alive ($p < .05$). Further factors increasing adolescent distress at 2 years included baseline severity of parental physical health symptoms and parental emotional distress. Post-intervention results found significant differences of fewer problem behaviours and fewer sexual partners amongst the intervention group, but no effect on emotional distress.

Descriptive Studies in Africa:

A number of studies without control groups have also been carried out in Africa. Foster et al (1997) conducted focus-group discussions and non-standardised interviews with 40 orphans, 25 caregivers and 33 community workers in rural Zimbabwe. Children reported anxiety, fear,

stigmatisation from friends and community, depression and stress. Nampanya-Serpell (1998, unpublished thesis) interviewed families of 645 urban orphans and 291 rural orphans in Zambia. Structured interviews with caregivers (but not children) were used, and the study cautions that this made interpretation difficult ‘with respect to the influence of caregiver identity and familiarity’. A non-standardised ‘Emotional Well-Being Check-List’ was developed to measure internalising and externalising problems, and was administered to caregivers. Findings in the urban (but not rural) sample indicate that orphans separated from siblings showed more emotional disturbance ($p=.05$). In the rural (but not urban) sample, a higher number of adults in the caregiving family was associated with more reported emotional disturbance in the children ($p<.001$).

Volle et al (2002, unpublished conference abstract only) interviewed 788 adolescent orphans, randomly selected from 4 districts in Zambia. They used non-standardised interviews by interviewers and psychosocial support workers. They found that 89% of orphans were ‘always or sometimes unhappy’, and 18.6% had run away from their new homes. Makaya et al (2002, unpublished conference abstract only), in the Democratic Republic of Congo, used interviews with 354 orphans, conducted by clinical psychologists. They found that 20.1% presented ‘psychological troubles’, of those 34% had ‘affective troubles – depression, anxiety, irritability, rivalry feeling’. 27% had ‘adaption troubles – school or home fugue, robbery tendency, offending and hyper kinetic behaviour’. 39% were experiencing post-traumatic stress. Only a conference abstract could be found for this study.

In Rwanda, World Vision interviewed 692 heads of Youth-Headed Households (aged up to 25; 72% aged 19-24), orphaned by a number of causes including HIV/AIDS and war. Various standardised scales were either incorporated into or informed the survey instrument. Initial findings from the Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977) reports that 55% of child household heads scored above the cut-off for depression and 4% reported suicide attempts in the previous 2 months. Females scored higher for both depression ($p<.05$) and suicide attempts. Males reported more externalising behaviours such as delinquency and substance abuse (L. Brown et al., 2005). This survey served as baseline data for an ongoing community intervention, and findings from both further scales and longitudinal data are anticipated.

One study found in Africa was unable to be accessed at this time. Gelman (2003, unpublished thesis, no information available), in Zimbabwe, is mentioned by Germann (2004). However, this reports only the finding that existing psychometric tools developed in the West should not be used in culturally different settings as results cannot be validated. The author of this study has been contacted for further information, but no responses have been received.

Descriptive Studies in the USA:

The New York City Division of AIDS services (Draimin, Hudis, & Segura, 1992; Hudis, 1995), used quantitative standardised instruments (scales not given) with 59 children and caregivers aged 10-19. Half the children were orphaned, half had living, HIV+ parents. There was no non-affected control group. 34% of caregivers reported youth externalising problems, 73% of the youths reported problems in school, and 58% reported a decline in schoolwork linked to parental illness. 38% reported peer relationship problems.

Also in New York, Pivnick and Villegas (2000), interviewed 25 children aged 10-18, all of whom were orphaned or had a parent who was HIV+. Participants were recruited from a mental health and primary health care programme for HIV+ women. There was no control group. They used ethnographic and clinical interviews, and the Beck Depression Inventory (Beck et al., 1961). Findings included heightened anxiety and depression, as well as sleeping, eating and somatisation problems. Children also reported difficulty concentrating at school. No evidence was found of conduct problems or risk behaviours.

Non-quantitative literature

It is helpful to mention some of the wider literature which contributes to understanding of mental health problems for orphaned children. Much of the early work on orphaned children was in the US, and based on clinical experience or case studies (ie Geballe, Gruendal, & Andiman, 1995; Levine & Dane, 1994; Siegal & Gorey, 1994). Other non-quantitative research includes an unpublished psychotherapeutic exploration of orphans' experiences in South Africa (Hough,

2001). Ongoing studies include a qualitative study of experiences of child-headed households in Kwa-Zulu Natal, South Africa (Nkomo & Chiroro, 2007).

Distress Prior to parental death by AIDS

The mental health of AIDS-orphaned children will necessarily be influenced by their experiences during parental illness and prior to parental death. Only two longitudinal studies, both in the US, explore mental health before and after orphanhood. We do not yet have enough evidence to determine the relationship between psychological problems prior to and after orphanhood. Despite this, research on mental health for children with HIV+ or AIDS-unwell parents is useful. Several studies, all in the developed world, have explored effects of maternal disclosure of HIV+ status on children. These have often been from the adult viewpoint, for example qualitative research finding that children tend to be accepting and supportive of HIV+ mothers (Ciambrone, 2002; Tompkins, Henker, Whalen, Axelrod, & Comer, 1999; Winstead et al., 2002), and to take on a caring role, such as reminding mothers to take medication (Marcenko & Samost, 1999). These studies did not measure mental health reactions of children, and therefore it is unknown whether children's support of unwell parents or roles as young carers represents psychological resilience or masks distress. Other studies report children's fears of separation and death following maternal disclosure, and adverse behavioural reactions (Ciambrone, 2002; Winstead et al., 2002). Research using standardised questionnaires to measure child outcomes shows mixed findings. A longitudinal study of disclosure found that mothers reported an increase in child behaviour problems and decrease in mother-child relationship quality from pre to post-disclosure of HIV+ status (Shaffer et al., 2001). In contrast, three studies showed no relationship between maternal disclosure and child outcomes (Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001; Bauman, Camacho, Silver, Hudis, & Draimin, 2002; Forehand et al., 1998).

There is further evidence that, prior to parental death, parental AIDS-illness may have led to compromised parenting (Johnson & Labo, 2001; Kotchick et al., 1997), and that child distress may increase as parents become more symptomatic (Forsyth & Damour, 1996; Pilowsky, Zybert, Hsieh P, Vlahov D, & Susser, 2003; Poulter, 1996). In Uganda, symptomatic mothers were less able to interact positively with infants than asymptomatic mothers (Peterson, Drotar, & Olness, 2001).

Parental depression, connected to HIV-status and AIDS illness, may also reduce capacity for parenting (A. Stein et al., 2005; Wight, 2000). In the US, levels of emotional distress amongst children were strongly related to depression amongst AIDS-unwell parents (Rotheram-Borus, Lightfoot, & Shen, 1999).

2.5 Discussion

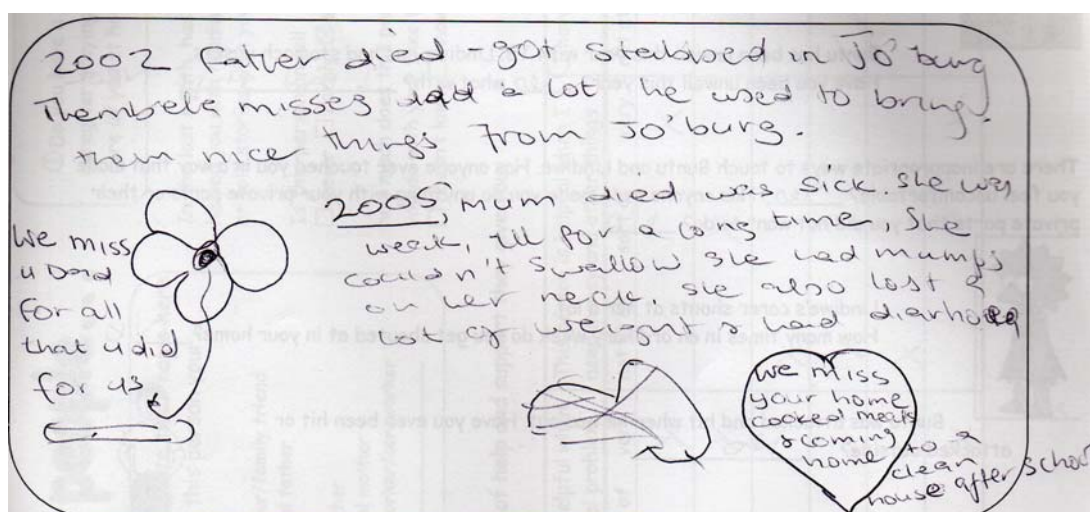


Figure 11: Has anyone close to you died? Could you tell us who they were?' boy, 12, Khayelitsha

Empirical research on the mental health of children orphaned by AIDS remains relatively limited and some unpublished studies are difficult to access. The variability of studies in terms of recruitment, ages of children, choice of control groups and instruments, makes comparison difficult and meta-analysis impossible. Inconsistencies between control groups create particular difficulties in determining effects of AIDS-orphanhood. For example, studies comparing AIDS-orphaned to non-orphaned children (without a control group of children orphaned by non-AIDS causes) do not allow a separation of the effects of AIDS-orphanhood from those of orphanhood more generally. More longitudinal studies or studies with a control group of children living with AIDS-unwell caregivers are also necessary. These can improve understanding of the chronology of distress for children within the process of parental illness and death.

Further methodological discrepancies include the choice of respondent. Children are more likely to under-report externalising problems, and caregivers more likely to under-report children's internalising problems (Angold et al., 1987; Barrett et al., 1991). Agreement across informants of teachers, parents and children has been found to be low for multi-informant scales such as the Child Behaviour Checklist and Child Depression Inventory (Achenbach, McConaughy, & Howell, 1987). Ideally, future studies would compare reports from multiple informants, but this can be exceptionally difficult in research with orphaned children who may have no adult carers (such as those in child-headed households), adult carers who do not know them well, or adult carers who are themselves unwell.

Interviewer characteristics are also important. Clinically-trained interviewers are helpful in allowing diagnosis and in using instruments such as the K-SADS (J. Kaufman, Birmaher, Brent, Rao, & Ryan, 1996). But shortage of qualified practitioners in Sub-Saharan Africa (Swartz, 2002), and the desirability of matching interviewers and participants by cultural group and language, means that lay interviewers are a more realistic option. It is important that these interviewers are adequately trained in working with vulnerable, AIDS-affected children. Reliability can be improved by the checking of a subset of interviews by clinically-trained staff.

There are self-evident problems with the use of standardised scales which have been normed and validated on (almost exclusively) developed country populations (Carter et al., 2005). However, the use of multiple newly-created instruments in studies of orphan well-being, hinders the possibility of comparison across studies, as well as preventing analysis of clinical cut-offs which are constituted by established scales. There is a clear need for scales to be normed on sub-Saharan African populations (Flisher et al., 2006), and it is important that such scales be appropriate for use by non-clinically trained interviewers (Andrew Dawes, Bray, Kvalsvig, & Richter, 2007). Until this has been achieved, I argue that the advantages of using a single set of standardised scales, across studies of orphanhood, would outweigh the methodological difficulties of cross-cultural transferability.

Despite these limitations, a pooled approach to findings does reveal some patterns. Of the twelve controlled studies measuring internalising problems, nine found evidence of heightened difficulties (7 in Africa, 2 in the US). The seven non-controlled studies are much harder to draw conclusions from. However, all non-controlled studies measuring internalising problems found evidence of difficulties (6 in Africa, 1 in the US). Of the six controlled studies measuring externalising behaviours such as conduct disorders, only two found evidence of increased difficulties (1 in Africa, 2 in the US). Of the three non-controlled studies looking at externalising problems, two found evidence of difficulties (1 African, 1 US). The three studies measuring PTSD lacked non-orphan controls for this measure, were Africa-based, and all showed high levels of symptoms amongst orphans.

Implications for future policy and research

The evidence is still too limited for conclusive findings. However, there is increasing evidence of internalising problems amongst orphaned children, and much less evidence for externalising problems, especially in African studies. This review further challenges fears of orphaned children as ‘unsocialised’ ‘juvenile delinquents’ and ‘potential rebels’ (Barnett & Whiteside, 2002; Hunter, 1990), and may have implications for policy concerning orphanhood. The high number of studies finding internalising problems, and low number finding externalising problems, seem to suggest that (particularly in Africa) orphans are more likely to experience difficulties such as depression and anxiety, than conduct disorders or problem behaviours.

A further finding of this review is that children orphaned by AIDS do seem to be experiencing high levels of psychological difficulties. However, the increase in studies in recent years still leaves the field uncertain as to the most appropriate targets for intervention. If future research is to inform interventions and policy for orphaned children, studies must look beyond the prevalence of psychological difficulties, to explore factors in these children’s lives which are acting as stressors or buffers in mental health outcomes. In reviewing studies specifically addressing risk and protective factors in the psychological health of AIDS-orphaned children, only one was found (Wild et al., 2006, July), although some other studies include a helpful range of demographic data

(ie Bhargava, 2005). Evaluations of interventions such as Rotheram-Borus et al. (2004) and Brown et al (L. Brown et al., 2005) can also provide guidance on improving child outcomes.

AIDS-orphaned children do seem to be experiencing psychological distress. But it is important that we know more about whether this is specific to parental death from AIDS, or related to orphanhood by any cause. This will allow a stronger evidence base for policies and provision of aid, which currently fluctuate between focusing on AIDS-bereaved children and wider groups such as ‘orphans and vulnerable children’. It needs clarifying whether these groups have distinct mental health needs or not. Ideally, research will also include larger sample sizes, to allow for distinctions within groups. For example, caregiving arrangements post-bereavement may influence mental health outcomes: life experiences may be very different for children living with grandmothers, non-kin foster parents, in child-headed households or living on the streets. This review shows a clear need for large-scale, controlled studies which use rigorous methodologies to determine psychological effects of AIDS-orphanhood.

2.6 Summary and conclusions

This chapter has reviewed research on the mental health and psychological outcomes of children who are orphaned by AIDS. Worldwide, 23 studies were found, with wide variations in sample characteristics, outcome measurements, and control groups. Three of these studies are ongoing. Internalising problems for orphaned children were found in 15 studies (of the 18 studies which measured them) and externalising problems were found in 4 studies (of 9 which measured them). This review identifies a clear need for further, and rigorous, research into mental health, and risk and protective factors for children orphaned by AIDS. Furthermore, it is critical that research adopts a more coordinated approach, which allows for meaningful comparisons of child outcomes in different areas.

This review provides support for the concept that a single, severe environmental risk factor – in this case that of AIDS-orphanhood – may have a negative effect on child psychological health (Rutter, 2005). A range of studies, using various methodologies and amongst different cultures, provide largely consistent findings of heightened psychological problems associated with AIDS-

orphanhood. The findings of this review may tentatively support a trauma-approach hypothesis (as discussed in Chapter 1) of greater psychological risk arising from some types of death than from others. However, many of the studies reviewed in the current chapter do not fulfil the requirements which Rutter identifies as necessary for determination of environmental effects, and which are discussed in more detail in Chapter 7. These include controlling for socio-demographic factors which may influence outcomes, and the use of standardised tools (Rutter, 2000).

There are many challenges in conducting rigorous research with children orphaned by AIDS. These include practical complications of data collection in poor, sometimes high-crime areas (Robertson, Ensink, Parry, & Chalton, 1999), and methodological difficulties of conducting AIDS-related research in contexts of stigma and secrecy. Few standardised psychological questionnaires have been normed in African countries, and therefore interpretation may be difficult. Ethical challenges include tensions between confidentiality and child protection concerns, and the extent of children's knowledge around causes of parental death. Furthermore, higher HIV/AIDS prevalence amongst the poorest communities, mean that many orphans live in contexts which are already high-risk for psychological problems such as PTSD (Ensink, Robertson, Zissis, & Leger, 1997).

Despite such challenges, there is a growing evidence-base on psychological outcomes for orphaned children. Wild's review of 2001 found 8 studies (6 published and 2 unpublished), of which only 2 were based in Africa, and only one comparing orphaned to non-orphaned controls (Wild, 2001). In 5 years, the number of studies has increased to 24, with an increased focus on sub-Saharan Africa. However, research has lagged far behind the rapid increase in orphan numbers. Whilst the evidence-base is improving, it remains variable, often with small sample sizes and limited or no controls. Bray (2004) noted that,

‘the most striking features of the literature existing on the impact of AIDS on children, are the scarcity of reliable empirical data, and the alarming reliance on a few, localised studies, in supporting arguments on a more general level’.

Studies reviewed show wide discrepancies, particularly in choice of control groups and measurement instruments. Given the clear need for information in this area, I argue that future

research could usefully aim for a more synchronized approach. This would allow for meta-analysis of findings (and thus more reliable conclusions) and would provide a valuable opportunity to compare different cohorts across time, between areas, and in differing socio-economic and cultural settings. A co-ordinated approach would ideally comprise the use of a single set of standardised instruments (allowing for difficulties in cross-cultural use of such tools), and include groups of AIDS-orphaned children, children orphaned by non-AIDS causes, non-orphaned children, and children living with alive but unwell caregivers.

The epidemiology of orphaned children is also changing. Numbers of orphans are continuing to rise; the capacity of caregiving structures are changing in response; and there have been far-reaching developments in (and differing levels of access to) anti-retroviral medication. As the geographical location of the AIDS epidemic changes, research is increasingly needed in areas of emerging epidemics such as China, India and Eastern Europe.

The available evidence does suggest that there are increased risks for psychological problems amongst AIDS-orphaned children. Risk and resilience theory suggests that the environmental risk factor of parental death by AIDS may be mediated by other risk and protective factors. If this is so, it is essential that we also explore the range of risk and protective factors in their lives which are mediating those mental health difficulties. Very few of the studies above explore risk factors beyond basic socio-demographic factors (although some do measure factors such as sibling separation and quality of care). Chapter 3 focuses on these risk and protective factors. It reviews any measurement of socio-demographic or risk factors which take place in the studies of AIDS-orphanhood. Chapter 3 goes further also to explore evidence of risk and protective factors in more general child mental health research, and amongst other vulnerable groups of children.

Table 5: Psychological research with AIDS-orphaned children: a brief summary of controlled studies

Country, date	Authors	Sample Characteristics	Control groups	Respondent	Standardised Instruments?	Brief findings
Zambia (1996)	Poulter et al	22 households with orphans, 66 with HIV+ parents, 75 community controls	1) Children with HIV+ parents 2) Community controls	Caregivers	Standardised	Orphans more unhappy and worried than other groups. No evidence of conduct problems
Uganda (1997)	Sengendo & Nambi	169 AIDS-orphaned children 24 non-orphans	Non-orphans	Children Teachers Some guardians	Unstandardised	Orphans had higher depression and lower optimism
Tanzania (2002)	Makame et al	41 AIDS-orphaned children with 41 non-orphans	Non-orphans	Children	Unstandardised	Orphans showed higher internalising problems
Mozambique (2002)	Manuel et al	76 AIDS-orphaned children 74 non-orphans	Non-orphans	Children	Unstandardised	Orphans showed higher depression scores and less likely to have trusted adult or friend
Uganda (2005)	Atwine et al	123 AIDS-orphaned children 110 non-orphans	Non-orphans	Children	Standardised	Orphans more anxious, depressed, more anger, hopelessness and suicidal ideation
Rwanda and Zambia (2005)	Chatterji et al	1160 AIDS-orphaned children, children with sick caregivers & non-affected children	1) Children with sick caregivers 2) non-affected children	Children	Unstandardised	Rwanda: orphans showed higher worry/stress than other groups. Zambia: orphans & children with ill caregivers showed higher worry/stress than non-affected children
Ethiopia (2005)	Bhargava	479 AIDS-orphaned children 574 orphans by non-	Children orphaned by non-AIDS causes	Children	Standardised	AIDS-orphaned children showed more social and emotional adjustment problems

South Africa (2006)	Cluver & Gardner	AIDS causes 30 AIDS-orphaned children, 30 non-orphans	Non-orphans	Children	Standardised	No subscale differences. Orphans less likely to have good friends, high levels of PTSD
Zimbabwe (2006)	Nyamukapa et al	5,321 children in total	Non-orphans	Children	Unstandardised	Orphans showed more psychosocial disorders and more severe symptoms
Zimbabwe (2006)	Gilborn et al	1,258 OVC, 65% orphans (cause of death not given)	Non-orphaned 'OVC'	Children	Unstandardised	Orphans showed higher daily stress and psychosocial distress on 6 items of depression, and lower psychosocial well- being on 2 items (single item analysis)
South Africa (conference paper)	Wild, Flisher, Laas and Robertson	81 AIDS-orphaned children, 78 orphaned by non-AIDS causes, 43 non-orphans	1) Non-orphans 2) Children orphaned by non- AIDS causes	Children	Standardised	Children orphaned by other causes showed more depression and anxiety than non-orphans, with AIDS-orphaned children not differing from either. No differences on externalising problems
Kenya (ongoing) Uganda (ongoing)	Elmore- Meegan et al Lamphear and Jones	Planned 400 children 137 AIDS-orphaned children, 98 children orphaned by non-AIDS causes, 99 non-orphans	Non-orphans 1) Non-orphans 2) orphans by non-AIDS causes	Children and caregivers Children	Unstandardised Standardised	Data collection in progress Data in analysis
USA - New Orleans (1999, 2005)	Forehand, Pelton et al Longitudinal study	20 AIDS-orphaned children, compared to children with HIV+ mothers and non- orphaned community controls	1) children with HIV+ mothers 2) non-orphaned children with, HIV- mothers	Children and caregivers	Standardised	Children of HIV+ mothers showed more internalising and externalising problems than community controls 6 months post-orphanhood, non- significant improvements. 2 years post-orphanhood, orphans had

USA	Hirsch	16 AIDS-orphaned children, 12 children orphaned by non-AIDS causes	Children orphaned by non-AIDS causes	Children	Standardised	more internalising and externalising problems than both control groups
(2001)						
USA - New York	Rotheram-Borus et al	73 AIDS-orphaned children, 138 children with HIV+ parents	Children with HIV+ parents	Children	Standardised	Children orphaned by non-AIDS causes showed higher depression, anxiety and conduct problems than AIDS-orphaned children.
(2001,2004)	longitudinal study					AIDS-orphaned children showed more emotional distress and more problem behaviours than children with alive, HIV+ parents

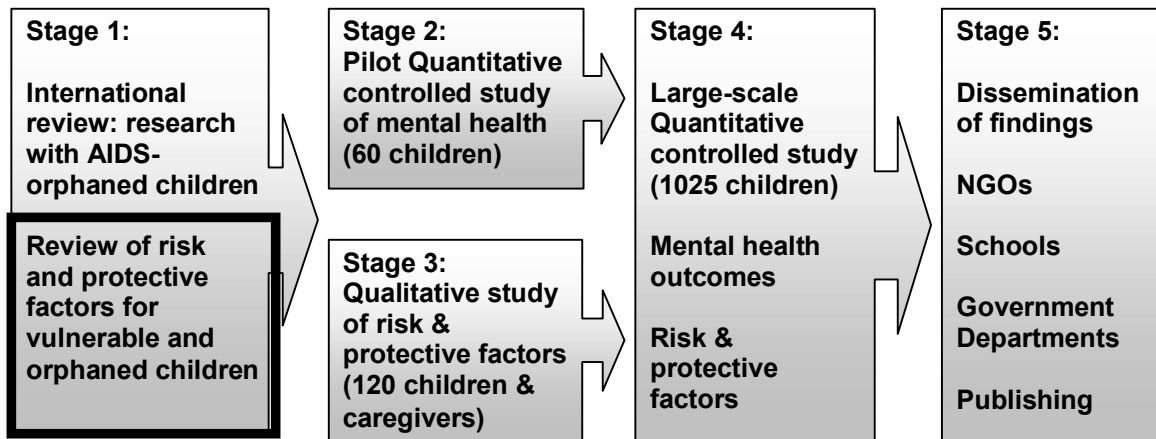
Chapter 3: Literature Review 2: Potential Risk and Protective Factors

- 3.1 Introduction
- 3.2 Search strategy
- 3.3 Overview of types of literature reviewed
- 3.4 Results of the review:
 - Individual/child factors
 - Demographic factors
 - Physical health
 - Caregiver/Family network factors
 - Bereavement factors
 - Parental characteristics
 - Economic factors
 - School attendance factors
 - Housework and Employment
 - Household factors
 - Placement of children
 - Caregiving factors
 - Abuse and domestic violence
 - Community-level factors
 - Community traumas
 - AIDS-related stigma
 - Positive activities and other community factors
 - Social support
- 3.5 Summary and conclusions



Figure 12: Informal settlement, Philippi

3.1 Introduction



Chapter 2 presented a review of studies which tested associations between AIDS-orphanhood and psychological distress. It concluded that there was evidence of heightened risk of mental health problems amongst AIDS-orphaned children. However, the available evidence was scattered, and often of poor methodological quality.

The present chapter addresses the second part of Stage 1 of this research. It details the methodology and findings of a review of risk and protective factors for vulnerable and orphaned children. It aims to inform the second question of the study: ‘What risk and protective factors are mediating any differences in mental health problems experienced by different groups of children?’

A social science study is only able to test a limited number of factors in a child’s life. It is important that the choice of factors to be tested is based on a sound theoretical framework (here the ecological framework presented in Chapter 1 is used), supported by evidence, and (in the case of this study) also includes factors identified in qualitative research with this particular sample group.

As discussed in Chapter 2, there are few studies which focus specifically on psychological outcomes of AIDS-orphanhood. The studies that exist are of variable methodological quality and very few test risk and protective factors beyond basic demographic variables such as age and gender.

Chapter 3 aims to review research on risk and protective factors which may influence the mental health of children in the current study. In light of the lack of direct evidence regarding risk and protective factors for AIDS-orphaned children, Chapter 3's review focuses on five types of research.

Firstly, it reviews the quantitative evidence, exploring associations of risk and protective factors in the mental health of AIDS-orphaned children. Secondly, it reviews studies of risk and protective factors amongst children in general. Thirdly, it reviews studies on groups of children who may share some similar life experiences to those of AIDS-orphaned children (such as refugee children and children bereaved by non-AIDS causes). Fourthly, non-psychological research is reviewed on children affected and orphaned by AIDS, and on vulnerable children in South Africa, in order to determine which of the factors identified in more general research are relevant to our study groups. Fifthly, the review looks at research which may not be particular to AIDS-orphaned or orphaned children, but which explores mental health risks for children in South Africa and in Cape Town, with its distinct social and cultural context.

The review focuses on environmental factors which may be mediating the relationship between orphanhood status and child mental health (Rutter, 2000). It follows the theoretical model of risk and resilience which was described in Chapter 1, and explores both risk factors and protective factors (Werner, 2000). Factors which are included are broadly approached within Bronfenbrenner's ecological framework (Bronfenbrenner, 1979), and the adapted framework presented by Richter, Foster and Sherr (2006), but may also bridge distinctions between ecological levels. For example, AIDS-related stigma may be experienced by children at one or more of micro-system, meso-system and macro-system levels (or one or more of caregiver, family and community levels). But the utility of an ecological framework for this review lies in its identification of the existence of risk/protective factors in multiple areas of children's lives, and the potential for those factors to mediate distress caused by a trauma in another part of children's lives (Rutter, 1985).

It is recognized that personal resilience factors have been shown to be important in determining child mental health (Masten, 2001; Masten & Coatsworth, 1998). However, this present review explicitly seeks to elucidate social, family, community and economic conditions which increase or diminish the likelihood of children developing mental health problems.

This review was aimed at providing an evidence-based list of potential risk and protective factors, to be tested in the quantitative survey stage of the research project. The study focuses primarily on those factors which can be enhanced or reduced by public policy and interventions (Garmezy, 1983). It also focuses on factors which may provide information for targeting of services, such as age, gender and community-level factors. For this reason, this review is not an exhaustive or systematic review of risk and protective factors in child mental health.

A number of factors are not included in the review. For example, the important influence of genetic factors on child mental health is recognized (O'Connor, 2002; Rutter, 2000), and there is strong evidence of the interaction of genetic factors with environmental risk factors (Heim & Nemeroff, 2001; Rutter, Moffitt, & Caspi, 2006). However, in the context of this study genetic factors are neither measurable nor currently relevant to policy, and are therefore excluded. Further factors are excluded due to impossibility of measurement for the orphaned sample: for example early parent-child attachment (C. Graham & Easterbrooks, 2000; Rutter, 1989). Instead, this chapter focuses on factors which are specific, measurable, relevant to the current study, and have practical policy implications.

3.2 Search strategy

As in the previous review (see Chapter 2), this review draws on both published and unpublished studies. However, it does concentrate on primary research with children, or

literature which uses primary evidence, rather than non-scientific reports of child hardship (which are common in the literature on AIDS-orphaned children). Keyword searches were made of: *Electronic databases*: PsycINFO, Medline, and the Index to South African Periodicals (ISAP), BMJ, TDNet, Zetoc, Cambridge Scientific Abstracts, Web of Science. *Specific AIDS-related databases*: Avert, UNICEF, UNAIDS, World Health Organisation, Association Xavier-Francois Bagnoud, the Centre for Social Science Research (University of Cape Town), *Government Publications*: Department of Health (South Africa), Department of Social Development (South Africa) *South African literature*: Human Sciences Research Council (South Africa), *University working papers*: University of Cape Town, University of the Witwatersrand, University of Pretoria, University of the Western Cape, University of Kwa-Zulu Natal, The Children's Institute *Journals*: JAIDS, AIDS, AIDS Care, Vulnerable Children and Youth Studies, AIDS Bulletin, ChildrenFirst, the Journal of Child and Adolescent Mental Health. *Conference proceedings*: South African AIDS conferences (2000-2005), AIDS Impact Conferences (2005, 2003), International AIDS Conferences. *Thesis searches*: SABINET (1995-2005), SilverPlatter, Dissertation Abstracts International. *Search engines*: Google, Google Scholar, findarticles.com. *Ongoing and unpublished research*: In order to access ongoing research in the study area, relevant seminars were attended at the University of Cape Town, Stellenbosch University, the Red Cross Children's Hospital and the Human Sciences Research Council.

3.3 Overview of types of literature reviewed

At the time of reviewing (2005, updated in 2007), only one (ongoing) study specifically explored risk and protective factors for mental health outcomes of AIDS-orphaned children (Wild et al., 2006, July), and I was able to see initial analyses in 2005. Further studies of mental health amongst AIDS-orphaned children have looked at associations between mental health and various socio-demographic factors (such as caregiver monitoring, socio-economic status) (i.e Atwine et al., 2005; Nampanya-Serpell, 2001), and these findings have been included in the review. All risk and protective factors measured in studies of mental health of AIDS-orphaned children have been summarised

in Table 1. In light of the limited available literature on risk and protective factors amongst the study group, this review also aimed to include a range of literature which may reflect the experiences of AIDS-orphaned, other-orphaned and non-orphaned isiXhosa-speaking children in Cape Town.

Quantitative and qualitative studies of risk and protective factors

This review explored (largely quantitative) literature on risk and protective factors in general child mental health. This included more complex studies of cumulative risk (Appleyard et al., 2004; Atzaba-Poria et al., 2004) and intra-familial responses to risk factors (O'Connor, Dunn, Jenkins, Pickering, & Rasbash, 2001).

Further literature investigated risk and protective factors amongst groups of children who may share some similar life experiences to orphaned children. For example, refugee children and AIDS-orphaned children may both experience multiple moves and migration, which have been found to be a risk factor for depression (Tousignant et al., 1999). Research on young carers in the developed world (Dearden & Becker, 2004) and developing world (Robson, 2000) may reflect some of the experiences of children caring for AIDS-unwell family members. International studies exploring outcomes of children in state care are helpful, although these may be very specific to differing state systems. For example, Eastern-European state orphanages differ markedly from British Local Authority care (Meltzer, Corbin, Gatward, Goodman, & Ford, 2003). Research with children in long-term foster care was reviewed (i.e Minty, 1999), but this is largely based in the developed world, where kin-foster care is less common than that developed in response to the AIDS epidemic in South Africa. Available research on homeless children and streetchildren was also reviewed.

Some more general research on parental bereavement explores risk and protective factors (Stoppelbein, 2000), as does literature on sibling bereavement (which is experienced by some AIDS-orphaned children through peri-natal infection of younger siblings). Specific studies of traumatic parental bereavement (i.e Black & Harris-Hendricks, 1992) were

used to examine impacts of different types of parental death. Post-traumatic stress literature was reviewed in detail, and included studies of children who have experienced trauma through war or disasters (Yule, 1992).

Research on children orphaned and affected by AIDS

This study aimed to test risk and protective factors which are relevant to orphaned children in South Africa. Firstly, reviewing identified potential risk and protective factors. Secondly, reviewing identified which of those factors were shown to be applicable to our study group. Studies were reviewed which do not focus on mental health, but which explore other aspects of well-being amongst affected and orphaned children. These include participatory focus-group research (ACCESS, 2002; Giese, Meintjies, & Proudlock, 2001) and qualitative studies (i.e Strode & Barrett Grant, 2001). Quantitative research included studies of factors in orphan circumstances such as education, immunisation, caregiving and physical health. Reports such as ‘Children on the Brink’ (UNAIDS, 2004; UNAIDS & UNICEF, 2002) and other international reports provide useful overviews, although these often make broad statements based on single studies or case studies. Specifically, research on AIDS-orphaned and other-orphaned children in Sub-Saharan Africa was included (i.e Foster et al., 1997), and research (both published and unpublished) from South Africa.

In South Africa, survey data also provided useful information on orphan well-being, often with large sample sizes. This included data from demographic surveillance areas of the Africa Centre and Agincourt (Case & Ardington, 2005), surveys focused on affected families (Vermaak, Mavimbela, Chege, & Esu-Williams, 2004) and nationally-representative surveys such as the National Youth HIV and Sexual Behaviour Study (Operario, Pettifor, Cluver, MacPhail, & Rees, 2007; A. Pettifor et al., 2003).

Research on children with HIV+ parents

Reviewing additionally explored research on children (both HIV-infected and uninfected) living with HIV+ or AIDS-unwell parents (Kotchick et al., 1997; Shaffer et al., 2001), and relationships between HIV+ parents (almost exclusively mothers) and their infants. This body of research has important implications for understanding risk and protective factors for orphaned children. There is a great need for future longitudinal studies to distinguish risk factors experienced by children during parental illness, from those experienced after parental death.

Research on children in South Africa and in Cape Town

Many risk and protective factors in the lives of orphaned children are unrelated to AIDS or to orphanhood. Literature review included research on general well-being of children in South Africa (Berry & Guthrie, 2003), of children living in poverty in South Africa (Noble, Wright, & Cluver, 2006), and of factors which are particularly relevant to South Africa, such as sexual abuse (A Dawes, 2002). Finally, factors specific to children's lives in Cape Town included research on community violence in townships (Zissis, Ensink, & Robertson, 2000) and cultural aspects particular to childhood in amaXhosa society (A Dawes & Donald, 1994).

3.4 Results of the review

Individual/child factors

Demographic Factors

There are eighteen completed studies on the mental health of AIDS-orphaned children (by 2006). Many of these have explored associations between mental health outcomes and basic demographic factors such as age and gender. Older children reported more internalising problems in a Zimbabwean study (Gilborn et al., 2006), and lower self-esteem in South Africa (Wild et al., 2006, July). However, age was not associated with

child outcomes in four other studies (Atwine et al., 2005; Makame et al., 2002; Nampanya-Serpell, 1998; Nyamukapa et al., 2006).

Findings on the influence of gender are more mixed: three studies of AIDS-orphaned children (all in Africa) found no associations between gender and psychological problems (Atwine et al., 2005; Makame et al., 2002; Nampanya-Serpell, 1998). In contrast, five African studies found higher levels of distress amongst female orphans (Bhargava, 2005; Boris, Thurman, Snider, Spencer, & Brown, 2006; Gilborn et al., 2006; Nyamukapa et al., 2006; Wild et al., 2006, July).

In wider child mental health research, a range of socio-demographic factors have been shown to influence outcomes. These include gender, where studies show higher levels of internalising problems amongst bereaved girls and of externalising problems amongst bereaved boys (Dowdney et al., 1999a; Kranzler, Shaffer, Wasserman, & Davies, 1990). Amongst refugee children, gender does not emerge consistently as either a risk or protective factor, and it is suggested that gender influences may be culturally dependent (Lustig et al., 2003).

Psychological problems have been shown to increase with children's age, and older children may show differing problems to those of younger children. Ethnicity or cultural factors may also be important: for example, Stansfield (2004) found that Bengali ethnicity in the UK seemed to act as a protective factor for children, independently of socio-economic status. However, the current study focused almost exclusively on Black African children, of whom the vast majority (97%) were amaXhosa, and so ethnic differences could not be tested.

Physical Health factors

There is widespread evidence of the negative impact of poor physical health on children's mental health. For example, chronic childhood illness has been found to double the risk of psychiatric problems in Canada (Cadman, Boyle, Szatmari, & Offord, 1987). Physical problems such as iron deficiency anaemia (common in South Africa) have been shown to

raise risks of depression (Dallman, 1987). There are also mental health risks associated with potential HIV-infection amongst children in the sample group (please see Chapter 5 for a detailed discussion of this possibility) (Gosling, Burns, & Hirst, 2004; Mellins et al., 2007; Melvin, Krechevsky, & Divac, 2005; Nozyce, Lee, & Wiznia, 2006). Only one study of mental health amongst AIDS-orphaned children examined associations between physical and mental health, and found none (Atwine et al., 2005).

The present thesis was community-based, and lacked financial resources to allow medical examination of children. In the South African context, there is limited access to healthcare amongst the poor (Ijumba & Padarath, 2006; Wilkinson, Gouws, Sach, & Karim, 2001), as well as regular use of traditional healers (Ensink & Robertson, 1996). This means that clinic cards or clinical records are unreliable sources of evidence regarding physical health. Thus, without research conducting a medical examination, measures of physical health are largely reliant on child report, which may be confused by method overlap between self-perceived physical health and somatising symptoms of distress (Kleinman & Good, 1985). Crossover between somatic symptoms of psychological distress and symptoms of illness is a contested area (De Gugth & Fischler, 2002; Kirmayer, Robbins, Dworkind, & Yaffe, 1993). Evidence for the prevalence of somatisation of psychiatric symptoms amongst Black Africans is widespread but disputed (MacGregor, 2004; Okulate, Olayinka, & Jones, 2004; Swartz, 2002). A recent anthropological study with adults in Khayelitsha, found evidence of a range of manifestations of mental illness, including somatic symptoms such as whole body ache, waist-ache and painful neck veins (MacGregor, 2004). In our pilot study (Cluver & Gardner, 2006), orphaned children were significantly more likely to report frequent stomach aches, headaches and sickness (40%) than non-orphans (17% $p=.05$). Qualitative and anecdotal research with AIDS-orphaned children suggests somatic symptoms such as bedwetting, non-organic pain and interrupted sleep (ACCESS, 2002; Cluver & Gardner, 2007b; Foster et al., 1997).

Thus there seems to be potential for confusion and coexistence of poor physical health and somatic symptoms of distress. Without objective medical examination and access to

reliable medical records, assessment of physical health is likely to be inadequate. However, in light of the importance of physical health as a factor in mental health outcomes, this study did attempt to measure illness and physical health outcomes. Chapter 7 outlines the difficulties in interpreting findings of somatising factors.

Caregiver/Family network factors

Bereavement Factors

Parental Bereavement

There is mixed evidence, largely based in the developed world, of parental bereavement as a risk factor for psychological problems in children. A review (Dowdney, 2000) concludes that there is evidence of poorer outcomes, but that these seem to be mediated by a number of environmental and personal factors. For example, attendees at child psychiatric clinics showed a higher incidence of parental bereavement than controls (Rutter, 1966) as did retrospective studies of clinical samples of adults (G. Brown, Harris, & Copeland, 1977). However many study findings are drawn into question by methodological inadequacies, particularly lack of control for mediating variables.

Controlled studies with community samples show higher rates of depression and dysphoria amongst parentally bereaved children (Van Eederwegh, Bieri, Parrilla, & Clayton, 1982; Van Eederwegh, Clayton, & Van Eerdewegh, 1985). However, lack of demographically matched control groups in many studies mean that the comparative prevalence of depression amongst bereaved children remains unclear. Weller et al report high levels of suicidal ideation (Weller et al., 1991), with no actual suicide attempts amongst the 23 children who expressed suicidal ideation. This study concluded that bereaved children were less likely than clinically depressed children to actually attempt suicide. There is little other evidence of increased suicide attempts amongst parentally bereaved children, although some studies indicate high levels of suicidal ideation amongst children of parents or siblings who have themselves committed suicide (Pfeffer

et al., 1997). This may be confused by the higher likelihood of prior psychiatric morbidity amongst suicide victims and their immediate families (Brent, Bridge, Johnson, & Connolly, 1996; Dowdney, 2000).

There is little evidence for associations between parental bereavement and anxiety or somatising disorders, or of behavioural problems (Dowdney, 2000). However, studies using standardised questionnaires and children bereaved by a variety of causes, show bereaved children as presenting higher levels of overall child disturbance than non-bereaved controls (Dowdney et al., 1999a; Kranzler et al., 1990).

Time since orphanhood and age at orphanhood

Children's grief reactions (like adults') do seem to reduce over the first year post-bereavement (Silverman & Worden, 1992; Van Eederwegh et al., 1982). However, where mental health problems are shown, they can be more persistent (Dowdney et al., 1999b).

The impact of orphanhood at different developmental stages in the child's life may be an important factor in outcomes, and reflect developing understandings of the meaning of death (Christ, 2000; Siegal & Gorey, 1994). Very young age at trauma was found to be protective amongst refugee children (Sourander, 1998) and children exposed to war (Barenbaum et al., 2004). Other studies have found similar levels of disturbance in bereavement, but manifested in age-appropriate ways, such as increased levels of separation anxiety and bedwetting amongst younger children (Van Eederwegh et al., 1982). Barenbaum also found that adolescents were more able to cope with war-related trauma than 5-9 year olds. Exploring the effects of major trauma on young women, Maercker et al found that pre-adolescent exposure to trauma heightened risk of depression, whilst trauma during adolescence heightened risk of post-traumatic stress (Maercker et al., 2004). For the current study, the existence of double orphans within the sample raises questions about *which* parental death to measure the date of trauma exposure from.

Maternal or paternal death

Several studies of mental health amongst AIDS-orphaned children have found no differences in outcomes between maternal and paternal bereavement (Atwine et al., 2005; Nampanya-Serpell, 2001). However, the evidence-base for this finding is limited by the concentration in much of the literature on maternal orphans (i.e. Forehand et al., 1998; Manuel, 2002). There is little evidence in the developed world bereavement literature to suggest differential mental health outcomes according to maternal or paternal death, although some longitudinal studies suggest particularly negative impacts of maternal bereavement on girls (Black, 1978). However, non-psychological research with orphaned children in sub-Saharan Africa does suggest that maternal death may have greater effects on child outcomes than paternal death, particularly regarding educational outcomes (Case & Ardington, 2005). In South Africa, single female-headed households are common, and only 32% of children lived with both parents in 1998 (Department of Health, 1998). This may suggest that maternal death is more pertinent to children's lives. However, paternal death has been shown to have particular and serious financial implications, which can affect orphan outcomes (Giese et al., 2003). Emotional impacts of the death of either parent will depend on quality of family relationships prior to bereavement. It may be that maternal and paternal death have similar impacts, but through differing causal mechanisms.

Violent parental death

Effects of violent parental death are important because of the second control group in this study: children orphaned by non-AIDS causes. Many of these parental deaths were due to homicide. There is limited research on child outcomes after violent parental death, and existing studies largely focus on death by murder, war or suicide. One study suggests high rates of post-traumatic stress amongst children where one parent has killed the other (Black & Harris-Hendricks, 1992), but this finding may reflect a number of stressors in

families where this has occurred. Parental suicide may also lead to high rates of PTSD, which may be co-morbid with depression (Pfeffer et al., 1997).

A study of Israeli kibbutz children, whose fathers had died in war, found severe disturbance amongst 45% of children over the age of two (Elizur & Kaffman, 1983; Kaffman & Elizur, 1979). However, this study did not distinguish the effects of parental death from the impact of war. Interestingly, a study of martyrs' children in Iran found that despite the violent and sudden death of fathers, children showed improved well-being compared to community controls (Kalantari, Yule, & Gardner, 1993). This may have been attributable to high levels of state financial support and community support for families of martyrs, suggesting the importance of environmental factors in mediating post-bereavement outcomes.

Death by HIV/AIDS

At the time of reviewing (2005, updated in 2007), only one study of AIDS-orphaned children allowed isolation of AIDS-related death from other deaths (Wild et al., 2006, July). In this study, children orphaned by other causes showed more depression and anxiety than non-orphans, with AIDS-orphaned children not differing from either group. There were no differences on externalising problems. However, the authors of the study questioned the findings, suggesting that they may have resulted from sampling of AIDS-orphaned children exclusively from support services, and thus reflect an unrepresentative group (Wild, 2007, personal communication)

Due to the lack of evidence regarding AIDS-orphaned children, the potential risks of AIDS-related loss were explored amongst other groups of people who experience bereavements by AIDS. UK-based research with HIV+ children suggests that AIDS-related death of parents was associated with psychological trauma (Gosling et al., 2004; Melvin et al., 2005). Research with HIV+ men, also in the UK, found high levels of distress related to multiple AIDS-related deaths of friends and partners (Sherr et al., 1992). Qualitative studies with HIV+ women have reported distress related to AIDS-

related deaths of family members (Goggin et al., 2001; Semple et al., 1993; Sherr et al., 1997). However, it is notable that almost all the above studies focus on bereavement responses amongst HIV+ people. It is possible that for this group in particular, AIDS-related deaths of family and friends may be additionally stressful as a reminder of personal illness and death.

Where younger siblings have been peri-natally infected, sibling bereavement may be an additional loss for orphaned children. Studies of sibling bereavement (with non-AIDS affected groups) show associations with increased rates of depression amongst surviving siblings (Holliday, 2002). Only one study of mental health of AIDS-orphaned children examines multiple versus single bereavement, and found no associations with psychological outcomes (Atwine et al., 2005).

Parental characteristics

A number of potential risk and protective factors are related to characteristics of the deceased parent or of the surviving parent. These include mental health problems experienced by the deceased parent prior to death (Van Eederwegh et al., 1982). There is extensive evidence of (in particular) maternal depression and anxiety as risk factors for psychological problems in children (Bifulco et al., 2002; C. Graham & Easterbrooks, 2000; Spence, Najman, Bor, O'Callaghan, & Williams, 2002). This may be highly relevant to children orphaned by AIDS: evidence shows increased risk of depression, anxiety and other disorders amongst HIV+ parents (Brandt, 2007; Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002; Rotheram-Borus et al., 1999), as well as AIDS-related neuropsychiatric disorders such as psychosis. For mothers in particular, HIV diagnosis often occurs at pregnancy, and has been shown to be associated with depression (Rochat et al., 2006). However, the retrospective study design precluded any measurement of parental characteristics, and retrospective recall of children on parental mental health was judged to be too unreliable to measure.

Grief reactions and mental health problems amongst the surviving parent have also been shown to correlate highly with child depression, anxiety and PTSD (Pfeffer et al., 1997).

Many orphans in South Africa have no surviving parent, or no parent acting as caregiver. There is also evidence of heightened distress amongst non-parent caregivers of orphaned children, who are often grandparents grieving the loss of their adult child (Ferreira et al., 2001; Manuel, 2002). Two studies have compared levels of depression in caregivers and AIDS-orphaned children. In Mozambique, self-reported child depression was correlated with caregiver depression (Manuel, 2002). In Rwanda, self-reported caregiver depression amongst youth heads of households was correlated with emotional problems amongst young children in their care, although this was measured by caregiver report and may therefore have been affected by the mental health state of the youth caregivers who reported it (Boris et al., 2006). However, the same difficulties which prevented the use of caregiver report in this study (i.e lack of surviving parent for double orphans, lack of any adult caregiver for child-headed households and streetchildren, surviving caregivers who are often AIDS-unwell) precluded consistent measurement of these factors in the current study.

Economic Factors

Economic factors have effects and causes at multiple levels of the ecological framework: family, community and services. At exosystem and macrosystem levels, structural unemployment and apartheid legacy contribute to the poverty experienced by orphaned children in Cape Town. However, in the context of the AIDS epidemic, evidence suggests that the effects of such structural poverty may be experienced at a heightened level in AIDS-affected families.

Studies of mental health amongst AIDS-orphaned children provide mixed evidence of associations with poverty. In Zambia and Uganda, no associations were found between psychological outcomes and economic stress (Atwine et al., 2005; Poulter, 1996). However, studies in Rwanda, Zimbabwe, Tanzania and Ethiopia all found evidence of increased psychological problems for AIDS-orphaned children living in poorer households (Chatterji et al., 2005; Nyamukapa et al., 2006) and experiencing hunger or material deprivation (Bhargava, 2005; Makame et al., 2002). In the developed world, general child bereavement literature provides some evidence of associations between

poverty which occurs after parental death, and poor child mental health (Stoppelbein, 2000).

More general child-focused research also provides mixed evidence regarding the relationship of mental health outcomes to socio-economic status (SES). Some studies suggest more behaviour problems amongst lower SES groups, and some suggest more anxiety or depression amongst middle-class children. Community-based studies in the developed world have found correlations between low SES (including parental unemployment) and internalising problems (C. Graham & Easterbrooks, 2000; Sund, Larsson, & Wichstrom, 2003), as have studies of children in high-risk families (Radke-Yarrow & Brown, 1993). A more nuanced finding is shown in some developed world research, showing that poverty alone does not seem to be a risk factor for psychopathology (Rutter, Giller, & Hagell, 1998), but that it does have impacts on other mediating factors, such as family functioning and good parenting.

However, much of AIDS orphanhood in South Africa occurs within already low income groups (Booyesen & Bachman, 2002), exacerbated by high unemployment and remaining post-apartheid economic disparities. This means that ‘economic factors’ in this sample group refer to the difference between already-high poverty levels in the community and extreme, or absolute, poverty (Noble et al., 2006). It may be that the extreme nature of poverty is distressing in ways that are not captured in developed world literature.

There is strong evidence of increased poverty amongst AIDS-affected families in South Africa (Vermaak et al., 2004), and heightened poverty amongst households caring for orphans (Case, Paxson, & Ableidinger, 2002). Qualitative research with AIDS-affected families shows perceptions of distress related to a range of poverty-related factors. These include food insecurity (Leclerc-Madlala, 2006), lack of money for education (Bauman et al., 2006) and feelings of social exclusion (ACCESS, 2002; Cluver & Gardner, 2007b).

School attendance factors



Figure 13: Imbasa Primary School, Old Crossroads

In the developed world, school non-attendance is largely related to either school refusal or truancy (Lauchlan, 2003). The latter has been linked to conduct problems, and the former to separation anxiety or victimization by bullying (Osler, Street, Lall, & Vincent, 2001). Other reasons include pregnancy (Pellegrini, 2007) and illness. Amongst orphaned children in South Africa, studies have found the primary cause of non-attendance to be inability to afford school fees, books and uniforms (Oni, Obi, Okorie, Thabede, & Jordan, 2002; Porteus et al., 2000), and school non-attendance is thus closely correlated with poverty (Edmonds, 2006; Nelson Mandela Foundation & Human Sciences Research Council, 2005; Reddy, 2005). Thus in the context of this review, school non-attendance is grouped under ‘family-level’ factors.

Orphaned children may experience lowered likelihood of attending school, due to the impact of HIV/AIDS on ‘decreasing and redirecting family incomes’ (Williamson, 1995). Data from ten African countries found that orphans were less likely to attend school than non-orphans, and that this was dependent largely on the distance of biological relationship between orphans and current caregivers (Case et al., 2002). Further South African evidence suggests that orphaned children may be discriminated against within families, regarding allocation of resources for education. In Kwa-Zulu Natal, maternal orphans had lower school enrolment than non-orphans, even when controlling for household income (Case & Ardington, 2005). Studies further suggest that girls are more

likely to be removed from school than boys (M. Steinberg, S. Johnson, G. Schierhout, & D. Ndegwa, 2002), and that older children are more likely to leave school due to necessity to support the household (Booyesen & Arntz, 2002). However, a review of data from 28 countries found considerable between-country diversity on rates of orphan compared to non-orphan enrolment (Ainsworth & Filmer, 2002).

Only two studies explore associations between mental health outcomes amongst AIDS-orphaned children and school attendance. In Uganda, no associations were found (Atwine et al., 2005), whereas in Tanzania, internalising problems were associated with both non-attendance of school, and poor educational achievement (Makame et al., 2002).

More general child mental health research finds school achievement to be a protective factor (Buchanan, Flouri, & Ten Brinke, 2002; Masten et al., 1999), and school is the context for access to a range of other potential protective factors, such as peer and teacher support, opportunities for achievement, and what Rutter describes as ‘positive pathways’ (Rutter, 1989). Research in the developed world shows school ‘dropout’ associated with more psychological problems (Kandel, Ravies, & Kandel, 1984; Rumberger, 1987). Problems associated with non-attendance include both behaviour problems and mood disorders (Berg et al., 1993). However, as discussed above, this may be linked to the very different reasons for school non-attendance in the developed world.

Very little evidence is available concerning the mental health of children in the developing world who are not enrolled in school. A study comparing school-attending and non school-attending children in Khayelitsha, found no differences in mental health, but concluded that the main reason for non-attendance was poverty (Liang, Flisher, & Chalton, 2002). A study in a high-violence area of Cape Town found that school support was associated with lower levels of depression and conduct problems amongst 11-16 year olds (Ward, Martin, Theron, & Distiller, 2007).

Housework and employment

Mental health effects of child employment and child housework are more contested areas in the South African context (Lachman, 1996). Most children in South Africa engage in domestic work (Statistics SA, 2001). When undertaken in moderation, this has been found to be non-harmful and even beneficial in terms of social responsibility and inclusion (Bray, 2003b; Cigno, Guarcello, Lyon, Noguchi, & Rosati, 2003; Clacherty & Budlender, 2003). Part-time employment during adolescence has been found to be protective in the developed world (Finch, Shanahan, Mortimer, & Ryu, 1991).

It is clear that some children in South Africa are working under conditions or for hours which are detrimental to their well-being (Budlender & Bosch, 2002), and that this can negatively impact on factors such as education (Dachi & Garrett, 2003). The Children's Act (Section 1.1) defines 'child labour' as work which 'places at risk the child's well-being, education, physical or mental health, or spiritual, moral, emotional or social development' (Republic of South Africa, 2005). It is not clear whether AIDS-orphaned children are engaging in more domestic or paid work than other children.

Excessive work or domestic labour have been identified as highly distressing in qualitative research with orphaned and AIDS-affected children (Giese et al., 2003). In Uganda, a study of AIDS-orphaned children found that anger scores were higher amongst orphans who performed household chores 'sometimes/always' rather than 'seldom/never' (although this is difficult to interpret due to lack of clarity in measurement on a single item) (Atwine et al., 2005). No other studies with AIDS-orphaned children explore associations of work and mental health.

Household factors

Household-level factors are commonly measured in assessments of child mental health (i.e. Dubow & Luster, 1990), and can overlap with measures of poverty (i.e. overcrowding). Factors which have been found to affect mental health in community studies include family size and composition (Dishion & McMahon, 1998; O'Connor et al., 2001), although O'Connor's review concluded that stresses within the family were more important predictors of child problems than family type. Large family size and

overcrowding in the home have been found to be associated with behaviour problems (Rutter, 1979a). Other household factors are particularly relevant to fostered children, or children living in families which are not their own. Minty (1999) reviewed outcomes for children in long-term foster family care, using evidence largely from the developed world. He found that placement of foster children in a family with a biological child of the same age, or under the age of 5, predicted reduced placement stability and longevity for the fostered child (Berridge & Cleaver, 1987). Placement with relatives was found to be more secure than placement with strangers (Berridge & Cleaver, 1987; Rowe, Hundleby, & Garnett, 1989).

Certain household-level factors were highlighted in qualitative literature as particularly important to AIDS-orphaned children, but have not been tested in mental health research. These included factors which reflect caregiving decisions and resource-poor settings, such as fostering situations where the orphaned child sleeps in the kitchen or bathroom, rather than in a bedroom (Cluver & Gardner, 2007b; Giese et al., 2003).

Placement of children

Few studies of orphan mental health have explored in detail the effects of differing caregiving arrangements on child outcomes. In Uganda, Sengendo and Nambi (1997) found that children living with surviving fathers were more depressed than children living with surviving mothers, and that depression was particularly acute amongst younger children living with fathers. No other differences were found between caregiving arrangements of living with parents, grandparents, other adult relatives and child-headed households. In Tanzania, subgroup numbers were too small for analysis, but authors noted that orphans living alone or with non-relatives reported higher levels of internalising problems than those living with grandparents, who reported higher levels than those living with surviving parents or other relatives (Makame et al., 2002). In Zimbabwe, more problems were reported by orphaned children living in male-headed households, and amongst those whose closest caregiver was a non-relative (Nyamukapa et al., 2006).

The presence of (at least one) loving and supportive caregiver has been found to be a crucial protective factor in multiple community studies (Masten, Best, & Garmezy, 1990; Rutter, 1979a). It has also been found protective for fostered children (Dozier, Albus, Fisher, & Sepulveda, 2002), and in a study of AIDS-affected families in the US (Dutra et al., 2000). The strength of the biological relationship of caregiver to child may also be important, and has been shown to influence allocation of resources within poor households in South Africa (Case, Lin, & McLanahan, 2000).

Particular types of caregiving patterns have been shown to be associated with poor mental health outcomes amongst children. These include living on the streets (Ennew, 1996) and living in child-headed households (Thurman et al., 2006) although no controlled studies assessing mental health outcomes for these groups were found. There is no reliable data in South Africa regarding proportions of AIDS-orphaned, other-orphaned and non-orphaned children who become streetchildren or live in child-headed households. Number of moves between different households, or between different caregivers, have been found as risk factors for poor adjustment in refugee children (Tousignant et al., 1999) and for fostered children (Sigrid, John, Donald, & Laurel, 2004).

Placement with siblings has been explored in three studies of mental health amongst AIDS-orphaned children. In Zambia, sibling dispersion was associated with more problems in an urban, but not in a rural sample (Nampanya-Serpell, 1998). In urban Tanzania, sibling dispersion was not associated with outcomes (Makame et al., 2002). Sibling dispersion was also not associated with mental health for children in AIDS-affected families in the US (Dutra et al., 2000). For some AIDS-orphaned children, placement with siblings may be associated with stress due to 'parentification': caring roles taken on in place of parents. In Rwanda, heads of youth-headed households were found to experience high levels of strain related to their caregiving responsibilities for younger siblings (L. Brown et al., 2005; Thurman et al., 2006).



Figure 14: Children in an informal orphanage (Nyanga)

Caregiving Factors

Caregiving factors are major predictors of emotional and behavioural outcomes in children (Rutter, 2000). Studies of mental health amongst AIDS-orphaned children provide a notably consistent set of findings regarding caregiving effects, although none have shared measurement items, so direct comparison between studies is difficult.

In Ethiopia, orphans' perceptions of an unsympathetic foster family, and unequal distribution of food in the home were associated with higher emotional and social adjustment problems (Bhargava, 2005). In South Africa, Wild et al (2006, July) found that better adjustment was associated with youth perceptions of connection, regulation and autonomy in the orphaned adolescents' relationship with their carer. Specifically, greater caregiver control was associated with more anxiety in children, poorer caregiver-child connection was associated with more depression, and lower caregiver regulation was associated with more antisocial behaviour. Other African studies found protective associations with caregiver rewards for good behaviour (Makame et al., 2002) and 'psychosocial support' from caregivers (Nyamukapa et al., 2006). Interestingly, an intervention study in the US, Rotheram-Borus et al (Rotheram-Borus et al., 2004) found that a parenting intervention had positive effects on parenting skills of HIV+ parents, but

that this had no effect on child mental health. There is evidence of increased levels of attention deficit disorders and behaviour problems amongst uninfected children of HIV-infected mothers. This is hypothesised to be related to mechanisms of maternal depression (associated with HIV status) resulting in compromised parenting (A. Stein, Ramchanani, & Murray, in press), but there is little empirical evidence available.

Caregiving factors and their effects on children are more complex issues within child-headed and youth headed households. In these types of households, AIDS-orphaned children are both caregivers and children in need of care. In Rwanda, Boris et al (2006) interviewed youth heads of households, and found that their depression scores correlated with their report of poorer mental health for children in their care. This may, however, reflect youth caregivers' own sense of helplessness or lowered mood, and self-report measurements of the younger children would be necessary in order to confirm this finding. In this study, depression amongst youth household heads was further associated with lack of adult support.

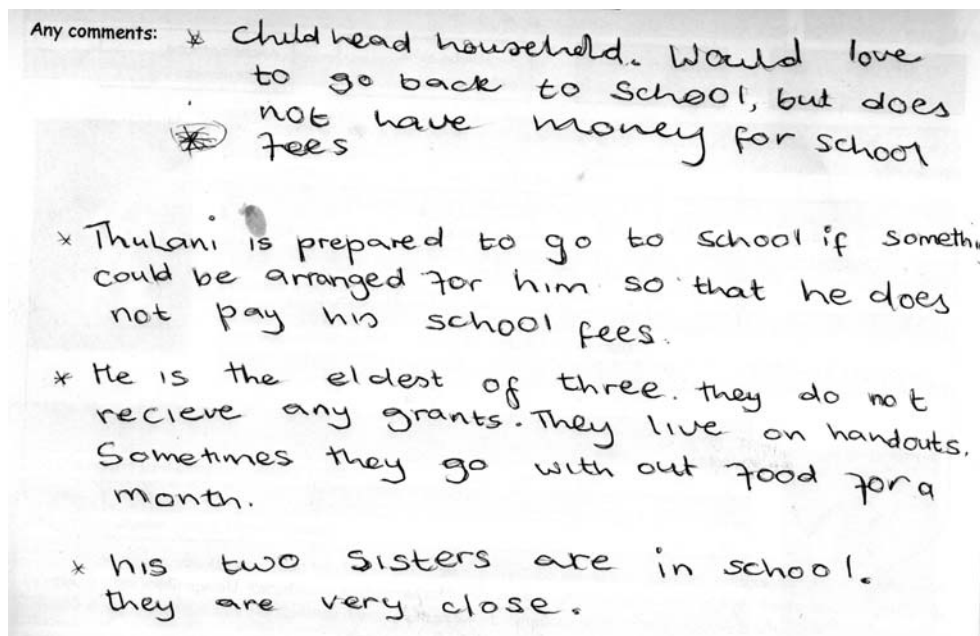


Figure 15: interviewer comments on boy, 16, Khayelitsha

Characteristics of caregivers may also be associated with child outcomes. In studies of parental illness, there is mixed evidence regarding mental health effects on children. Where effects are shown, these may be moderated by factors such as family structure and parenting styles (A. Stein et al., in press). Amongst orphans, caregiver illness was found in two Zambian studies to be associated with more child mental health problems (Nampanya-Serpell, 2001; Poulter, 1996). Caregiver illness was associated with higher 'worry/stress' in both Rwanda and Zambia (Chatterji et al., 2005). Studies of HIV+ women suggest that caregiver illness may be associated with caregiver psychological distress, diminished regulation and children acting as young carers (Brandt, 2007), all of which have been shown to negatively affect child mental health outcomes.

Many AIDS-orphaned children act as (or have acted as) young carers to AIDS-unwell family members. Little quantitative evidence could be found on psychological impacts of acting as a young carer. In one developed world study of sibling bereavement, caregiving roles of children were associated with a positive perception of involvement, although mental health outcomes were not measured (Holliday, 2002). A review of young carers in the UK reports a combination of positive sense of efficacy, and stresses associated with the emotional, physical and time pressures of caregiving (Dearden & Becker, 2004). Qualitative evidence in sub-Saharan Africa reports distress associated with caring responsibilities in the context of HIV and AIDS, including subsequent reduced access to education, and heightened risk of contracting HIV (Robson, 2000).

Other factors within the caregiving environment, even if they are not directed at children themselves, are also strongly associated with child outcomes. General child mental health literature shows marital discord or family conflict to be important risk factors (Rutter, 1979a; Spence et al., 2002), with domestic violence at the extreme end (see section on abuse and domestic violence). A wide range of risk and protective factors have been found in relation to quality of child care (O'Connor, 2002). This current study focused both on factors which were applicable to all children, and on factors which were thought to be particularly pertinent to orphaned children in a poor setting.

Evidence from wider child mental health studies show parental supervision and monitoring to be key protective factors in child behavioural outcomes (Rutter et al., 1998; Simons et al., 2002). Studies show good monitoring to be a protective factor even in high-violence neighbourhoods (O'Connor, 2002), and with AIDS-affected and AIDS-orphaned children (Dutra et al., 2000; Wild et al., 2006, July). Further positive factors in parenting include praise and parent-child activities (Buchanan et al., 2002; Gardner, Burton, & Klimes, 2006). Studies of homeless children report positive perceptions of visits from family members, even when relationships were strained (Vostanis, 2002). Active and sensitive parenting in foster care has been found to positively affect child outcomes in longitudinal studies (Schofield & Beek, 2005).

Complexities emerge when attempting to measure factors such as parent-child or caregiver-child interaction amongst orphaned children. For example, should we be attempting to assess quality of caregiving from the deceased parent, or from subsequent sets of caregivers? Does this depend on how long ago the child was orphaned, or how old the child was when orphaned? Ongoing research in South Africa suggests that HIV+ status may impact negatively on women's capacity to parent (Brandt, 2007; A. Stein et al., 2005). The cross-sectional design of this present study precluded effective measurement of past relationships, and so the study limited to information on current caregiving situation.

Abuse and domestic violence

Longitudinal studies show that experience of all categories of abuse in childhood does increase risk of emotional and behavioural problems (Deblinger, Lippman, & Steer, 1996; Rowan & Foy, 1993; Widom, 1989). However, Rutter highlights the methodological difficulties in distinguishing effects of abuse from the situations of family malfunction in which abuse often takes place (Rutter, 2000).

Physical abuse

In the US, maternal use of regular physical punishment was found to predict the effect of current (but not persistent) poverty on poor mental health in children (McLeod & Shanahan, 1993). In the neighbourhoods in which current study took place, physical punishment of children is commonplace, and may reflect a community norm (A Dawes, Long, Alexander, & Ward, 2006). However, children in the qualitative and quantitative studies were able to distinguish between physical punishment and ‘unnecessary or unprovoked’ beatings by caregivers: the latter causing high levels of distress. Whilst there is no accurate reporting of child abuse rates in South Africa (A Dawes & Mushwana, 2007), qualitative evidence suggests the possibility of higher rates of physical abuse towards AIDS-affected and fostered children.

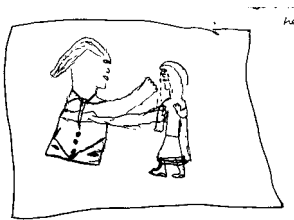


Figure 16: ‘Being hit: (qualitative data)’ Girl (streetchild), 16, City Bowl

Sexual abuse

In the developed world, associations between sexual abuse, emotional problems and PTSD in children are well-established (Bifulco et al., 2002; Cohen & Mannarino, 1996; De Bellis, 2001). A review of evidence from sub-Saharan Africa found few studies conducted outside South Africa, and no national surveys (Lalor, 2004). Rates of sexual abuse in the Western Cape, although again lacking in accurate reporting, are shown to be high. Data from Childline, sexual assault treatment centres and hospital data show consistently high rates of sexual abuse in the past decade (A Dawes, Long et al., 2006). There is no known evidence of heightened vulnerability of AIDS-orphaned children to sexual abuse, although children living outside their direct biological family may be at particular risk (Richter, Dawes, & Higson-Smith, 2004). Using a national survey of HIV and risk amongst 15-24 year olds, orphaned children (by any cause) were found to be

more likely to have contracted HIV (Operario et al., 2007), but there were no associations found between orphanhood and reported experience of forced or transactional sex.

Emotional abuse and neglect

Emotional abuse and neglect are also shown to be associated with poor child mental health outcomes, particularly emotional disorders (Appleyard et al., 2004; Bifulco et al., 2002). However, both present serious measurement difficulties in this survey. The complexity of these types of abuse and sometimes-subtle distinctions make assessment exceptionally difficult within a child-report survey and an environment of sometimes extreme poverty.

Domestic violence

Witnessing of domestic violence has been found to be a risk factor in child psychopathology (McCloskey, Figueredo, & Koss, 1995; Moffitt & Caspi, 1998). A study in Langa township (one of the research areas) found that witnessing of domestic violence predicted post-traumatic stress symptoms in children (Heath & Kaminer, 2004). The 2005 National Youth Victimization survey (disaggregated for the Western Cape) found 20% of children aged 12-17 exposed to domestic violence, and 8% exposed to domestic violence in which a weapon was used. Dawes et al suggest that partner violence occurs most in families under extreme stress (A Dawes, De Sas Kroppiwinski, Kafaar, & Richter, 2006), and studies in South Africa have shown levels of domestic violence to be heightened in AIDS-affected families (Jewkes, Levin, & Penn-Kekana, 2003; Kistner, 2003).

Community-level factors

Community Traumas

Children who are exposed to high levels of community trauma are more likely to show behaviour problems and PTSD. This has been found consistently in both developing and

developed world contexts (Barbarin, Richter, & deWet, 2001; Cooley-Quille, Turner, & Beidel, 1995; Ensink et al., 1997; Hurt, Malmud, Brodsky, & Gianneta, 2001; Simons et al., 2002). Many explanations are given for the persistently high levels of crime and community violence in South African townships, including history of political violence (Shaw, 2002), continuing inequalities, high unemployment, and socio-cultural norms (Pinnock, 1997).



Figure 17: Boy, 11, Plilippi. ‘What would I like to be when I grow up?’

Poor urban communities of Cape Town experience exceptionally high levels of community violence (South African Police Services, 2004), including murder, assault, robbery and sexual crimes. Studies have consistently found high levels of children witnessing and being victimized by violence in poor communities of the Western Cape (Andersson et al., 2004; Farr, Dawes, & Parker, 2003; Human Rights Watch, 2000; Richter, Palmay, & de Wet, 2000; Zissis et al., 2000). They also show correlations between exposure to violence and behaviour problems (Van der Merwe & Dawes, 2000; Ward, Flisher, Zissis, Muller, & Lombard, 2001), emotional problems (Ward et al., 2007; Zissis et al., 2000) and post-traumatic stress (Seedat, van Nood, Vythilingum, Stein, & Kaminer, 2000; Zissis et al., 2000). There is no evidence to suggest that orphaned and non-orphaned children would be differentially exposed to community violence, except where orphanhood leads to children living on the streets (Ennew, 1996).

For children, bullying may be a particularly distressing community (or school) experience. There is evidence of associations between bullying and psychological problems amongst children generally (Deater-Deckard, 2001; Hay, Payne, & Chadwick, 2004), and in other stigmatised groups such as refugee children (Almqvist & Broberg, 1999). Studies of bullying in South Africa seem to be limited, perhaps due to high levels

of other forms of victimization of children. These include gang warfare and other violent crimes which are more studied amongst children.

AIDS-related stigma

No known studies quantitatively explore associations of AIDS-related stigma and mental health outcomes amongst non-infected but AIDS-affected children. However, there is evidence of associations between AIDS-related stigma and psychological distress amongst HIV+ adults (Green & Smith, 2004; L. Kahn, 2004; Skinner & Mfecane, 2004). It is noted that there is a high risk of method overlap: experience of stigma can only be measured subjectively, and may be influenced by depressed mood (Maughan Brown, ongoing).

There is increasing evidence that AIDS-orphaned children do suffer from what is termed 'courtesy stigma' (Goffman, 1963) associated with the illness and death of their parents. A study of youth-headed households in Rwanda reported that AIDS-orphaned children had strong perceptions of felt and enacted stigma (Thurman et al., 2006), and orphans in Zimbabwe reported that stigma resulted in feelings of anxiety and depression (Foster et al., 1995). In South Africa, a survey of child-headed households suggested that AIDS-orphaned children may experience discrimination from basic social services and education (Nelson Mandela Children's Foundation, 2001). Further studies also suggest that AIDS-affected and orphaned children experience high levels of stigma (Murphy, Roberts, & Hoffman, 2002; Strode & Barrett Grant, 2001; Van Wyk, 1998), and this is supported by qualitative and anecdotal evidence of discrimination towards orphans in education and healthcare (Giese et al., 2003; Irin, 2005). Specific types of stigma towards AIDS-orphaned children in Cape Town have been identified in qualitative research, and include gossip, taunting and verbal abuse of surviving HIV+ parents (Cluver & Gardner, 2007b; Ferreira et al., 2001).

Positive Activities and other community factors

Studies of AIDS-orphaned children have tested a small number of community-level factors in relation to mental health. In Rwanda, community cohesion was correlated with

lower scores on an unstandardised ‘worry/stress’ scale (Chatterji et al., 2005). In South Africa, poorer neighbourhood regulation was associated with more anxiety and antisocial behaviour, and greater neighbourhood connection was associated with higher self-esteem (Wild et al., 2006, July).

Research from the developed world, mostly focusing on reduction of behaviour problems or delinquency, suggests a range of ‘protective’ activities and community factors. Limited evidence from the developed world suggests associations between positive recreational activities and better psychological outcomes (Strong et al., 2005). Effective use of leisure time in organised activities have been found protective where these provide children with opportunities to succeed (Hoge et al., 1996). Deater-Deckard’s review of this topic, however, distinguishes between structured extra-curricular activities, which were found to be protective against externalizing problems, and unstructured activities, which were associated with higher risk (Deater-Deckard, 2001). A study of children in a high violence community in Cape Town found that involvement in after-school activities was associated with reduced anxiety scores (Ward et al., 2007).

Religious affiliation may be a particularly pertinent factor to orphaned children in the study area. Some studies have found participation at church or another place of worship to be associated with improved outcomes for children in highly stressful situations (Masten et al., 1990). Experiences of religion for AIDS-orphaned children may be more mixed: qualitative research reports churches as a source of both support and stigma for AIDS-affected families in Cape Town (Giese et al., 2001). Anecdotal evidence includes examples of emotional and material support from religious organizations (Mulama, 2004). It also includes examples of stigmatization towards perceived moral degeneracy of AIDS-victims, and discrimination around aspects of religion such as unwillingness to share the communion cup with HIV+ congregation members (Bowers, 2006; Ferreira et al., 2001; Giese et al., 2001).



Figure 18: Boy, 13, Brown’s Farm. ‘What would I like to be when I grow up?’

Social Support

Social support occurs at all levels of the ecological framework. In addition to support from caregivers, children can gain social support from their peer group, school, other family members, and other adults (Rutter, 2000). ‘Support’ can often be a vague and widely-interpreted term, but there is evidence that perceived social support can have important impacts on children, especially where more usual sources of support are lacking (Bronfenbrenner, 1979).

Potential sources of support for orphaned children have been identified in more general literature on AIDS-orphanhood, and include school, extended family and community workers (M. Kelly, 2005; Richter et al., 2006). In South Africa (Wild et al., 2006, July) better adjustment amongst AIDS-orphaned and other-orphaned children was associated with youth perceptions of good connections and regulation in the neighbourhood context. This study also explored associations between peer relationships and mental health. Poorer peer regulation was associated with more antisocial behaviour and more depression, and greater peer connection was associated with higher self-esteem,

In the qualitative stage of this thesis, peer support and good peer relationships were highlighted as perceived protective factors by AIDS-orphaned children and caregivers (Cluver & Gardner, 2007b). A study of mental health amongst AIDS-orphaned children in Uganda (Atwine et al., 2005) found that self-concept scores were higher amongst orphans who were currently in contact with other orphaned children, although the nature or extent of such contact was not explored further. In Rwanda, depression amongst heads of youth-headed households was positively correlated with social marginalization (Boris et al., 2006). International evidence shows peer support as a buffer against emotional disorders in contexts of difficult life circumstances (Deater-Deckard, 2001; Sund et al., 2003). Positive peer relationships were also found to be protective amongst refugee children (Almqvist & Broberg, 1999). However, delinquent peer groups have been found

to increase adolescent antisocial behaviour (Dishion, McCord, & Poulin, 1999; McCord, 2003; Rutter et al., 1998), and so the influence of peer support may be equivocal.

For orphaned children, having the opportunity to discuss their bereavement with someone (whether a friend, relative or professional) may also be a protective factor. In the UK, studies with HIV+ children found that lack of opportunity to discuss death (due to taboos around HIV/AIDS or around discussing death with children) was associated with child distress (Gosling et al., 2004). Qualitative evidence from South Africa suggests that cultural beliefs about childhood, and stigma surrounding AIDS, limit communication to children about parental death, and that children may find this distressing (Giese et al., 2001; Marcus, 1999a).

3.5 Summary and conclusions

Studies of mental health amongst AIDS-orphaned children have tested a limited number of risk and protective factors against psychological outcomes. However, there is a range of difficulties associated with using this evidence-base. The small number of available studies includes a wide range of sample groups, control groups and sample sizes. Use of standardised questionnaires is limited, and some do not measure established psychological disorders, focusing instead on more general symptoms of distress. Many studies measure only a small number of socio-demographic factors, precluding adequate controlling of other factors in determining risk and protective influences. There are difficulties associated with method overlap between mental health symptoms and some self-reported risk factors such as social support. There are also difficulties associated with caregiver report of child symptoms. Comparison or meta-analysis of risk and protective findings is made impossible by the lack of shared measurement tools.

Despite these methodological limitations, there is value in comparing the evidence available from studies of orphan mental health with broader evidence on child mental health. Many of the risk and protective factors which are identified in studies of mental health amongst AIDS-orphaned children are supported by research in general child mental health, or studies with groups such as refugee children. These similarities also

allowed corroboration of study findings from the generally unpublished literature of mental health of AIDS-orphaned children, with peer-reviewed, methodologically sound studies from wider literature.

Review of qualitative and anecdotal literature on AIDS orphanhood, whilst not focused on psychological outcomes, provided helpful indications of potential factors which were particular to AIDS-orphaned children. These included stigma-related risk factors and factors related to AIDS-death. Finally, review of risk and protective factors for poor children living in South African townships, allowed the inclusion of factors which may not have emerged from reviews of developed world literature.

This review showed potential risk and protective factors in multiple ecological areas of a child's life. Home, school and community environments all provided a range of factors which may influence mental health outcomes (Bronfenbrenner, 1979). A number of 'domains' of child well-being are also represented in risk and protective factors, including material deprivation, education, caregiving, health and social capital (Noble et al., 2006). Within these environments and domains, a wide range of individual potential risk and protective factors was identified for quantitative testing in the major data collection stage of this study (Chapters 5 and 6). Not all of the factors identified in this review were able to be measured: factors were prioritised by relevance to policy, measurability and objectivity.

The literature review described in this present chapter provided many of the potential risk and protective factors to be measured in Stage 4. Two further sources of risk and protective factors were also used. Firstly, factors were added after suggestion by South African government agencies and NGOs (described in Chapter 5). Secondly, a qualitative study was conducted as part of this thesis. The qualitative study allowed AIDS-orphaned children in Cape Town, their caregivers, and professionals working with those children, to identify factors which they perceived to be risk or protective for orphans' mental health. Some of the findings of the qualitative study have been incorporated in the present chapter. The full study is reported in the following Chapter 4.

Table 6: Studies of mental health amongst AIDS-orphaned children which measure risk and protective factors

Country	Sample Characteristics	Outcomes	Factors tested against mental health outcomes	Brief findings
Poulter et al Zambia (1996)	22 households with orphans, 66 with HIV+ parents, 75 community controls	Internalising externalising	Economic stress	Economic stress not associated with outcomes
Sengendo & Nambi Uganda (1997)	169 AIDS-orphaned children 24 non-orphans	Internalising	Differing family caregiving arrangements (living with father, mother, grandparents or other relatives)	- Children living with widowed fathers more depressed than those living with widowed fathers ($p < .04$) - Young children (10-14) living with widowed fathers more depressed than older children (15-19) living with widowed fathers ($p < .001$) - No other differences between caregiving arrangements
Nampunya-Serpell Zambia (1998)	645 AIDS-orphaned children (rural) 291 AIDS-orphaned children (urban)	Internalising Externalising	Age Gender Sibling dispersion Health of caregiver Household composition	- Age not associated with outcomes - Gender not associated with outcomes - In the urban sample, placement apart from siblings associated with more problems ($p < .05$) - In the rural sample, living in a household with more adults associated with more problems ($p < .001$) - In the urban sample, caregiver illness associated with more problems ($p < .05$)
Makame et al Tanzania (2002)	41 AIDS-orphaned children with 41 non-orphans	internalising	Gender Age Placement with siblings Length of time with caregiver Food security School attendance School achievement Rewards at home	- Gender not associated with outcomes - Age not associated with outcomes - Living apart from siblings not associated with outcomes - Length of time with current caregiver not associated with outcomes - Going to bed hungry associated with internalising problems - Not attending school associated with internalising problems ($p < .001$)

				• Arithmetic score negatively correlated with internalising problems ($p < .001$) • Reward for good behaviour at home negatively associated with internalising problems ($p < .05$) • Numbers too small for analysis, but orphans living alone or with non-relatives reported most problems, followed by those living with grandparents. Orphans living with surviving parents or adult relatives reported fewest problems.
Manuel et al Mozambique (2002)	76 AIDS- orphaned children 74 non-orphans	internalising	Caregiver mental health	• Child depression correlated with caregiver's depression ($p < .01$) • Caregiver depression correlated negatively with social support ($p < .01$)
Forehand, Pelton et al USA - New Orleans Longitudinal study (1999, 2005)	20 AIDS- orphaned children, compared to children with HIV+ mothers and non- orphaned community controls	Internalising externalising	Range of parenting and household variables examined for children with alive but HIV+ mothers	• Amongst children with HIV+ mothers, parent-child relationship, parental monitoring and routines/organisation in the home, were protective for internalising and externalising problems. • Amongst children with HIV+ mothers, parental disclosure of HIV+ status to children was associated with increase in parent-reported child behaviour problems.
Atwine et al Uganda (2005)	123 AIDS- orphaned children 110 non-orphans	Internalising externalising	Age Gender Socioeconomic group Household size School attendance Currently doing chores Multiple bereavement by AIDS Current health problems	• Age not associated with any outcomes • Gender not associated with any outcomes • Socio-Economic group not associated with any outcomes • Household size not associated with any outcomes • School attendance not associated with any outcomes • Currently doing chores not associated with any outcomes But anger scores higher in orphans performing more chores • Multiple bereavement not associated with any outcomes • Current health not associated with any outcomes

		Taken to clinic quickly when ill	Taken to clinic quickly not associated with any outcomes
Chatterji et al Rwanda and Zambia (2005)	1160 AIDS- orphaned children, children with sick caregivers & non-affected children	Worry/stress	• Taken to clinic quickly not associated with any outcomes • In Rwanda, socio-economic status negatively correlated with worry/stress scores ($p<.03$) • In Rwanda, community cohesion negatively correlated with worry/stress scores ($p<.001$) • In Zambia and Rwanda, having an ill caregiver associated with worry/stress ($p<.04$ and $.03$ respectively)
Bhargava Ethiopia (2005)	479 AIDS- orphaned children 574 orphans by non-AIDS causes	Internalising Social adjustment	• Female gender associated with more internalising and social adjustment problems ($p<.05$) • Father preparing meals for child associated with fewer problems ($p<.05$) • Lower foster household income associated with more social adjustment problems ($p<.05$) • Inadequate feeding associated with more internalising and social adjustment problems ($p<.05$) • Inequal distribution of food associated with more social adjustment problems ($p<.05$) • Poor clothing associated with more internalising problems ($p<.05$) • Unsympathetic foster family associated with more internalising and social adjustment problems ($p<.05$)
Nyamukapa et al Zimbabwe (2006)	5,321 children in total	Internalising externalising	• Female gender associated with more psychosocial problems ($p<.05$) • Age not associated with any outcomes • Living in an urban area associated with more problems ($p<.05$) • Living on a commercial farm associated with more problems ($p<.05$) • Living in poor household associated with more problems ($p<.05$) • Not being related to closest caregiver associated with more problems ($p<.05$)
		Gender Age Location Socio-Economic status Caregiving arrangements	

				• Male-headed households associated with more problems ($p<.05$) • Less psychosocial support from closest caregiver associated with more problems ($p<.05$) • Female gender associated with more internalising problems ($p<.05$) • Greater age associated with more internalising problems
Gilborn et al Zimbabwe (2006)	1,258 OVC, 65% orphans (cause of death not given)	internalising	Gender Age	
Wild, Flisher, Laas and Robertson South Africa (conference paper)	81 AIDS- orphaned children, 78 orphaned by non-AIDS causes, 43 non- orphans	Internalising externalising	Caregiver connection, regulation, control Peer connection, regulation, control Neighbourhood connection, regulation	• Female gender associated with more anxiety ($p<.05$) • Greater control (less psychological autonomy) from caregiver associated with more anxiety ($p<.001$) • Poorer neighbourhood regulation associated with more anxiety ($p<.01$) • Poorer caregiver connection associated with more depression ($p<.01$) • Poorer peer regulation associated with more depression ($p<.05$) • Greater peer connection associated with higher self-esteem ($p<.001$) • Greater neighbourhood connection associated with higher self-esteem ($p<.001$) • Younger age associated with higher self-esteem ($p<.001$) • Lower caregiver regulation associated with more antisocial behaviour ($p<.05$) • Lower peer regulation associated with more antisocial behaviour ($p<.001$) • Lower neighbourhood regulation associated with more antisocial behaviour ($p<.01$) • Female gender associated with more internalising problems ($p<.03$) • Higher caregiver depression, social isolation or lack of adult support (amongst youth heads of households) associated with more internalising problems amongst under-5s
Boris et al In submission	692 Youth- headed households	Internalising	Gender Social isolation Social marginalisation Adult support	

Rwanda

- Social marginalisation correlated with more depression (.6)
- Lack of adult support correlated with more depression (.5)

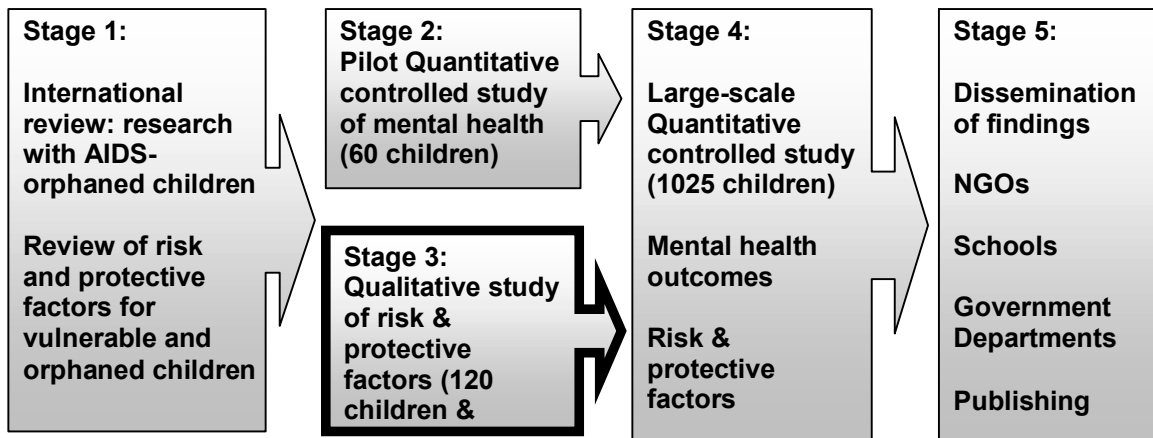
Chapter 4: Risk and Protective Factors: A qualitative study of children and caregivers' perspectives

- 4.1 Introduction
- 4.2 Research questions and aims
- 4.3 Qualitative methodology
 - Sample group: children
 - Sample group: caregivers
 - Sample group: professionals
 - Procedures
 - Interviewers
 - Ethical considerations
 - Analysis strategy
- 4.4 Results from qualitative research
- 4.5 Discussion
 - Limitations of the study
- 4.6 Summary and conclusions

because of your
(b) when you don't have parents.
no one to buy you clothes.
maybe you live with another family and
they buy clothes for their own kids
and you get none.

Figure 19: Qualitative data: Boy (streetchild), 13, Khayelitsha

4.1 Introduction



This chapter addresses Stage 3 of the research. It outlines the methodology and findings of a qualitative study of risk and protective factors amongst AIDS-orphaned children in Cape Town.

Chapter 3 reviewed literature on risk and protective factors for AIDS-orphaned and other vulnerable children. That review provided a list of potential risk and protective factors to measure in the quantitative stage of this study. However, a reliance on literature review (especially given the very limited number of studies on AIDS-orphaned children) risked the omission of factors which are particular to AIDS-orphaned children in South Africa. The present chapter reports a qualitative study which aimed to explore the perspectives of AIDS-orphaned children and their caregivers. This was intended to supplement the literature review process in determining possible risk and protective factors for future quantitative measurement. This study used qualitative methods to explore the perceptions of orphaned children, their caregivers, and care professionals about factors contributing to psychological well-being in orphaned children.

Risk and Protective factors in mental health for orphaned children

Chapter 3 describes a detailed literature review of potential risk and protective factors. In summary, searches found very little available research on psychological risk and protective factors for orphaned children. Only one quantitative study focused specifically

on risk and protective factors (Wild et al., 2006, July). Using standardised questionnaires, greater caregiver connection and greater neighbourhood and peer regulation were associated with less anxiety and depression. Other quantitative evidence identified risk factors such as greater household size (Atwine et al., 2005), sibling separation (Nampanya-Serpell, 1998) and parenting factors (Dutra et al., 2000). Qualitative research with AIDS-affected families in South Africa has not focused on psychological health, but gives valuable indications for areas of potential risk and protective factors. For examples, churches provide both support and stigma (Ferreira et al., 2001), and poverty is a key cause of distress (ACCESS, 2002; Giese et al., 2001).

Broader child mental health literature suggests mediating factors such as genetic traits (O'Connor et al., 2001) and experience of abuse (Appleyard et al., 2004). Certain factors may be particularly relevant to South Africa, such as affordability of school fees (Berry & Guthrie, 2003), violent crime and sexual abuse (A Dawes, 2002), domestic violence (Heath & Kaminer, 2004) and community violence (Zissis et al., 2000).

Orphans' experiences may overlap with the experiences of other groups. Research with HIV+ adults identifies risks such as taboos on discussing death (Gosling et al., 2004), and multiple bereavement (Sherr et al., 1992). For example, many children report distress resulting from the deaths of both parents and other family members (Richter et al. 2004). Risks associated with childhood bereavement include witnessing traumatic death (Black & Harris-Hendricks, 1992) and financial instability (Stansfeld et al., 2004). Witnessing, and caring for, a parent dying of AIDS may be particularly traumatic for a child (Richter et al. 2004). Refugee children may share orphans' experiences such as displacement (Fazel & Stein, 2003), multiple moves (Tousignant et al., 1999) and bullying (Almqvist & Broburg 1999). Many South African orphans are (formally or informally) fostered, and a review based in the developed world showed age at fosterhood and foster-family structure to affect placement stability (Minty, 1999). For orphaned children who are living as streetchildren, the little available research identifies difficulties around lacking parental supervision (Richter & Van der Walt, 1996) and qualitative reports of ambivalence around family contact (Vostanis, 2002).

However, a reliance on available literature-based evidence was considered insufficient. Firstly, available quantitative studies only tested a limited number of researcher-identified factors. Secondly, reliance on research with groups whose experiences only partially overlap with those of AIDS-orphaned children risks inclusion of inappropriate factors. Thirdly, there may be factors which are specific to urban African orphans, and have not yet been identified. In light of these concerns, I undertook a qualitative study to elicit the perceptions of AIDS-orphaned children, their caregivers, and professionals working with orphaned children. Open questions were used, and participants identified their perceptions of factors contributing to emotional and behavioural well-being of orphaned children. The choice of a qualitative methodology was crucial in allowing the research to focus on participants' experienced meaning and human experience, and allowed a variety of data collection methods (Colaizzi, 1978) to understand more about a new phenomenon (Tesch, 1990).

4.2 Research Questions and aims

This qualitative stage of the research aimed to elicit expert views of perceived risk and protective factors in the emotional and behavioural health of AIDS-orphaned children. Following broader research on child well-being in South Africa (Noble et al., 2006), the views of children, caregivers and professionals were all sought. Research questions were:

- 1) What factors are perceived to increase emotional problems of AIDS-orphaned children? (risk factors for internalising problems)
- 2) What factors are perceived to reduce emotional problems of AIDS-orphaned children? (protective factors against internalising problems)
- 3) What factors are perceived to increase behavioural problems of AIDS-orphaned children? (risk factors for externalising problems)
- 4) What factors are perceived to reduce behavioural problems of AIDS-orphaned children? (protective factors against externalising problems)
- 5) What coping mechanisms are used by children and caregivers?

4.3 Qualitative methodology

Sample Group: Children

For the qualitative stage of this study, recruitment aimed for a sample of children with a range of age, gender, caregiving situations and differing life experiences. 60 children participated: 50% were sampled through 3 schools (in Khayelitsha and Old Crossroads), 27% through 3 shelters for streetchildren, and 23% through Cape Town Child Welfare (Guguletu and Khayelitsha branches).

The study had 122 participants. These included children orphaned by HIV/AIDS (60), caregivers of orphaned children (42), and care professionals working with AIDS-orphaned children (20). Children were recruited through three schools (50%), three shelters or feeding schemes for streetchildren (27%), and, in order to access non school-attending children, through welfare services (23%). Participants lived in deprived (formal and informal) Cape Flats settlements or in shelters for streetchildren. Professionals were interviewed at several welfare and community organisations.

Child participants were Black African, 43% male, aged 8-19 (mean 13.3 years, SD 2.7). Three children were aged less than 10 years. Relationship to primary carer is shown in Figure 20. All streetchildren lived in centres. Of non-streetchildren, 61% lived in a concrete or brick home, 39% in a shack. 43% shared a room with 4+ people. 52% of homes had running water, 82% had access to electricity, and 52% were waterproof. 42% of children reported going to bed hungry more than 1 night in the past week. 93% of children reported regular school attendance⁵, with 2.5% attending 'sometimes' and 2.5% not enrolled. Of those attending school, half (47%) were 1-4 years behind their age-grade.

23% of children were reported as maternal orphans, 27% as paternal orphans, and 20% as double orphans (information was unknown in some cases). In many cases, one parent's

⁵ This includes streetchildren, who attended a 'Learn to Live' School, designed to help children make the transition to regular school.

whereabouts was unknown to the child (30%). These were usually fathers who had abandoned children (and who may or may not subsequently have died), but included a small number of mothers who had left children. High levels of internal migration and low levels of maintenance paid by fathers contributed to this high number of parents whose whereabouts was unknown to children or their current caregivers. 61% of children lived with neither parent. Orphanhood was defined here as children under 18, where one or both parents have died (UNAIDS & UNICEF, 2002). However, it is recognised (as discussed in Chapter 1) that this definition may not reflect the importance of multiple caregiving arrangements, extended family, abandonment and wider familial losses due to HIV/AIDS in South Africa (Meintjies, Budlender, Giese, & Johnson, 2003).

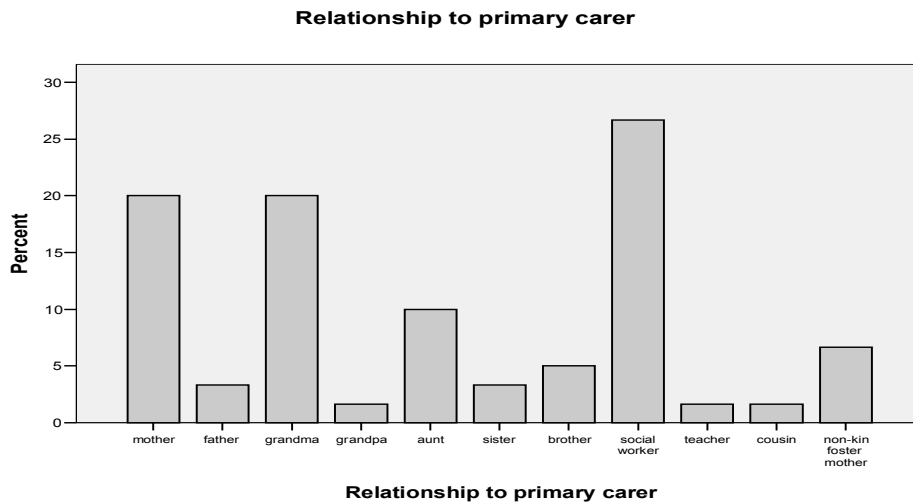
Sample Group: Caregivers

Caregivers (n=42) were 90% female, and aged 20-70 (estimated). All were Black African, and were sampled through Cape Town Child Welfare branches (Guguletu n=18 and Khayelitsha n=24).

Sample Group: Professionals

Recruitment aimed to interview professionals who were directly working with, or undertaking research with, AIDS-orphaned children. Professionals worked with children living in a range of caregiving arrangements such as foster care, street shelters and projects for child-headed households. Both qualified professionals (i.e. social workers) and unqualified community workers were interviewed. Interviews with social workers and careworkers took place at a number of social work agencies, community organisations, and shelters for streetchildren (i.e. Cape Town Child Welfare, The Bridge, Ons Plek, the Homestead, Planned Parenthood Association of the Western Cape, the Memory Box Project). Interviews with academic and psychiatric staff took place at the Human Sciences Research Council (i.e. Human Sciences Research Council's Child Youth and Family Unit, the Child Guidance Clinic, and the University of Cape Town Departments of Psychiatry and Psychology).

Figure 20: Qualitative data: Relationship of child participants to their primary carer



Procedures: children

Child participants were identified by teachers and social workers, and interviewed in schools, homes and welfare centres. Children were given a choice of worksheet-based semi-structured interviews, featuring popular cartoon characters⁶. Questions were ‘what makes children/you happy?’, ‘what makes children/you sad?’ ‘what makes children/you angry?’ and then asked about coping factors. Please see Appendix 5 for copies of worksheets. A study of AIDS-related stigma amongst AIDS-orphaned children reported that the use of vignettes allowed children to identify personal experiences, but without talking about themselves specifically (Strode & Barrett Grant, 2001). Cartoons, vignettes and drawings have been found to be useful in other studies of HIV/AIDS-affected and low-literacy homeless children (ACESS, 2002; Giese et al., 2001; Herth, 1998; Thomas, Subotsky, Almeleh, & Stratton, 2002).

⁶ Worksheets were available as ‘Bart Simpson’ and ‘Lisa Simpson’ (re-named Buntu and Lindiwe respectively) or ‘DragonBall-Z’: the current cartoon craze for children in Cape Town.

Interviews explored factors which children perceived as affecting their happiness, sadness, anger, and coping strategies. In order not to influence responses, bereavement was not mentioned unless children raised the topic independently. Children chose to conduct interviews in isiXhosa (52%), English (15%), or dual-language (33%). Children opted whether to answer questions in relation to themselves (1st person) or in relation to the cartoon characters Bart, Lisa or DragonBallZ (3rd person). Children also chose whether to respond in writing, drawings, or verbally, independently or with interviewer assistance. These plural qualitative methods (Colaizzi, 1978) made the research more participatory (Strode & Barrett Grant, 2001), and allowed flexibility for a range of literacy levels amongst participants.

Procedures: Caregivers

Caregivers were interviewed in focus groups of between 4 and 9 participants. Groups took place at the Child Welfare Guguletu office and in homes in Khayelitsha Sites C and B. Groups were conducted in a combination of isiXhosa and English, and were recorded in writing, but not tape-recorded. Written records were verbatim reports of caregivers' words (this was possible as focus groups were aiming to generate lists of potential factors). Where caregivers gave long explanations or stories, they were asked to clarify which potential risk or protective factors they were referring to, and this was recorded. Focus group records were in the language spoken by the caregiver, and (where this was isiXhosa) were subsequently translated and back-translated. It is noted that the method of recording in writing, rather than tape-recording, transcribing and coding, was a serious limitation on the quality of data obtained.

Caregivers were asked to comment on 'children in this community', but often chose to talk specifically about the child whom they were caring for. The focus group questions followed those asked to children, i.e. exploring perceptions of what makes children happy, unhappy or angry, and what makes children happier if they are feeling sad.

Caregivers were also asked what things *should* be done but were currently not done, to make children in their community happier.

As with child participants, privacy was attempted as much as possible, but full privacy for groups was not possible. All caregivers were given full (verbal) explanations of the study, and informed consent was sought. 2 caregivers chose not to participate in the discussions. The focus groups aimed to create a supportive environment for caregivers. During the group process advice, support and comfort was exchanged between caregivers. As a focus group coordinator and a social worker at Cape Town Child Welfare, the PI was also able to give advice on agencies to contact and resources to access. In order to attempt to maintain the focus of data collection, advice from the facilitator to individual caregivers was given after the end of the focus group. However, the exchange of advice and support *between* caregivers may have influenced the research process in terms of quality of data given. In some cases, caregiver advice was a method of expressing perceived risk or protective factors (i.e. ‘You must make sure they know that their mother has died. I did not tell my granddaughter and it caused problems when she became a teenager’). However, the methodology of conducting focus groups which in some way resembled support groups may also have influenced the responses given by caregivers. For example, this format may have encouraged caregivers to discuss perceived factors which they saw as relevant to orphans generally, rather than those which they considered particular to the orphan in their care.

Procedures: Professionals

Interviews with social workers, careworkers, psychiatric staff and academics used a semi-structured questionnaire format, exploring views on risk and protective factors for AIDS-orphaned children. After discussion, professionals were given a list of the factors identified by the literature review in Chapter 3, and asked to comment on a) their applicability to orphaned children in Cape Town, and b) whether anything was missed out.

This qualitative study aimed for triangulation through multiple informants (Pendleton, Cavalli, Pargament, & Nasr, 2002) and through multiple data collection methods: interviews, focus groups and worksheets (Giese et al., 2003; Kay, Cree, Tisdall, & Wallace, 2003; Morrow, 2001). Worksheets are presented in Appendix 5. All interviews and worksheets used open-ended questions and did not prompt responses. If a participant identified a particular factor (ie. abuse) interviewers would enquire further. Data collected included worksheets and interview notes.

Interviewers:

Interviewers were myself and a qualified, isiXhosa-speaking auxiliary social worker (Hilda Ntjana), both with extensive experience of working with HIV/AIDS-affected families. Focus groups were conducted jointly.

Ethical Considerations:

Please see Chapter 5 for full details of ethical procedures, which were paralleled in the qualitative and quantitative studies. In brief, Oxford University and Cape Town Child Welfare gave ethical approval. Interviewers were isiXhosa and English-speaking social workers or auxiliaries, trained in working with HIV/AIDS-affected families. Participants were given refreshments and certificates.

Due to variable literacy levels, information and consent leaflets were also explained. For children, consent was also obtained from guardians, social workers or eldest siblings in child-headed households. All data were treated as confidential, except information suggesting that children were at risk of significant harm (Alderson & Morrow, 2004).

Low rates of disclosure in South Africa (Andersson et al., 2004) and high perceived stigma (Maughan Brown, 2004) mean many children are unaware of their parents' HIV status (Armistead et al., 1999). Following the ethical procedures used in the pilot quantitative stage (Chapter 1) and in the main quantitative stage (Chapter 5), HIV/AIDS was not mentioned in recruitment or interviews. This approach follows other

psychological research with AIDS-orphaned children in sub-Saharan Africa (Makame et al., 2002; Manuel, 2002; Poulter, 1996; Wild et al., 2006, July).

Feedback to participants was prioritised within the research design (Herth, 1998). All participants were sent a thank-you letter, a summary of the qualitative study findings (Kay et al., 2003), and list of local resources for counselling etc (Appendix 6). Any children who identified risk of significant harm were referred to social services. Chapter 5 gives full details of ethical procedures followed in both the qualitative and quantitative stages of the study.

Analysis strategy:

Analysis strategy used content analysis of written data: both qualitative and quantitative operations on the text; (Weber, 1985). Interviewer notes, participant writings and drawings were read through and significant statements extracted (Colaizzi, 1978). Meanings were formulated in order to produce clusters of themes. Themes were compared within and across categories to establish consistency (Glaser & Strauss, 1967) and referred back to original interviews in order to validate them. Priority was given to factors endorsed by high numbers of participants, and with high agreement between children, caregivers and professionals. In light of the phenomenological nature of our research questions, this study used a grounded theory approach (Glaser & Strauss, 1967) to develop hypotheses. However, it is important to consider potential bias in analysis and selection of data for presentation. The study aimed to identify ‘factors’ likely to be measurable and useful in intervention design. This may have caused bias against more intangible responses, such as general statements about positivity and hope. A peer audit was conducted on the final selection of themes, by 15 representatives from UNICEF, WHO and local NGOs.

4.4 Results from qualitative research

Several key themes emerged from the data, and many factors were perceived as affecting both emotional and behavioural difficulties. Table 22 shows all themes which participants raised. The most commonly-raised themes are discussed below.

Bereavement Factors

Children (n=23), caregivers (n=10) and professionals (n=6) identified parental (particularly maternal) bereavement as a key risk for emotional/behavioural problems: 'When my mother goes out and never comes back'. Children felt that happiness would come from 'Having parents alive to take care of me' and, 'If I could see my dead parents again'. Multiple bereavements resulted in distress: 'When my friends, neighbours and classmates die', and survivor guilt 'She feels it is her fault her mother died'. Professionals highlighted anger and grief for teenage heads of child-headed households.

Caregiving factors

All participant groups stressed the importance (risk and protective) of the primary caregiver, for example 'My sister does her best to look after us and we attend school regularly...She washes our clothes when we're at school and allows us to play as children'. Children talked positively about 'being loved', attention, respect, 'being wanted', fun with caregivers and having boundaries; 'Being told if I've done wrong', as well as basic care 'When I am sick my grandmother takes me to hospital'. Five children described unhappiness from lacking any caregiver 'Having nobody to take care of me'.

Caregivers (n=41) perceived care as a crucial protective factor, including support, honesty, praise and closeness, help with homework, reading and stories, advice on education and attending school meetings. Professionals identified caregivers' mental health, social support, and caregiver access to anti-retrovirals as affecting children's well-being.

Harmful caregiving was highlighted by children (n=29), caregivers (n=24) and professionals (n=14). Risks particularly relevant to orphaned children included multiple moves, caregiver changes, and caregiver illness (for HIV+ or elderly caregivers). Others included family conflict, separation, domestic violence and alcohol abuse (all common in the research communities).

Abuse

Child abuse featured in all groups' perceived risk factors for both emotional and behavioural problems (n=28). Twenty-three children identified shouting, and 14 described beatings with sticks or belts. Neglect included 'children locked in the shack whilst foster parent goes out'. Seven children identified distress caused by sexual abuse, including rape. Two children witnessed abuse 'When I see a child my age being abused it makes me very sad'.

New homes and 'a sense of belonging'

Many participants were acutely aware of tensions associated with orphans' position as the non-biological child in the home: 'I am angry when the family is fighting and they refer to me as 'the orphan''. Caregivers described children's sense of abandonment and 'not belonging' within the family. Complexities emerged around disclosure to a child of their orphanhood: 'It is bad to deceive a child and tell them you're their mother when you're not... now I know'. Caregivers and children also described positive factors: feeling accepted, wanted, and 'part of the family' (n=7). A child described his sister: 'She takes care of us, gives us the love we need as if we were her own children'.

Children were particularly unhappy when they felt discriminated against or different to other children in the home (n=10). This included unequal distribution of resources: 'When you're living with another family and they buy clothes for their children and not you', and were supported by adult data. Children also described isolation 'I want

somewhere where people don't say "it's not your home", and loneliness (n=4) 'I feel very alone in the world'.

Contact with extended family

Many participants saw lack of family contact as a risk for emotional problems. Children (n=6) described missing family, feeling separated, and 'being sent far away'. Streetchildren were upset by others' family visits. Conversely, immediate and extended family contact was perceived as protective by professionals (n=3) and children (n=19). Children (n=8) identified family, often aunts, as a source of consolation.

Poverty and access to services

Almost all participants described poverty as a risk for emotional and behavioural distress. Primarily, lack of food or starvation was identified by children (n=53) caregivers (n=12) and professionals (n=10). Twelve children said 'enough food' would improve well-being. Concerns included insufficient food to take to school and going to school starving (n=3).

Specific poverty-related risk factors were homelessness (n=6), unemployment and lack of medical care. Housing problems included overcrowding, leaking or burned-down shacks (n=4), no toilets, electricity or water. Caregivers highlighted difficulties around accessing social welfare grants, birth certificates, medical care, and social workers.

Caregivers and children identified orphans' sense of social exclusion, including inability to afford washing powder, haircare, a bath/shower and lack of birthday celebrations or activities with friends. Concerns around clothes (total n=25) included lack of school shoes and uniforms (required for school attendance), and winter clothes.

School and Peer Factors

Both school and friendships were important to children. Participants were distressed and angered by inability to afford school fees (n=10), or to afford compulsory equipment and uniform, school transport and outings. These concerns over schooling costs support recent evidence of maternal bereavement negatively affecting educational access (Case & Ardington, 2005). Where children did attend school, twenty-two identified it as a protective factor.

Children identified socialising as protective (n=20), and friends as a source of comfort (n=29). Lack of friends (n=9), bullying (n=10), teasing, fights (n=8) and being beaten by friends (n=23) were identified as risks: 'My friends make me sad because they bully me and swear me out and make fun of me...but I don't mind because they're my friends'. Heads of child-headed households identified responsibilities restricting peer friendships. More generally, parentification of children and inability to 'be a child' were stressed.

Physical safety and crime

Children in townships are frequently exposed to crime, and 16 children were distressed or angered by muggings, robbery and assault. Others witnessed robberies, imprisonment and violence towards friends and family: 'beating someone or being beaten or my daddy being stabbed with a bottle'. Caregivers and children saw lack of safe play areas as encouraging behavioural problems. Six children were distressed by poor physical health, including stomach problems, headaches, and general illness 'My head's terrible and my body's sicked'.

Stigma and gossip

Figure 21: Qualitative data: 'What makes me sad?' Boy, 16, Guguletu

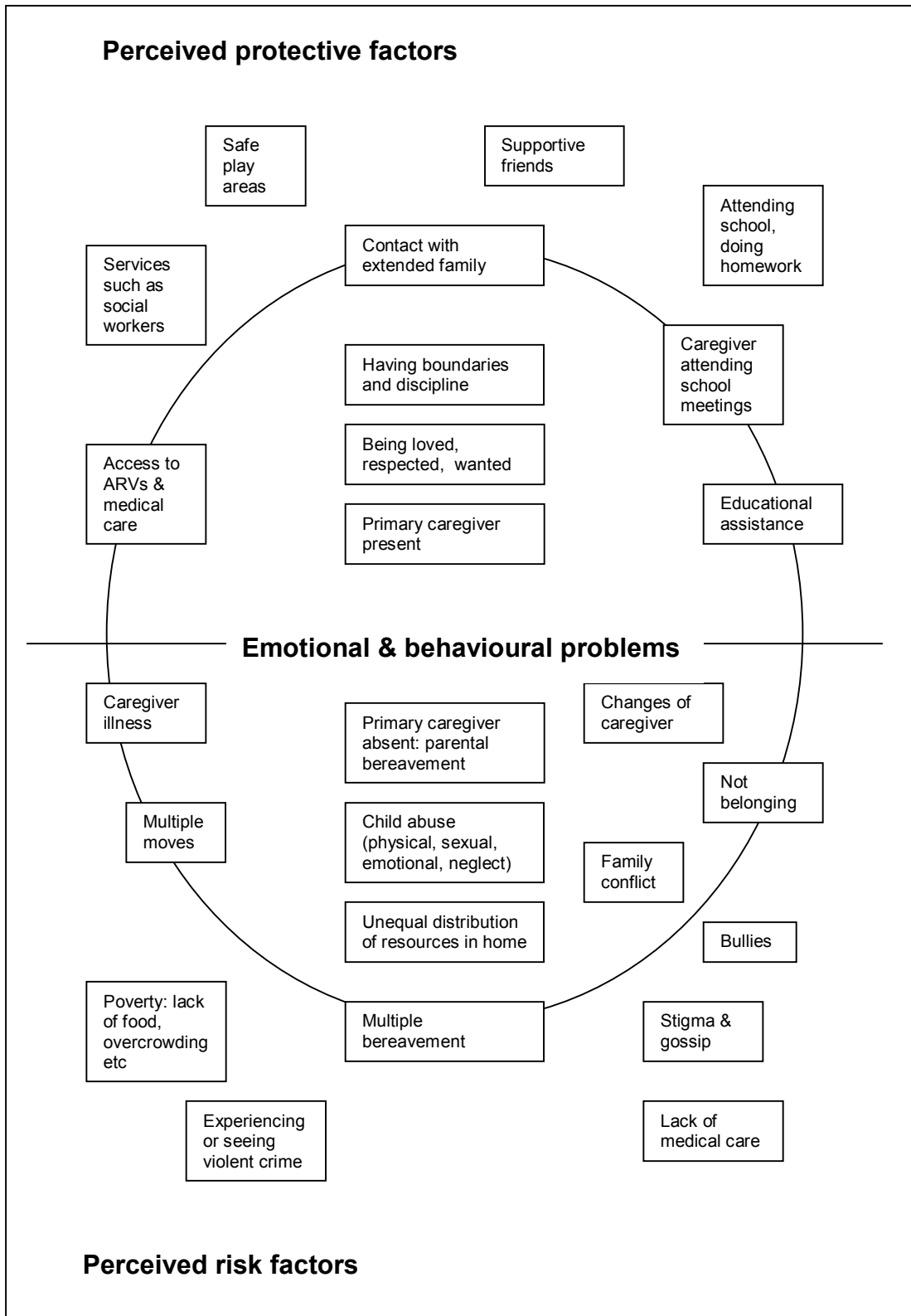
When some one is shouting at me
and when people are gossiping about
me or laugh at me or beat me up
When people swear at my mother

Fourteen children described stigma and gossip (although none mentioned HIV/AIDS specifically). This included 'Gossiping about me behind my back', teasing, and being shouted at in public. Distress was caused by people 'Talking about my parents' (n=4), and spreading rumours (n=6). Notably, three children were distressed by verbal abuse towards surviving (possibly HIV+) parents.

Positive Activities

All groups identified activities which improved well-being and provided comfort. These included sport (n=23), playing (n=18), TV (n=20) and outings (n=11), singing, music, dancing (n=10) and reading (n=12). Children gained comfort from homework, writing in diaries (n=5), library visits, TV (n=13), reading (n=6) spending time alone (n=6), sport (n=12) and prayer or church attendance (n=3). Many stressed the importance of having a trusted confidante.

Figure 22: A graphic overview of qualitative findings (factors perceived by participants)



4.5 Discussion

This study identified factors which orphaned children, their caregivers, and professionals perceived as affecting psychological well-being of AIDS-orphaned children. Many factors are consistent with those found in Chapter 3's review of literature on children experiencing other stressful life experiences. However, some factors have not been previously identified, or have not been identified as having particular importance for AIDS-orphaned children. For example, perceived unequal treatment within new homes may be especially relevant to orphans in contexts of stigma and limited resources. Multiple bereavement and stressors on heads of child-headed households reflect risks particularly (although not uniquely) relevant to AIDS orphanhood. Reported experience of gossip and teasing suggests HIV/AIDS-related stigma, supported by examples of gossiping and shouting at surviving parents.

Limitations of the study

The qualitative study shares a number of methodological limitations with the larger quantitative study, which are discussed in Chapter 7. These include: unknown HIV status of child and caregiver respondents, possible caregiver depression or distress, lack of longitudinal evidence, and problems with cross-cultural psychology. There are also a number of limitations particular to the qualitative study.

Sampling limitations

The study sampled only one ethnic group within Cape Town – that of isiXhosa children. This is the group most affected by HIV/AIDS in the Western Cape province. The sample included only urban children from low-income areas, and caregivers of children in urban, low-income areas. Professionals working with orphaned children included a range of ethnic groups, and educational levels, but were largely working with isiXhosa children.

Data collection limitations

A number of different data collection approaches were used, in order to allow children choice of response modes and to improve the participatory elements of the study. It also aimed to allow children different response modes according to literacy levels. However, this resulted in a range of different types of data for coding: responses were written by children, or written by interviewers using children's verbatim words, or were pictures drawn by children, or drawn by interviewers at children's request (or were a mixture of these response modes). This presents difficulties in interpretation of data, for example interviewers may have not fully recorded responses of children, or pictures may not have fully expressed children's responses. Ideally, these limitations in data would have been resolved by using taped qualitative interviews, or by supplementing the worksheet-based data with tape recordings of interviews, which would then have been transcribed, translated where necessary, and subsequently coded. This would have followed more traditional qualitative research techniques (Tesch, 1990). However, the use of tape-recorders or videos were not possible in the research areas, which at the time of data collection were experiencing a particularly high-crime period, and in which it was not safe at the time to use electronic equipment.

Interviewer limitations

More generally, the use of interviewers to assist children has both positive and negative impacts on the quality of data. Many children would not have been able to participate without interviewer assistance, but interviewers may bring bias and personal opinions to any qualitative data (Corden & Sainsbury, 2006). It is not possible to be sure that verbatim quotations from children were accurately recorded. There are also risks that children may have adjusted responses to interviewers, or may have hoped for material assistance by expressing material needs to a sympathetic adult. Interviewers may also have been limited by knowledge of current street slang (especially as used by streetchildren).

Focus Group limitations

The use of focus groups with caregivers of orphaned children was positive in encouraging caregivers to discuss experiences, and encouraged group responses. However, there are a number of limitations associated with the use of focus groups, particularly when discussing a highly-stigmatised issue such as HIV/AIDS (Morrow, 2001). The focus groups did not mention HIV/AIDS, and when caregivers discussed stigma there was generally a tacit understanding of what was being referred to, but the focus group method may have discouraged some caregivers from discussing other factors specific to HIV/AIDS orphanhood.

Practical limitations

Lack of privacy for focus groups may have affected responses, especially regarding the high levels of AIDS-related stigma in study areas. For focus groups in particular, windows often had to be left open in order to cool extremely hot rooms without air-conditioning. For interviews with children, it was often difficult to get total privacy in low-resource community environments.

Interpreting data in the light of methodological limitations

This study was aiming to generate list-based data of potential risk and protective factors, rather than in-depth qualitative responses (Ratcliffe et al., 2005). The use of interviewers, a range of response modes and the lack of taped, transcribed data mean that the data should not be interpreted beyond these generated lists of potential factors, and that thematic coding is limited by the nature of the data available.

Merging of data

Thematic coding of the data merged responses from three perspectives: orphaned children, caregivers, and professionals working with orphaned children. This presents

major difficulties in determining where differing perspectives may have produced different responses. For example, caregivers often stressed risk and protective factors related to caregiving, and some professionals gave a more psychological perspective (i.e. mentioning ‘parentification’ of heads of child-headed households). However, there was a surprisingly high level of agreement between group responses. The study aimed to produce a wide range of potential factors, which would be tested in the quantitative stage. Thus it was considered less important to distinguish between different perspectives in the qualitative data, as factors would be able to be quantitatively tested against mental health outcomes.

Study strengths include a good sample size of orphans and caregivers, and the use of a range of participants. In determining factors affecting child well-being, it is important to consider a range of sources of evidence, including those of service providers, caregivers and children themselves (Noble, Wright, & Cluver, 2007).

4.6 Summary and conclusions

This qualitative study focuses specifically on orphans’ and their caregivers’ perceptions of risk and protective factors for psychological well-being. The qualitative approach, through grounded theory, allowed us to develop hypotheses directly from the experiences of AIDS-affected families and from professionals, rather than by using prior theories from research based on different stressors. A qualitative approach was also important in allowing for participant-led identification of needs, and produced a high level of corroboration between participants on a number of factors. The use of positivistic, experimental methods to complement descriptive phenomenological methods allows for increased validation of findings within the overall study (Valle, King, & Halling, 1989).

Findings of this present stage of the research indicate potential risk and protective factors in a range of ecological levels (Bronfenbrenner, 1979), including bereavement, family functioning, social support, poverty, access to education and perceived stigma. Many factors reflected the literature identified in Chapter 3, on children experiencing similar

stressors (i.e. non HIV/AIDS-related bereavement). However, this study also identified factors which may be specific to this group, notably stigma, abuse and peer factors. Findings from this qualitative stage were combined with the literature review, and were also combined with items suggested by NGOs and government departments. Chapter 5 describes in full the final list of risk and protective factors which were tested in the quantitative stage of this thesis. It also describes the methods chosen to measure the selected risk and protective factors. Finally, it describes the process of quantitative data collection involved in determining the relevance of the factors identified in Chapters 3 and 4, on the mental health of a large sample of children in Cape Town.

Chapter 5: Quantitative Stage: Methodology

- 5.1 Introduction
- 5.2 Research Questions, hypotheses and aims
- 5.3 Sampling and data collection:
 - Sample Group
 - Control groups and matching
 - Sampling strategies
 - Determining AIDS death
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- 5.4 Fieldwork challenges and research constraints
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 - Giving back: to organisations, children
- 5.6 Instruments:
 - Questionnaire design and piloting
 - Child-friendly presentation
 - Choice of instruments: collaborations and added items
 - Risk and protective factors
 - Standardised mental health scales
- 5.7 Methodological limitations
- 5.8 Data entry and data cleaning
- 5.9 Analysis strategy
- 5.10 Dissemination of findings
- 5.11 Summary and conclusions

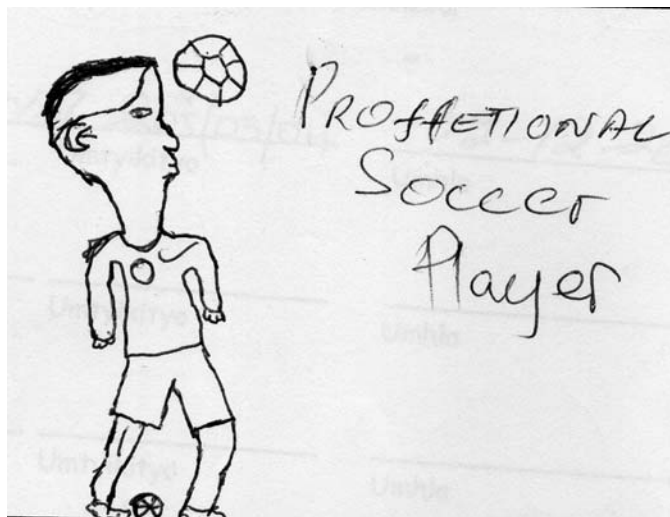
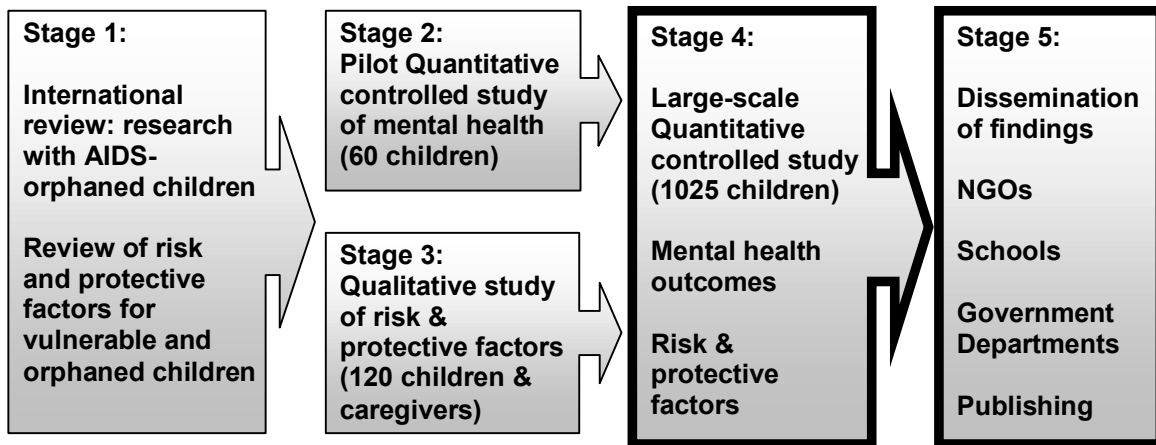


Figure 23: Boy, 13, Nyanga 'What do you want to be when you grow up?'

5.1 Introduction



The present chapter addresses Stage 4 and Stage 5 of the research design. It outlines the methodology and fieldwork of the quantitative stage of the research, and the dissemination of study findings.

Chapter 2 reviewed international evidence, which suggested that AIDS-orphanhood may be associated with psychological problems. Chapter 3 reviewed evidence on potential risk and protective factors in the mental health of AIDS-orphaned and other vulnerable children. Chapter 4 described the findings of a qualitative study which identified child and caregiver perceptions of risk and protective factors. Chapter 5 describes the mental health outcomes, risk and protective factors measured, and the measurement tools used. It further describes the sampling, fieldwork and ethical methodologies used to test the research questions in a large quantitative sample. Finally, it describes the dissemination strategy outlined in Stage 5 of the research design.

5.2 Research Questions, Aims and Hypotheses

This research investigates the mental health of, and risk and protective factors for, non HIV-infected children orphaned by HIV/AIDS. It is hoped that the findings of this study will help to inform future interventions and policy for orphans. There is a consensus within the HIV/AIDS literature that research is critically necessary in the area of orphan mental health. (Armistead & Forehand, 1995; Bowsky, Nnamdi-Okagbue, Tembo,

Sangiwa, & VanPraag, 2002; Bradshaw, Johnson, Schneider, Bourne, & Dorrington, 2002; Bray, 2003a, 2004; M. Freeman, 2003; Giese et al., 2003; Smart, 2000; J. Stein, 2003; UNAIDS, 2004) There is also a need to increase understanding of risk and protective factors for orphans, in order to inform effective interventions.

Research Aims

Part 1 investigated the mental health of orphans compared to control groups of non-orphaned children and children orphaned by causes other than AIDS. Aims were a) to determine whether children orphaned by AIDS experience more mental health difficulties than non-orphaned children and b) to explore what types of mental health problems orphaned children may be experiencing. A further aim was c) to cautiously compare proportions of children scoring in the clinical-range, to Western norms.

Part 2 investigated risk and protective factors affecting mental health for orphaned children. Aims were to explore associations of these factors to mental health outcomes and to inequalities in outcomes between orphanhood groups. The study aimed to explore risk and protective factors in all key areas of children's lives: home, school, peer groups and the wider community. A further aim was to examine interactions between risk factors which may be producing a cumulative effect on mental health problems. The study focused on factors which had relevance for policy and interventions.

Research Hypotheses

1. Children orphaned by AIDS show a higher incidence of some mental health difficulties than non-orphaned children from the same community
2. Children orphaned by AIDS may show a higher incidence of mental health difficulties than children orphaned by non-AIDS causes from the same community.

3. The relationships between orphanhood and psychological difficulties are mediated by risk and protective factors (such as caregiving, community and economic factors) in addition to emotional distress resulting from the loss of a parent.

5.3 Sampling and Data Collection

Sample Group

Summary of characteristics of orphan sample group

- Between the ages of 10 and 19,
- Have experienced the death of either, or both parent/s to HIV/AIDS,
- Not known to be HIV+,
- Have not been bereaved in the past 6 months.
- Oversampling of orphaned streetchildren and child-headed households

Decisions regarding selection criteria for sample and control groups took place within the context of a wider debate around categories of children in South Africa. This study compares children orphaned by AIDS, children orphaned by non-AIDS causes, and non-orphaned children. There is ongoing debate regarding definitions of these groups, and categorisation of groups as distinct. There is further debate on the policy implications of these definitions and distinctions.

‘Orphans or Orphans and Vulnerable Children’

The definitions and terms used for particularly vulnerable groups of children are important, and affect both policy and attitudes towards those children. For this reason, it is helpful to discuss in more detail the definitions used in this study, and the sampling implications of those definitions.

AIDS-orphaned children are included within the wider category of ‘OVC’: Orphans and Vulnerable Children’ or ‘Other Vulnerable Children’, or ‘Vulnerable children’. This category has been identified as the most valuable and non-stigmatising definition for use at community and at policy-levels.

However, there is little agreement or clear definition on criteria for belonging to this category (Richter et al., 2006), and definitions further differ between countries in sub-Saharan Africa (Skinner et al., 2004; Smart, 2003). Examples of groups included in the ‘OVC’ category are: children separated from parents, children experiencing hardship due to illness, incarceration, disability, children of single or teenaged mothers, and all children living in poverty. Other categories of children included in the definition are

‘children are regarded as vulnerable when they are separated from caregivers, are malnourished, abused, neglected, out of school, disabled, ill, required to do excessive work, or lack access to services’ (Richter et al., 2006).

The Children’s Institute at the University of Cape Town proposes a narrower definition of ‘Orphans and Vulnerable Children’:

‘Children whose care is compromised as a result of one of the following: The terminal illness of an adult who contributes to the care and/or financial support of the child, or the death of an adult who contributed substantially to the care and/or financial support of the child’ (Giese et al., 2003).

A similar term (now less commonly used in South Africa) is ‘Children in Distress’ (CINDI). Within the wider group of ‘OVC’, literature has also focused on the groups of ‘Children Affected By AIDS (CABA)’ or ‘children affected and infected by HIV/AIDS’. Definitions of this group are also broad and interpreted in differing ways. ‘Children affected by AIDS’ could arguably include all children in South Africa (given the high prevalence of HIV), but is generally used to refer to children who are HIV+ or who have HIV+ family members. Within the group of ‘Children affected by AIDS’, is a sub-group of ‘children orphaned by AIDS’.

It is important to recognise also, that ‘orphanhood by AIDS’ is not an event, but a process. Concentration on orphaned children may exclude many children who live with

sick parents, and little is known about numbers of children living with, or caring for, sick parents (Richter et al., 2006).

Using the categories of ‘OVC’, ‘Vulnerable children’ or ‘Children affected by AIDS’ has many advantages. They provide a more nuanced understanding of vulnerability in the context of the HIV/AIDS epidemic, and include children who may not be parentally bereaved, but whose well-being is compromised. The terms are flexible, avoid stigmatising labelling, and allow for community identification of need. However, for the purposes of a rigorous sampling methodology, the lack of clear or agreed definitions of these definitions is problematic. It is also necessary to provide clear evidence of any differentiation of need within the wider group of ‘vulnerable children’.

This study hypothesises that ‘orphanhood by AIDS’ may have psychological consequences independent of, or greater than, those associated with being a part of the wider groups of ‘affected’ or ‘vulnerable’ children. However, it is important to note that the definitions of ‘orphan’ and ‘orphan by AIDS’ are themselves contested terms in the context of sub-Saharan Africa.

Contested definitions of orphanhood

A range of contested definitions within orphanhood are currently used, and have implications for the sampling frame used for this study.

UN definition: The UN definition of ‘children orphaned by AIDS’ is “a child who has at least one parent dead from AIDS” (UNAIDS, 2004). Within this is a distinct category of ‘double orphans due to AIDS’ as “a child whose mother and father have both died, at least one due to AIDS”. Distinctions are made between maternal, paternal and double orphans, with all groups included within ‘total orphans’ (UNAIDS & UNICEF, 2002) (see Figure 24).

Figure 24: Double orphanhood by AIDS (UNAIDS, 2004)

		Mother			
Father			Dead		Alive
			AIDS	Other	
	Dead	AIDS	Double Orphan (AIDS)	Double Orphan (AIDS)	Paternal AIDS
		Other	Double Orphan (AIDS)	Double Orphan (Non-AIDS)	
	Alive		Maternal AIDS		

South African legislation: At the time of data collection, the draft South African Children’s Bill (12 August 2003) did not define the term ‘orphan’(Republic of South Africa, 2003).

The Children’s Bill was further refined into the Children’s Act of 2005, which was passed but has not to date been entered into statute (Republic of South Africa, 2005). A definition from an earlier draft (of October 2002) was re-introduced: **“orphan”** means a child who has no surviving parent caring for him or her; **“parent”**, in relation to a child, includes the adoptive parent (1.1). No specific mention or distinction is made between children orphaned by AIDS and children orphaned by other causes.

‘Parents’ or ‘Caregivers’?

Both UN and SA legislative definitions of orphanhood focus on the loss of biological parents. This is argued to be insensitive to multiple child raising forms in South Africa. Research by the Children’s Institute such as Meintjies et al (2003) and Giese et al (2003), emphasise that child caregiving arrangements in South Africa are often fluid.

‘There is a long history of children not being constantly parented by either one of their biological parents, and living with other adults as caregivers for at least periods of their lives’. (Meintjies et al., 2003)

Other research supports the notion of non-nuclear caregiving arrangements for (in particular) Black African children in South Africa (Russell, 2002; Spiegel & Mehlwana, 1996). For AIDS-affected families, qualitative research has shown that children’s

migration between family members functions as a response to illness, orphanhood and family needs (Ansell & Young, 2004; Young & Ansell, 2003).

These views suggest that biological orphanhood may not be a sampling frame which is sensitive to the South African context. However, the 1998 October Household Survey found only 25.1% of children under 14 living with neither parent, (20.6% of children with both parents alive). Within the Western Cape, only 11.8% of children lived with neither parent (9% of children with both parents alive). In 2005, 19% of children (under 15) whose mothers were alive, lived in a different household to their mothers (Anderson & Phillips, 2006).

Implications for study design

It is important to remember that the definitions above are intended for use in policy, and address a wider context of orphan needs than those of this research study, which concentrates narrowly on the mental health effects of orphanhood. However, some of these divergent definitions have implications for study design.

Firstly, if children normally experience different caregivers, it is possible to argue that the death by AIDS of any of these caregivers (whether a biological parent or not) could have psychological implications. This study defines orphanhood as loss of a biological parent. Is this culturally inappropriate to extended family caregiving arrangements?

Literature exploring the effects of parental bereavement on children has been discussed in more detail in Chapter 3. The vast majority of studies have taken place in the developing world, and in the context of nuclear families (ie. Dowdney et al., 1999a; Stoppelbein, 2000; Thompson, 1998; Van Eederwegh, Clayton, & Van Eederwegh, 1985), although some has been carried out elsewhere (Kalantari et al., 1993). Allowing for inevitable difficulties in cross-cultural comparison, the evidence from this body of research suggests that parental bereavement does affect the mental health of children. Searches have found

little available research on children's responses to the deaths of non-parental primary caregivers.

Secondly, if 'orphanhood' is extended to include children with unwell caregivers, as suggested by the Children's Institute, it becomes impossible to distinguish within the research, the mental health effects of parental bereavement on children.

Thirdly, if orphanhood is limited to the Children's Act definition of 'no surviving parent caring for him/her', it excludes a large number of children who have been parentally bereaved, and are cared for by a surviving, but AIDS-infected parent.

Sample group: Orphaned children: Whilst acknowledging the complexity of caregiving arrangements, this study has chosen to define orphanhood, and AIDS-orphanhood, according to the UN definition and terminology. The UN definitions, whilst having drawbacks detailed above, provide a useful and clear distinction for sampling purposes. Available evidence suggests that a large number of children do live with biological parents (for at least part of the time), and that death of biological parents may have mental health implications. Furthermore, the UN definition is currently the only internationally accepted definition of orphanhood. The South African Children's Act has undergone multiple changes, is currently under amendment, and has not yet been entered into statute.

In summary, this study recognises that the deaths of both parental and non-parental caregivers may have important effects on children. However, for the purposes of a clearly-defined sample group which concurs with international definitions of orphanhood, this study will focus on children who are maternally, paternally or doubly parentally bereaved.

Further narrowing of the sample group: Age of children

The UN definition of ‘orphanhood’ has moved from the 2002 limit of 15 years (UNAIDS & UNICEF, 2002) to 18 years, (UNAIDS, 2004). This concurs with both the UNICEF definition of childhood (UNICEF, 1989), and the South African Constitution (Republic of South Africa, 1996b). However, many sources continue to use 15 as the upper age limit for orphanhood (Anderson & Phillips, 2006; Department of Health, 1998). Despite this, UN data finds that 88% of orphans worldwide are aged 6-17 (55% aged 12-17) (UNAIDS, 2004). The current study focuses on children and adolescents above age 10.

The lower age limit of 10 years is based on a number of methodological and contextual considerations. Children under 10 in the pilot study (Cluver & Gardner, 2006) had difficulty in understanding some of the items in standardised questionnaires (even those aimed at younger children in the developed world). Evidence shows that orphans are likely to have educational difficulties (Operario, Pettifor, Cluver, MacPhail, & Rees, in press), lowered school attendance (Case & Ardington, 2005; Muller, Sen, & Nsubuga, 1999), and difficulties with schoolwork due to caregiving responsibilities, worry and stress (Cluver & Gardner, 2006; Giese et al., 2001; Sengendo & Nambi, 1997). Quantitative studies have found lower educational achievement amongst orphans than non-orphans (Draimin et al., 1992; Forehand et al., 1999; Sengendo & Nambi, 1997). Therefore, it was hypothesised that this particularly vulnerable group may find the length and activities of standardised questionnaires difficult, and that children under aged 10 should be excluded from the sample.

The upper age limit for this study was 19 years old, in accordance with the World Health Organisation definition of adolescence (World Health Organisation, 2003). The University of Cape Town research in the Eastern Cape (Wild et al., 2006, July) used age limits of 10-19. However, it is recognised that 10-19 years is a large age range when taking into account the developmental changes which take place during late childhood and adolescence. This may be a limitation of the study.

HIV+ Children

Children who are infected with HIV are clearly a vulnerable group, and their mental health is an important area for research. However, children who were known to be HIV+, including those who were AIDS-unwell, were not included in this study.

HIV-related mental health problems present a potential confounding factor in determining psychological effects of orphanhood. There is growing evidence that an HIV+ diagnosis and illness have adverse mental health effects, independent of orphanhood, in both adults (Baingana, Thomas, & Comblain, 2005; Brandt, 2007; Olley et al., 2003; Tedstone & Tarrier, 2003) and children (Gosling et al., 2004; Green & Smith, 2004). Furthermore, children may experience AIDS-related psychosis through syndromes such as encephalopathy, and AIDS-associated dementia or delirium at later stages of illness. Possible psychiatric effects of HIV infection include delirium, dementia, neurocognitive impairment and sleep disorders (Moultrie & Kleintjies, 2006). The relationship between depression and decreases in immune function amongst children is not yet clear (McDaniel et al., 2000), although studies suggest heightened prevalence of concentration, behavioural and emotional problems (Gosling et al., 2004; Nozyce et al., 2006). There may also be indirect effects of HIV infection, such as virus-induced lethargy, and mental health impacts of poor general physical health. Some HIV-infected children receive psychological support through treatment programmes, whilst others do not.

However, there are limitations to the extent to which researchers can be certain of the HIV status of non-clinical samples in sub-Saharan Africa. Given low levels of testing in study areas (Kalichman & Simbayi, 2003), and in South Africa as a whole (Department of Health (South Africa), 2002) most children were not aware of their HIV status. In practical terms, this meant that the study did not include children who were *known* to be HIV+, or who were clearly ill with AIDS-related infections⁷. However, proportions of

⁷ This category included children who showed clear physical signs of AIDS-related illness, such as Kaposi's sarcoma, or children who reported concurrent infections such as tuberculosis and shingles. However, this was very rare amongst the sample group, and mainly occurred amongst streetchildren. Interviewers all had extensive experience of working with HIV and AIDS-affected families. However, the exclusion of children who seemed very likely to be suffering from AIDS was not intended to be a primary

HIV-infected children in the Western Cape are 2-6%, suggesting that it is very likely that some participants were HIV-infected. HIV-testing was not conducted as part of this study due to the high cost associated with collecting, storing, transporting and testing of samples, and due to ethical implications of HIV-testing in a study which did not mention HIV/AIDS (due to children's frequent lack of knowledge regarding cause of parental death). Methodological limitations associated with low levels of testing and the lack of HIV testing in this study are further discussed in Chapter 7.

Children experiencing acute bereavement

There is conflicting and insufficient evidence regarding the duration of bereavement reactions amongst children. However, there is some evidence of acute reactions immediately after parental death (Silverman & Worden, 1992; Van Eederwegh et al., 1982). Following other research in sub-Saharan Africa on psychological distress amongst children orphaned by AIDS (Makame et al., 2002; Manuel, 2002; Wild, Robertson, & Flisher, 2001), this study excluded from the sample group any child who had been parentally bereaved in the previous 6 months. This was intended to prevent the potential confounding factor of acute bereavement on children's mental health.

Caregiving arrangements: including relevant groups

One focus of this study was the exploration of effects of differing caregiving arrangements for orphaned children. Within the orphan 'population' are children living in a range of differing care arrangements. These include children living with surviving parents, living with grandparents, with other family members, streetchildren, child-headed households, children in non-kin foster care, and institutionalised children. The research aimed to recruit sufficient numbers of children in all types of caregiving arrangement to include in analyses.

method of excluding HIV+ children from the sample. It is recognised that HIV+ children were almost certainly included in the sample without the interviewers' or PI's knowledge.

A representative sample of orphans in Cape Town, would have been likely to provide insufficient numbers in some subgroups for inclusion in regressions. In particular, children in child-headed households, and children living on the streets were unlikely to be adequately represented in school or household surveys. Therefore, a strategy for purposive oversampling was developed. This study included both school and community sampling, with supplementary samples from welfare agencies, community and faith-based organisations, schemes for streetchildren, and organisations working with child-headed households. Very small proportions of orphaned children are reported to be living in institutions such as orphanages. This study hoped to recruit orphaned children living in institutions, but there were a very small number of orphanages or children's homes in the study area, and those available tended to admit only HIV+ children.

Control Groups and Matching

This study aimed to explore associations between AIDS orphanhood, risk and protective factors, and mental health outcomes. Rutter (2000) emphasises the need for research to 'pull apart' variables that normally go together. In order to isolate psychological effects of orphanhood by AIDS from the effects of orphanhood more generally, the study included two control groups:

- Children orphaned by causes other than AIDS
- Non-orphaned children

Summary of sample and control groups

In summary, this study recruited sample groups of

- *AIDS-orphaned group*: Children orphaned by AIDS (mother and/or father has died, not known to be HIV+, and where parental death is >6 months before recruitment)

- *Other-orphaned group*: Children orphaned by causes other than AIDS (mother or father has died, not known to be HIV+, and parental death is >6 months before recruitment)
- *Non-orphaned group*: Children who have not experienced the death of a parent.

All groups were matched on gender, age and close geographical proximity. Orphaned streetchildren were matched with non-orphaned streetchildren from the same shelter or feeding scheme. Certain groups were oversampled to allow sufficient numbers for analysis.

Matching: conceptual and methodological challenges

Case-controls were matched by gender, age, and close geographical proximity. Where schools and organisations included both orphaned and non-orphaned children, an element of random selection of controls was obtained by using alphabetical selection of non-orphaned child of the same gender and age from school registers and organisation files.

It should be noted that this method of matching did create one unexpected difficulty. In the South African education system, children who do not 'pass' the year or who cannot pay school fees for that year, stay behind and repeat the previous grade. In school sampling, orphaned children were matched with alphabetically succeeding children of the same gender and school class. It was assumed that children's ages would be comparable within the same school class and grade. However (see Chapter 6 for reporting of this result), children orphaned by AIDS were more likely to be 2 or more years behind at school (33.2%) than children orphaned by other causes (25.8%) ($p < .05$ χ^2 3.87) and non-orphans (18%) ($p < .001$ χ^2 18.19). This meant that age was not sufficiently matched in the school samples, and consequently was controlled for in all analyses.

The extent to which a study of this kind should aim to match control and sample groups on socio-demographic variables raises a difficult methodological issue. If the study attempts to match on all current factors except orphanhood (such as household income,

educational status, caregiving arrangement), it aims to isolate the single factor of parental death in determining mental health difficulties. In the pilot study, where possible, orphans were matched with non-orphaned children in the same household, thus attempting to match on as many socio-demographic factors as possible (Cluver & Gardner, 2006).

However, orphanhood by AIDS in South Africa is characterised by a far wider set of accompanying experiences than just parental death. These include exacerbated poverty (Booyesen & Bachman, 2002), stigma and multiple changes of caregivers (Muller et al., 1999; Smart, 2000; UNAIDS & UNICEF, 1999). Some caregiving circumstances, in particular child-headed and youth-headed households, are almost entirely associated with AIDS-affected families. It is not known which of the factors (or combinations of factors) which make up the experience of orphanhood, may be affecting children's mental health.

By attempting to match for factors such as differing levels of poverty in orphan households, the study would have potentially created a false isolation of parental death within the experience of AIDS-orphanhood. Many of the demographic factors which could be matched, may be consequences of orphanhood and not confounding variables that need controlling out.

Matching strategy for community and school sampling: School and community samples of orphaned and non-orphaned children were matched on gender, age and close geographical proximity. Where orphaned children were recruited from schools and organisations including non-orphaned children, a randomly chosen sample of non-orphaned children was selected. Where orphans were recruited from orphan-specific projects, they were matched to control children in the same community, recruited through random door-to-door sampling. Community sampling was door-to door, and thus orphaned children were matched to non-orphans living in near proximity.

In this study area, matching of groups by geographical proximity and school class should have been sensitive to many socio-demographic variables. The Western Cape is highly differentiated by neighbourhood, with a high level of homogeneity within small

neighbourhoods on factors such as formal/informal housing, household income, ethnicity, migration status and employment levels (Noble et al., 2005). However, household-level impacts of HIV/AIDS on income, expenditure and employment, have resulted in impoverishment of affected families within communities (Booyesen, Bachmann, Matebesi, & Meyer, 2004; J. Steinberg, S. Johnson, G. Schierhout, & D. Ndegwa, 2002). This was reflected in the findings of this study, which showed AIDS-orphaned children to have similar access to community-level variables such as electricity and running water, but highly significant differences in household employment, food security and household possessions.

Matching strategy for streetchildren: Matching for orphaned streetchildren presented methodological and conceptual challenges. No reliable data exists on proportions of streetchildren who are orphaned, or who are orphaned by AIDS (Connolly & Ennew, 1996). If we had followed the sampling strategy used for the community and school samples, orphaned streetchildren should have been matched with non-orphaned non-streetchildren. This strategy would assume that orphaned children were living on the streets as a direct result of being orphaned (probably true, but with no available evidence to support this supposition), and that living on the streets is a direct and negative result of orphanhood.

However, matching orphaned streetchildren to non-orphaned children in their close geographical area would result in extensive sociodemographic discrepancies, as most sleep on the streets of high-income city central areas. Orphaned streetchildren could be compared with non-orphaned children who come from their area of origin, but this presents practical difficulties due to the high levels of migration of streetchildren from areas such as Gauteng, Durban and neighbouring countries.

There are further conceptual problems with matching of orphaned streetchildren to non-orphaned non-streetchildren. No known studies compare mental health of streetchildren to community samples. However, available studies suggest that life on the streets (or the circumstances leading children to leave home) has an extensive impact on mental health,

particularly with respect to behaviour problems, drug use and risk behaviour. Therefore, matching of streetchildren to community samples risks confounding the factor of orphanhood with the multiple potential mental health risk factors associated with the experience of life on the streets (Richter & Van der Walt, 1996). It would risk falsely raising levels of psychological distress amongst the orphaned group, by reflecting effects of being a streetchild.

This was a difficult methodological decision, and the potentially extreme nature of the ‘streetchild effect’ suggested that it was important to approach the sampling of this group differently from other community samples of caregiving arrangements. Streetchildren orphaned by AIDS were matched to streetchildren orphaned by non-AIDS causes and non-orphaned streetchildren, within the same shelters and feeding schemes.

Numbers in each group:

The study recruited 425 children orphaned by AIDS, 241 children orphaned by other causes and 278 non-orphaned children. The higher numbers in the group of AIDS-orphaned children was due to oversampling of orphaned children in particular living arrangements (such as child-headed households, living with aunts and uncles) to allow for sufficient numbers in each group for regression analyses.

Sampling Strategies

Summary of sampling strategy: In light of impossibility of random sampling and the unrepresentative nature of school sampling for this group of children, the study sampled children through a range of different sources:

- Schools (9)
- Door-to-door household sampling.
- Projects for child-headed households (2)
- Community projects for orphaned children (5)

- Community centres (3)
- Day centres for streetchildren (3)
- Shelters for streetchildren (6)

In some cases, more than one child in a family was recruited. This included cousins, half-siblings and full siblings. Of these children, some were living with other recruited children in one household (sometimes in different dwellings within a household group) or in different households. Living within the same household in an extended family structure meant that children within the same families often had different adult caregivers. Children were also recruited who were not biologically related but who were living in the same households as other child participants.

Sample size: Traditional sample size calculations based on ‘power’ do not apply directly to multiple comparisons (Hsu, 1996). As this study included 3 comparison groups (AIDS-orphaned children, other-orphaned children and non-orphaned children), determining a sufficiently-powered sample size for this study required the use of multiple comparison procedures⁸. Due to problems of underestimation of sample size identified for Scheffe’s, Bonferroni’s and Dunnett’s techniques (Pan & Kupper, 1999), we used an all-pairwise comparison using Tukey’s method (Guilbad’s technique). A confidence level of .95 was used, and standard deviations estimated using those established in standardisation studies of each psychological questionnaire. Subsequently, the minimal difference to be detected was derived using cut-off scores for clinical levels of each disorder: Child Depression Inventory, Revised Children’s Manifest Anxiety Scale, Strengths and Difficulties Questionnaire, Child Behaviour Checklist, Child PTSD Checklist. This varied by different standardised questionnaires, for example the Child Behaviour Checklist gives a range of scores for the ‘abnormal’ boundary, whilst the Child PTSD checklist requires a symptom score from each of the four symptom clusters of avoidance, numbing, hyperarousal and re-experiencing. In order to determine a conservative value for ‘minimal difference’, the required difference was such that it was able to distinguish

⁸ The power calculation was assisted by Jonathan Polonsky (London School of Hygiene and Tropical Medicine)

between a child's score which was clearly in the 'normal' range, and a score which was clearly in the 'abnormal' range. Sample size computations were undertaken for each scale individually, using a multiple comparison sample size calculator recommended by Hsu (1996) and provided by the Ohio State University Department of Statistics (<http://www.stat.osu.edu/~jch/ssinput.html>). The scale with the highest sample size required (the Child PTSD Checklist) was used in order to provide the most conservative sample size estimate. The minimum sample size was estimated to be 115 in each orphanhood group, with 345 children in the total sample. However, all of these calculations were based on norms which had been established on different populations of children to this South African sample. In light of this, it was decided to elevate the sample size beyond that estimated in the multiple comparison computation.

Sampling strategies not used

Random sampling: Ideally, this study would have recruited a representative sample of orphans, through a random sample from the population of all children orphaned by AIDS in Cape Town (with oversampling where necessary for small groups such as streetchildren). However, a completely random sample would be impossible in the context of stigma and secrecy surrounding AIDS, and lack of known numbers or locations of orphans (Dorrington, 2001).

School Sampling: Many South African studies of child psychological well-being use school-based sampling (ie. Seedat et al., 2000; Ward et al., 2001; Zissis et al., 2000). School sampling is especially useful in terms of identifying control children. However, evidence does differ on the extent to which a school sample of orphans represents the population of orphans as a whole. Recent Human Development Report data for South Africa (UN Development Programme, 2004) report the proportion of orphans to non-orphans who attend school as 95:100. These data are strongly challenged by both qualitative and quantitative research which finds lower levels of enrolment and more irregular attendance amongst orphans (Case & Ardington, 2005; Case et al., 2002), especially amongst child-headed households and streetchildren (Berry & Guthrie, 2003;

Ferreira et al., 2001; Giese, Meintjies, & Chamberlain, 2002). It is possible that orphans who are attending school may be relatively more advantaged (and perhaps more well-adjusted?) than orphans who are not attending school. In recognition of this, community and door-to-door sampling was undertaken in addition to school sampling. All door-to-door sampling was undertaken by local, community health workers.

Streetchildren and child-headed households: Purposive oversampling of streetchildren and child-headed households was also undertaken. This was for three reasons. Firstly, these groups were unlikely to be sufficiently represented in community or school samples. Secondly, sufficient numbers were necessary for inclusion in regressions, and thirdly, these are subgroups of orphans which are predicted to rise in numbers in the future.

In terms of recruitment practicalities, it must be noted that there are challenges associated in interviewing streetchildren (Richter & Van der Walt, 1996), including difficulties in recruiting samples who are not accessing any services, and ethical issues regarding consent (Ennew, 1996; Swart-Kruger & Richter, 1997). In the Cape Town context, it was considered unsafe to conduct fieldwork with streetchildren outside centres providing services. However, interviews were conducted in long-term and short-term shelters, and in feeding schemes, thereby ensuring that the sample included children currently living on the streets.

Child-headed households also present challenges for recruitment, as these families often slip through social services, state and voluntary organisations' safety nets (Ayieko, 1998; Desmond, Richter, Makiwane, & Amoateng, 2003; Foster, 1997b; Giese et al., 2001). Some child-headed and youth-headed households were interviewed as part of school or community sampling. Further targeted sampling took place through Cape Town's two NGOs working specifically with child-headed households.



Figure 25: Sinako Youth Centre (Child-Headed Household Project)

Figure 26: Participating Organisations and Schools

Imbasa Public Primary School (Old Crossroads/Nyanga)
 Kwamfundo Public Secondary School (Harare, Khayelitsha)
 Moshesh Public Primary School (Langa)
 Intshinga Public Primary School (Guguletu)
 Bongoletu Public Primary School (Philippi/Brown's Farm)
 Yomelela Public Primary School (Site B Khayelitsha)
 Vuzamanzi Public Primary School (Site C Khayelitsha)
 Isaiah Christian Academy (Blue Downs)

Planned Parenthood Association: Child-Headed Household Project, (Macassar)
 Siyaphambili Orphan support group and feeding scheme (Langa)
 St Michael's Church Orphan Support Group (Harare, Khayelitsha)
 Planned Parenthood: Sinako Youth Clinic (Macassar)
 Vukhuzakhe Orphan Project (Site A Khayelitsha)
 Themabalabantwana: Cape Town Child Welfare Guguletu (Guguletu)
 Mandela Park Stadium Football Ground (Makhaza, Khayelitsha)
 Mrs Maposela (informal children's home) (Nyanga)
 Women for Peace Centre (Mfuleni)
 Cape Town Child Welfare Society (Guguletu and Khayelitsha branches)

Yizani Drop-in Centre for streetchildren (City Bowl)
 Learn To Live School for streetchildren (Seapoint)
 GC Williams Home for Streetchildren: Streetwise project (Athlone)
 Ons Plek Shelter for Streetchildren (City Bowl)
 Siviwe home for streetchildren (Woodstock)
 One Love Drop-in centre (City Bowl)
 The Ark Place of Haven (Blue Downs)
 The Bridge/Elukhuselweni Halfway House for Streetchildren (Khayelitsha Site B)
 Don Bosco Home for streetchildren (Sea Point)

Determining AIDS Death

Research in South Africa presents serious methodological obstacles to posthumous determination of cause of deaths in the context of AIDS. The Western Cape is characterised by high levels of stigma concerning the disclosure of HIV+ status (Deacon, Inez, & Prosalendis, 2005; Mills, 2004). This results in a lack of open knowledge regarding causes of death (Skinner & Mfecane, 2004). Levels of HIV testing are low (Kalichman & Simbayi, 2003), and many parents and families do not disclose HIV status to children (Marcus, 1999a).

Guidelines for medical practitioners result in the majority of death certificates not using the term HIV/AIDS. Instead, cause of death is given as one of the opportunistic illnesses leading to death, such as 'pulmonary tuberculosis' or uses the euphemism 'natural causes'. This is due to a number of reasons, including desire to prevent discrimination for surviving family members, lack of knowledge of the deceased person's HIV status, or to avoid invalidating life insurance claims (Editorial, *The Lancet*, 2005).

The above factors combined to make the determination of cause of parental death a methodological challenge. Levels of stigma in research areas were such that the methods of orphan studies in other countries had to be used with great caution (i.e. using 'community knowledge' to identify AIDS-orphaned children (Makame et al., 2002)). Because of the potentially damaging effects of disclosure, and in common with other research in Southern Africa (Makame et al., 2002; Manuel, 2002; Poulter, 1996), interviewers did not mention HIV/AIDS to children, nor was the disease mentioned on information sheets, consent forms or questionnaires. Parental death by AIDS in this study was determined by several criteria.

1) A small proportion of families (n=23) were aware of, and spontaneously disclosed, HIV status of deceased parents. In all other cases:

2) A 'Verbal autopsy' method was used. This method has been validated in a South African population (Hosegood, Vanneste, & Timaeus, 2004) and is used in South African demographic surveillance systems the Africa Centre and Agincourt (Pronyk et al., 2004) as well as in Uganda, Ghana, Tanzania and Ethiopia (Kamali, Wagner, Kengeya Kayondo, Nakiyingi, & Mulder, 1994; Quigley, Chandramohan, Setel, Binka, & Rodrigues, 2000; Setel et al., 2006). In a South African validation study, sensitivity of the verbal autopsy method for adult communicable diseases was found to be 89%, specificity was 93% and positive predictive value 76% (K. Kahn, Tollman, Garenne, & Gear, 2000). Typically, a child would identify parental death due to causes such as tuberculosis, cancer or bewitchment. Interviewers would then ask a further set of symptom-related items, using the World Health Organization classification of AIDS-defining illnesses (WHO, 2005b). These items were not included in the questionnaire, but were on a separate sheet for interviewers. Parental death due to AIDS was determined by the presence of 3 or more AIDS-defining illnesses, such as oral candidiasis, Kaposi's sarcoma, pulmonary tuberculosis or HIV-wasting syndrome (WHO, 2005b).

3) Further indicators of AIDS death included death of both parents from illness within a few years and/or infant deaths of siblings from AIDS-defining illnesses.

4) Where possible, participant report was corroborated by consultation with teachers, social workers and surviving parents. This was approached with extreme sensitivity in order to prevent risk of stigma. Teacher's forms asked for any indication of the cause of parental death, and teachers were asked verbally to note 'V' on the forms if they thought the death had been AIDS-related (this was to prevent any risk of forms being left lying around and other teachers or students seeing them). Where teachers noted this, confidential discussions were conducted with the PI. Social workers shared information regarding parental death from case files, with the PI only, and this information was not shared with families or with other interviewers. Discussion of cause of parental death with surviving parents or caregivers was approached sensitively by interviewers, who had extensive experience of working with HIV-affected families. HIV or AIDS were not

mentioned by interviewers unless parents or caregivers raised the topic. However, surviving parents were sometimes able to refer obliquely to HIV/AIDS. For example, one parent referred to ‘the disease which killed my husband and which I am now sick with. You know – the sickness’. However, corroboration of verbal autopsy symptoms from surviving parents was not a systematic methodological approach to determining parental HIV status, and was used only as supporting evidence where it was possible and ethical to be obtained.

5) Where verbal autopsy diagnoses were in doubt, symptom checklists were reviewed by 3 independent, blinded medical practitioners (Dr A. Lawson, Baragwanath Hospital, Dr C Cluver, University of Stellenbosch, and Dr J Sargent, Broadreach anti-retroviral Programme)

Tuberculosis and HIV

Complexities emerged in distinguishing deaths from tuberculosis (TB) alone, against deaths from AIDS-related tuberculosis. TB is the most common opportunistic infection and the most common cause of mortality in people living with HIV in developing countries (Grimwood, Hausler, Almeleh, & Hassan, 2006). Amongst laypersons in South Africa, TB has become synonymous with AIDS, to the extent that TB is often referred to as ‘asthma’ in order to avoid AIDS-related stigma.

There is extensive evidence of high correlation of TB and HIV (Groenewald, Nannan, Bourne, Laubscher, & Bradshaw, 2005), and longitudinal studies suggest that HIV is driving the TB epidemic in South Africa (Lawn et al., 2006). The incidence of TB in AIDS patients is 500 times greater than that in the general population and an HIV+ status raises likelihood of mortality from TB by 2-3 times (Harrison, Wilkinson, Lurie, Connolly, & Karim, 1998). HIV may play a contributory role in 86% of diagnosed deaths by TB (Pronyk et al., 2004), and around 70% of all TB patients in South Africa are HIV+ (de Cock, 2007). Despite this evidence of high HIV/TB correlation, this study adopted

the more conservative approach of not including parental death by TB in the AIDS-orphaned group, unless the parents had exhibited two further AIDS-defining symptoms. Parental deaths by TB alone were removed from the sample and placed in the group described as ‘orphans by unknown causes’.

Cases where cause of death was unable to be determined

81 orphaned children were classified as ‘orphans by unknown causes’, due to inability to determine cause of parental death or lack of corroborating evidence. This group included cases where cause of death was not discussed (21%), deaths by tuberculosis with no other AIDS-defining symptoms (10%), or deaths by ‘bewitchment’ which may or may not have been AIDS-related (9%). Examples of each are given below (all classified as ‘orphans by unknown causes’):

‘My mother was sick for a very long time and then she went back to the Eastern Cape and they told me she was dead. I don’t know what she was sick with’

‘My mother and my father died. They wouldn’t let me visit them in hospital or go to the funeral or see them. Nobody will tell me what they died of’

‘My father was poisoned by a witch in the village where we come from. He became ill very fast and then he just died’

Research Staff

Recruitment

Six interviewers (also described as ‘research staff’) were recruited. Two interviewers were qualified social auxiliary workers (Hilda Ntjana) or research psychologists (Zethu Cakata), both with extensive research experience. Two were trained community health workers, specialising in HIV/AIDS-affected families (Julia Limba and Mantombi

Ntushele), but with no prior research experience. Two were volunteers on projects working with orphaned children (Nontobeko Mdudu and Nomhle Panyana), with no prior research experience.

All interviewers were female, isiXhosa-speaking and familiar with the communities in the study area. The recruitment process included submission of CVs, obtaining of references, interviews, and a trial period of work. Interviewers and PI signed contracts detailing research requirements. Payment of research staff was via bank transfer every two weeks, and was based on timesheets and records of numbers of interviews completed, checked against questionnaires returned weekly. Payment was a combination of an hourly rate of R36/hour, plus bonuses for fully completed questionnaires. Interviewers' travel expenses were paid.

Training and supervision

Interviewer training took place in three stages:

Training sessions: All interviewers had 1 day of training, which focused on research ethics, methodology, interviewing techniques, and role-playing of the interview process.

Shadowing of other interviewers: All interviewers observed 3 interviews undertaken by more experienced research staff. Observed interviews were discussed afterwards. This allowed a graded process towards unaccompanied interviewing.

Observation and feedback: All interviewers were observed by the PI for an initial two interviews, and feedback was given after interviews were completed. Further feedback was given throughout the fieldwork from checking of questionnaires. This allowed an ongoing process of training.

Supervision: All interviewers had weekly individual supervisions with the PI. These supervisions allowed discussion of employment conditions, payment and practical

challenges (such as privacy to conduct interviews). Supervisions also included helpful discussions of methodological difficulties such as the challenges of identifying familial relationships in a context of terms such as ‘cousin-brother’. Interviewers reported that they used a combination of languages in interviews: isiXhosa , Afrikaans, English, Tsotsi (street slang) and some Zulu where children did not understand terms. Monthly group supervisions with the research team were also used for ongoing training of interviewers. Interviewers also frequently contacted the PI by cellphone when experiencing any difficulties or queries during interviews.

Monitoring and Quality Control

The PI made daily, unannounced visits to all interviewers (who were often working in different locations). The PI was also frequently present at one research site and conducting interviews herself. All questionnaires were checked for accuracy and completeness by the PI. Where questions had been omitted, or there were discrepancies between item responses, questionnaires were returned to interviewers, who returned to the children to complete missing items.

Quality control was also provided by the taping of one interview per day (randomly selected). A random selection of tapes was sent to a qualified, bilingual isiXhosa and English-speaking child psychologist. The psychologist was blinded regarding interviewer identity, and reviewed the following:

- Were all items asked according to protocol?
- Were all items recorded as answered on the questionnaire?
- Were independent rating of symptoms from the tape recording (by the psychologist) matched to recorded symptoms (by the interviewer)?

Feedback on these checked interviews was given in weekly supervisions. All children were asked for permission to tape interviews for this purpose.

Further monitoring of interviewers was undertaken for door-to-door community interviewing. A random selection of participants from completed questionnaires were telephoned, in order to confirm that interviewers had visited the home.

Inter-rater reliability checking was not part of the study design. However, an unintended consequence of efforts to make the research enjoyable for children resulted in 14 children taking part twice in the study. These were usually children who were interviewed at school, and then visited at home by different interviewers⁹. Inter-rater reliability and test-retest reliability was high overall.

Further inter-rater reliability checking was undertaken by comparing demographic details from questionnaires of siblings interviewed by different research staff. Many details (such as household composition, cause of parental death, poverty factors etc) were manually checked for concurrence during the fieldwork period. Overall, manual checking showed agreement to be good. Correlations were not conducted as questionnaires of siblings sometimes took place at different times, and therefore demographic details such as household composition, or days in the previous week without food, may have changed. Manual checking of sibling data was not intended to be used as a systematic determinant of data reliability, but was useful as an ongoing measure during fieldwork.

Staff support and management

Good relationships within the research team were essential, especially as interviewers were often working alone. The research design was also aimed at capacity-building amongst research staff. Interviewers were consulted on questionnaire design and gave input during the piloting procedures. Staff felt that this contributed to a sense of involvement in, and ownership of, the study. Regular meetings, individual and group supervision allowed problems to be resolved swiftly. Supervisions were also used to plan for future employment of interviewers: all interviewers were assisted in designing

⁹ For these cases, the first interview was included in the sample, and the second interview used only for testing of inter-rater reliability.

curriculum vitae and in searching for jobs. References were provided for all interviewers. The PI also contacted colleagues with recommendations and arranged subsequent work for staff in further research projects.



Figure 27: Nomhle and Hilda, two of the interviewer team

5.4 Fieldwork challenges and Research Constraints

Political and Environmental factors

Shack fires: Fieldwork took place during a hot, dry summer, and within the context of ongoing disputes regarding provision of formal housing to informal settlements. Either due to accident or arson, two settlements burnt down entirely during fieldwork there (Site B Khayelitsha, in which 900 shacks were destroyed, and the Joe Slovo Settlement in Langa, in which more than 800 people were left homeless) (see Figure 29)

Power cuts: During 2005-2006 the Western Cape's power supplier, Eskom, was unable to provide enough electricity for the province (due to one or more of miscalculation, technical error or sabotage). For four months, Eskom introduced 'rolling' and unannounced power cuts of 3-12 hours. Power cuts resulted in unusable telephones, faxes, computers, email, closing of shops and fuel stations. This had a number of impacts on fieldwork, including regular closing of schools and organisations, communication

difficulties, transport delays due to the difficulty of buying fuel and travel chaos resulting from non-functioning traffic lights.



Figure 28: Power cuts, (Cape Times, 20 Feb 2006)

Political tensions: Fieldwork took place over a local election, and during a highly-publicised rape trial of a prominent government minister. Both events were politically and ethnically divisive, and a number of public demonstrations took place in fieldwork locations. Whilst none became violent, fieldwork was delayed due to pre-emptive closing of organisations, and decisions to cancel days of fieldwork at times of feared rioting.



Figure 29: Shack fire in Langa (Cape Argus, 23 November, 2005)

Crime-related challenges

Murders: Fieldwork took place in deprived, urban areas with extremely high levels of crime (South African Police Services, 2004). During fieldwork, a number of homicides

took place in schools and organisations, including murders of school pupils, streetchildren, and a school principal. All these resulted in closures, delays, and caused apprehension amongst research staff.

Taxi violence: Particular delays were caused by spates of ‘taxi wars’: violent disputes between different firms owning the minibuses which constitute public transport in township areas. This ranged from stone-throwing to machine-gun shootings of passengers waiting at the bus stops of rival firms. Taxi wars created difficulties for research staff in reaching places of work, and in Philippi (April 2005), fieldwork had to stop completely as a result of danger to research staff.

Burglary: Acquisitive and destructive crime caused further delays. Bongoletu Public Primary School in Brown’s Farm, and Cape Town Child Welfare in Guguletu were both burgled during fieldwork, and the extent of damage to property resulted in school closures of up to a week.

High-crime townships: Certain adaptations had to be made for fieldwork in an exceptionally high-crime environment. For example, no work could take place after sunset, certain areas could not be entered alone, and all routes had to be planned before leaving safe areas. Where staff were not in their immediate home area, all interviewing took place in safer contexts such as schools, clinics or community centres. Initial plans for quality control of interviewers included tape-recording of each interview, with a random selection of tapes blind-reviewed by a psychologist. However, interviewers were justifiably concerned that it would become known that they were carrying tape-recorders each day, and that they would become targets for mugging. The process was adapted so that tape recorders were brought during unannounced daily checks on all interviewers, and interviewers taped one interview per day

Drug-related violence: Risks associated with research in township areas tended to be external, and the children who were interviewed rarely showed signs of behaviour

problems. However, the streetchildren shelters presented a different kind of violence due to glue-sniffing, the taking of crack-cocaine and gang-related tensions.

Infrastructure limitations

In countries with highly developed welfare systems and good administrative infrastructure, research with highly vulnerable groups is often facilitated by information systems such as Child Protection Registers, databases of children in state care etc. At the time of research, the fieldwork areas had no national or provincial databases containing information on vulnerable children (although a database of demographic and educational information on school-attending children is currently being developed by the Western Cape Education Department). There was no database or register of fostered, state-cared, orphaned or abandoned children, or any register of streetchildren beyond paper records kept by some NGOs.

Unmapped areas: Many township areas are not included on any maps of the Cape Town municipality, which provide aerial photographs but no street names or place names. Other areas were mapped, but had all street signs and road signs stolen for use in building shacks.

School closures

Schools in the Western Cape were found to close frequently, for a range of reasons. These included deaths of teachers due to AIDS (necessitating entire staff to attend funerals, often in the Eastern Cape province), sports days, awareness days, ‘unofficial public holidays’ (which were the days between a public holiday and the nearest weekend), election days, and ‘half-days’ when weather was especially hot or the day before a public holiday.

A further and severe delay was caused by the timing of the long summer holiday during December 2005-Jan 2006. Many children are sent to family in the Eastern Cape for these

holidays on long-distance taxi journeys which cost R200-R300 each way, and which parents could only afford immediately after payday at the month's end. Because of the timing of school holidays dates and paydays, entire schools were emptied for three weeks before the beginning of school holidays in December and for two weeks after the end of school holidays in January until parents could afford to transport children back to urban areas.



Figure 30: School disruption (Cape Argus, November 20 2005)

Challenges with culture and psychology

Thorough piloting and back-translating of research tools addressed many of the potential difficulties with cultural differences. However, challenges remained around differing explanations of syndromes. For example, children reported affliction by 'tokoloshes' (demons which cause madness) and bewitchment. A more detailed discussion of issues surrounding cross-cultural psychology can be found in the methodological limitations (Chapter 7).

Budget Limitations

The study took place on a small budget. The ESRC provided £7000 towards flights, extra living expenses and research, and Oxford University gave supplementary grants of £1000 for the qualitative and £1000 for the quantitative stage. The major expenses of the study were interviewer wages, transport (taxis and fuel for cars) photocopying and printing. Collaboration with Cape Town Child Welfare allowed use of office facilities, photocopier

and staff cars (until regular hijacking reduced numbers of staff cars and personal cars were used instead). In return, a monitoring and evaluation system was designed for the agency, and social workers were trained in evidence-based social work.

Further income for the research was gained, whilst fieldwork took place, through writing book chapters for the Human Sciences Research Council (Cluver, Bray, & Dawes, 2007; Noble et al., 2007) and Research Assistant work for the Centre for the Analysis of South African Social Policy. Lecturing at the University of the Western Cape (Department of Social Work) also provided income. Finally, consultancy work was undertaken for the Regional Psychosocial Support Initiative (REPSSI) in designing an efficacy trial of an intervention with orphaned children.

5.5 Research Ethics

This study has been approved by ethics committees at:

- 1) The University of Oxford Departmental Research Ethics Committee (Department of Social Policy and Social Work),
- 2) The University of Cape Town Research Ethics Committee (Faculty of Health Sciences),
- 3) The Western Cape Education Department,
- 4) Cape Town Child Welfare Society

Ethics committee approval from Oxford University was required for the D.Phil. It was also considered important to gain approval from a local ethics committee. The University of Cape Town Health Sciences committee had assessed Wild et al's study of orphan mental health in the Eastern Cape (Wild et al., 2006, July), and so had experience of this topic. Ethical approval from the Western Cape Education department and from Cape Town Child Welfare was required in order to interview children in schools and welfare centres. Separate protocols were submitted to each ethics committee as each had differing

submission requirements. The separate protocols did not give rise to conflicting ethical mandates. A sample ethics protocol is included in Appendix 1.

Ethical considerations

Ethical guidelines for this study were informed by a combination of literature on research ethics, ethical requirements of stakeholders and practice guidelines. Searches were made of international and South African research ethics literature, focusing on research with HIV-affected populations (Resnick, 1998), vulnerable children and young people (ie. Alderson & Morrow, 2004; Van der Merwe, 2005). The study also aimed to fulfil ethical requirements of universities involved in designing the research (Oxford, UCT and Stellenbosch), and requirements of the South African provincial Department of Education and other organisations through which children were recruited, as well as the guidelines of the Economic and Social Research Council as primary funder of the D.Phil. Finally, research design further considered guidelines from the British Psychological Society (British Psychological Society, 1992, 2000), the Society for Research on Child Development (Society for Research on Child Development) and the South African Council for Social Services Professions (Code of Ethics).

Child and caregiver consent

Where research participants are under the age of 18, there is debate on the necessity of obtaining guardian consent. For example, American research on school-based health argues that obtaining written parental consent is possible and beneficial, although requires considerable resources and planning (O'Donnell et al., 1997). Other research questions the assumption that children have lower social competencies than adults and argues instead for consent methods which use 'children's cultures of communication' (Christiansen & Prout, 2002).

The British Psychological Society guidelines (2000) state that, where children are under 16 years old, consent should be obtained from someone *in loco parentis*, but that where

this is not possible, the study should be taken through ethics committee approval. The South African Children's Act does not mention research, but identifies capability of children to consent to medical treatment and HIV testing at age 12 (Republic of South Africa, 2005). The University of Cape Town and the Western Cape Education Department do not require written consent from children, but require an opt-out letter to caregivers. In light of such varying requirements, both child and caregiver consent was sought for all children. Opt-out parental/caregiver consent was sought via consent and information forms (in isiXhosa and English) sent to caregivers a week before interviews took place.

Lack of recognised guardian

Some children, especially streetchildren and those in child-headed households, lacked any adult caregiver who would be able to give 'parental' consent. Previous South African research with streetchildren has not sought caregiver consent (Ennew & Swart-Kruger, 2003; Richter & Van der Walt, 1996). A recent review of research with homeless youth in the USA argued that parental consent should not be sought for this group, but highlights the importance of working with local communities in order to determine how consent is obtained (Ensign, 2003). However, both streetchildren and child-headed households are highly vulnerable groups, and consent from some sort of responsible adult was preferred for this study.

For child-headed households, consent was obtained from the oldest child, non-resident caregiver or social worker whichever was most appropriate for the participant child's situation. For streetchildren with no responsible caregiver, consent was obtained from social workers or staff in shelters or feeding schemes. It is noted that this method of consent precluded the interviewing of streetchildren who were not accessing any services at all, and thus potentially created a sampling bias against the most vulnerable streetchildren.

Informed Consent from Children

Consent forms and information leaflets describing the study were provided in isiXhosa and English (see Appendix 3). Versions had been tested in the pilot study, and were found to realize a good level of understanding from participants (Cluver & Gardner, 2006).

Groups most severely hit by HIV/AIDS include those with low literacy and educational levels (Leclerc-Madlala, 2006). Orphaned children have poorer educational levels than non-orphans (Operario et al., in press). In order to ensure informed consent amongst this group, information leaflets were also explained orally (in the child's first spoken language) to all child participants, and both oral and written consent was obtained.

Interviewers explained to children that they could refuse to participate in the research at any point, and that this would not have any negative consequences. Following British Psychological Society guidelines (2000), any avoidance of the interview situation was taken as evidence of failure to consent. Children who refused to participate still received certificates and refreshments. In the 2003 pilot quantitative study, 1 child refused to participate in the research (Cluver & Gardner, 2006). None refused any individual questions. In the qualitative research stage, 1 child refused to participate in the research, 60 consented, and in one case the interview was cut short because the child became distressed¹⁰ (Cluver & Gardner, 2007b). In the major quantitative stage, 3 children refused to take part in the research.

Confidentiality

All data was treated as confidential. However, researchers have a responsibility in the case of children who may disclose information showing them to be at risk of severe harm (Alderson & Morrow, 2004). There were also complex issues in situations where

¹⁰ The worksheet was based on a cartoon character, 'Lindiwe', and the question was 'what sort of things make Lindiwe sad?'. The child identified that the death of her father had upset her.

breaking confidentiality may not have lead to greater protection for the child or may have put the child at further risk.

The code of ethics for the British Association of Social Work specifies the need to respect client confidentiality, and divulge information only with the consent of the client, 'except where there is clear evidence of serious danger...on the basis of professional consideration and consultation'. The South African Child Care Amendment Act (Republic of South Africa, 1996a) states that professionals working with children are required to report child abuse or the suspicion of child abuse¹¹.

Most research with vulnerable children in South Africa considers it an ethical principle to provide help for children identified as in need. For example, research undertaken by the Medical Research Council routinely refers children to child psychiatric services (Seedat, Nyamai, Njenga, Vythilingum, & Stein, 2004; Seedat et al., 2000). Wild et al's study in the Eastern Cape referred children in need to social services (Wild et al., 2006, July), as does ongoing research in the Africa Centre on HIV+ caregivers and infants (A. Stein et al., 2005).

Guidelines on reporting of child abuse are given in an ongoing HSRC/UNICEF study of psychosocial adjustment amongst young children (Andrew Dawes et al., 2007) and in the South African Children's Institute/ACCESS Child Participatory Poverty Research (ACCESS, 2002). These maintain confidentiality except where a child is shown through the research to be at risk, in which case (with the child's consent), they are referred to organisations which can provide assistance (ACCESS study), or caregivers will be told (HSRC/UNICEF study).

Two concerns were identified with this approach. Firstly, the prerequisite of children's consent for disclosure was potentially problematic in situations such as disclosure of sexual abuse, which is often accompanied by requests for secrecy (A Dawes, 2002). Secondly, the approach of informing the child's caregiver may be limited in the help this

¹¹ The Children's Act was not yet passed at fieldwork commencement, and has currently not been passed into statute. Thus existing legislation (the Child Care Amendment Act 96 of 1996) was used.

can provide for a child (for example where the child is experiencing neglect due to extreme poverty), or even increase risk if the caregiver has been involved in the child's negative experience.

Therefore, a modified approach was used, following protocols devised from research studies with similarly vulnerable groups (Bostock, 2002; Smith, 1999). Information leaflets informed all participants that the study maintained confidentiality unless it became clear that they were at risk of significant harm. If this occurred, the researcher discussed concerns with the child at the end of the interview. If the child consented, the caregiver was informed (unless this was thought to put the child at risk). If the child did not consent to sharing of information, and the harm was not considered to be significant, children were sent information about self-referral agencies such as ChildLine SA. If the harm was considered to be significant, the researcher made written referrals to relevant social services or child welfare organisations, and children were informed of these referrals.

In practice, the issue of child consent to referral was not problematic. Rather, children were desperate to access help. Referrals were made for all children disclosing abuse and for all children in child-headed households who were not receiving any support. All children who reported suicidal ideation were sent details of a local counselling centre, and these centres were contacted by the research team. A number of children reported past experience of abuse or rape, and were sent contact details of telephone support lines. Please see section 5.5 of this chapter, and Appendix 8 for full details of referrals.

Data confidentiality:

All efforts were made to ensure that data confidentiality was maintained, especially regarding the sensitive nature of the research. Data were kept in closed boxes within a locked office at all times. Electronic data files containing identifying details were kept secure.

Anonymity and Privacy

In resource-poor settings, maintaining anonymity and ensuring privacy are key ethical and methodological concerns. It was also important that child participants understood the concept of anonymity. The study used a method suggested by Boyden and Ennew (1997), where children identified their own pseudonym to be used in any reporting of the research. This was extremely successful in ensuring children's understanding that their responses would be reported only anonymously. Pseudonyms included music stars, sports players, politicians and characters from soap operas.

Privacy during interviews was maintained as much as possible, although difficulties were presented when interviewing took place in crowded homes or organisations. Interviewers often conducted interviews outside, and took paper and colouring pens to distract other children in the household. Interviews took place where possible in schools or community organisation premises although interviewers commented on noise and frequent interruptions.

Protecting participants from unintended disclosure and stigma.

Many people affected by HIV do not disclose to their community, or disclose selectively within their own family (Armistead & Forehand, 1995; Brandt, Dawes, & Bray, 2006; Greene, Derlega, Yep, & Petronio, 2003). Stigma associated with HIV/AIDS disclosure has been found to negatively affect families and orphans (Skinner & Mfecane, 2004; Strode & Barrett Grant, 2001). Reports of stigma and discrimination has included gossiping and taunting (Ferreira et al., 2001; Holzemer & Uys, 2004), and denial of access to schools (Skinner & Mfecane, 2004). In extreme cases, disclosure has led to violence or murder (Almeleh, 2004). Many children are not informed of the cause of parental death (Marcus, 1999a). It would be unethical for researchers to reveal this to children.

In order to prevent unintended disclosure, or community identification of research participants as HIV/AIDS-affected, HIV or AIDS was not mentioned in consent letters or information leaflets, and the study was not made known within communities as an HIV/AIDS study. This approach follows other studies of orphan mental health in sub-Saharan Africa (Makame et al., 2002; Manuel, 2002; Poulter, 1996; Wild et al., 2006, July). Where families or children identified themselves to the researcher as affected by HIV/AIDS, this aspect of the study was discussed sensitively and confidentially.

This decision is ethically complex. By omitting mention of HIV/AIDS, participants were potentially being withheld information as to one aspect of the study. ESRC guidelines require ‘honesty to research staff and subjects about the purpose, methods and intended and possible uses of the research’ (Economic and Social Research Council, 2004). Guidelines from the British Psychological Society (2000) and American Psychological Association (2002) address deception, but primarily in the context of research such as Milgram’s deliberate deception of participants (Milgram, 1983). It is judged that, in this specific case, the prevention of potential harm to participants by risking public knowledge of their family’s HIV status was the most significant responsibility of the researchers.

Giving back: to organisations, children

Referrals and Assistance:

Where interviews showed children to be at risk of harm, or families to be in extremely difficult circumstances, written and telephoned Child Protection referrals were made to relevant branches of Social Services. Referrals were also made to relevant NGOs and internally within Child Welfare, depending on the catchment criteria of children (31 child protection referrals were made: see examples in Appendix 8).

The questionnaire included an item on suicidal ideation. For all children who responded to this item with ‘I want to kill myself’, and for all children who had disclosed past experience of rape, attempted rape or sexual abuse, a letter was sent to the child with

basic advice, and tollfree telephone numbers of relevant helplines. All children in these groups were also given contact details of local child psychology clinics (such as Empoweni in Site B Khayelitsha), and access to counselling for these children was negotiated with management of clinics (26 letters and referrals were written).

School Fees: For children who were not attending school due to inability to pay fees, all carers were contacted and informed of the (little-known) fee exemption policy. Letters of advice on applying for fee exemptions were sent to all children, accompanied by letters of support from Cape Town Child Welfare to use in the application process (30 letters of advice and 30 letters of support written). In cases of child-headed households where there were no adults available to approach school governing boards, the research team themselves negotiated fee exemptions with schools.

Letters Home: Caregivers of children were contacted where interviews showed children to be eligible for, but not receiving, social security grants. Letters home were also sent with children who were found to be short- or long-sighted, advising caregivers of local school clinics which provided affordable or free access to reading glasses.

Ad-hoc advice: Throughout fieldwork, children and families took the opportunity of contact with the research team to discuss areas of concern or difficulty. Afternoon ‘clinics’ were also held in participating organisations. During these, individual problems could be addressed on an ad-hoc basis, with a qualified social worker. These ranged from problems getting ID documents or grants, to placement issues for child-headed households.

Grants workshops: Finally, ‘Grants workshops’ were held at all community-based organisations or support groups for caregivers of orphaned children. Caregivers (often grandparents with limited literacy) have poor levels of knowledge regarding complex eligibility criteria and process of accessing social security grants and child maintenance (Meintjies et al., 2003). Workshops lasted 3-4 hours. They covered eligibility for all available grants, documents necessary in order to obtain grants, and training in

negotiating the often-unfriendly official process. Particularly for elderly caregivers of orphans, workshops also addressed permanency planning for children after caregiver death, and provided training on writing wills in order to reduce property-grabbing (Izumi, 2007).

Direct payments: Many studies provide cash incentives for research participants. This study was cautious about the use of direct payments. Firstly, there were concerns regarding danger to child participants if it became known that they would be given cash in a high crime area. Secondly, it was unsafe for research staff to carry cash in many of the research areas. A third concern was the possibility of payments biasing results and sampling procedures. For example, a similar study in the Eastern Cape (Wild et al., 2006, July) had experienced families falsely claiming to be affected by HIV/AIDS in order to obtain the research incentive. Finally, there were concerns around groups such as streetchildren, who were likely to use incentives to buy street drugs (Ensign, 2003).

All children were given certificates of thanks for participation (see Appendices 4 and 6). Children chose isiXhosa or English versions. The certificates were found to be extremely popular in the pilot study and in the qualitative stage of the research. Children were also given refreshments whilst participating. In practice, incentives to take part in the research were not necessary, as children showed high levels of interest in the research and were largely eager to participate.

Giving back to participating organisations

As a community-based research study, a number of strategies took place to ‘give back’ to participants (Cooper et al., 2002). Prior to fieldwork, participating schools and organisations were consulted regarding what they would find helpful from the research team. The majority requested training for staff.

Staff Training: All participating organisations were offered staff training in a range of topics (see Appendix 7). They chose 2-4 training sessions on Child mental health, drugs,

child abuse identification and responses, basic counselling skills, working with parents and home visits, and research and evaluation (training programmes available on request). Training sessions lasted 1 ½ hours each, and included games, activities and worksheets. All participants filled in training evaluation forms at the end of workshops.

Resources: Participating organisations and schools were also supplied with HIV/AIDS and health-related resources from the Department of Health. These are provided by the national department, but are stored in the city centre office, and rarely reach the more deprived township areas. Resources included posters, leaflets, books and information comics (i.e Khomanani: Caring Together, 2004; Soul City, 2001).

Material Assistance: Where there was extreme need for material assistance, the research team facilitated access to donations through the Cape Town Child Welfare clothes, toys and shoes donations centre.

Figure 31: ‘Giving back’ to schools and organisations

School/NGO	Training	Other assistance
Kwamfundo Secondary School (site B Khayelitsha)	Teacher Training: Child abuse and child mental health	HIV/AIDS information from Department of Health
Imbasa Primary School (Nyanga/Old Crossroads)	Teacher Training: Child abuse & communicating with children	Support from twinned school in London. Child Welfare Donations HIV/AIDS information from Department of Health
Yomelela Primary School (Makhaza, Khayelitsha)	Teacher Training: Child abuse and working with parents	HIV/AIDS information from Department of Health
Intshinga Primary School (Guguletu)	Teacher Training	HIV/AIDS information from Department of Health
Moshesh Primary School (Langa)	Teacher Training (cancelled due to school closure)	HIV/AIDS information from Department of Health
Bongolethu Primary School	Teacher Training: Child abuse and communicating with children	HIV/AIDS information from Department of Health
Vuzamanzi Primary School	Teacher Training	HIV/AIDS information from Department of Health

Planned Parenthood Association of South Africa, Child-Headed Household Project	Training for staff and clients: Grants information workshop + training on writing wills	Child Welfare Donations (shoes and clothes) HIV/AIDS information from Department of Health
Siyaphambili Orphan support group and feeding scheme	Training for staff and clients: Grants information workshop + training on writing wills	Child Welfare Donations HIV/AIDS information from Department of Health
St Michael's Church Orphan Support Group	Didn't want training. Donations arranged for orphan feeding scheme	Child Welfare Donations HIV/AIDS information from Department of Health
Planned Parenthood: Sinako Youth Clinic	Training for staff and clients: Grants information workshop + training on writing wills	HIV/AIDS information from Department of Health
Vukuzhakhe project for child-headed households (Site A Khayelitsha)	Staff Training	Child Welfare Donations HIV/AIDS information from Department of Health
Themabalabantwana: Cape Town Child Welfare Guguletu	Staff training on Child abuse, research and evaluation	HIV/AIDS information from Department of Health
Mandela Park Stadium Football Ground	Training not possible as no permanent staff – all on day contracts	HIV/AIDS information from Department of Health
Mrs Maposela (feeding scheme for orphaned children)	Training not possible. Donations from foreign fundraisers arranged	Child Welfare Donations HIV/AIDS information from Department of Health
Women for Peace	Staff Training	HIV/AIDS information from Department of Health
Yizani day shelter for streetchildren	Staff training on research and evaluation	HIV/AIDS information from Department of Health
Learn to Live streetchildren school	Didn't want training	HIV/AIDS information from Department of Health
G C Williams Home	Staff training	HIV/AIDS information from Department of Health
Ons Plek shelter for streetchildren (Ons Plek and Siviwe)	Didn't want training	HIV/AIDS information from Department of Health
One Love Feeding scheme for streetchildren (City Bowl)	Staff training	HIV/AIDS information from Department of Health Donations of clothes from Child Welfare Linked organisation with photographer for fundraising

The Ark (Blue Downs)	Training for teachers and House Staff: Child mental health A and B, communicating with children and Home visits	HIV/AIDS information from Department of Health
The Bridge home for streetchildren (Khayelitsha)	Didn't want training	HIV/AIDS information from Department of Health
Don Bosco Home for streetchildren	Training not possible as staff about to leave or on sabbatical.	HIV/AIDS information from Department of Health

Maintaining good relationships with participating organisations:

Considerable effort was made to engage participating organisations in the research process. All potential schools and organisations were visited, to discuss the project, and were given an 'information pack'. This contained a summary of the project (in lay terms), copies of all research materials, details of the training opportunities, and organisation consent forms. Staff meetings were also held, during which staff could ask the PI any questions about the study. As staff in each research location got to know the research team, they increasingly approached the team for advice or help with referrals regarding particular children. Finally, large boxes of biscuits were taken to all staffrooms in thanks for participation.

Consultation throughout the planning process with stakeholders (such as NGO staff, local clergy and school principals) was intended to improve the quality of the research tools and processes. It also facilitated community access. This study benefited from a strong community perception of this research as important and relevant to their concerns. Such perceptions perhaps reflect the original conception of this study in collaboration with a community-based NGO.

Overall, schools and organisations showed a high level of interest and engagement with the study. They frequently expressed concerns regarding orphaned children (for example, one school had experienced two suicides of AIDS-orphaned children in the past year),

and felt that this area of research was helpful to the community. The most commonly-expressed reservation by staff was regarding feedback of research findings. All organisations felt that it was crucial that the researchers returned with information from the research, which could be used to inform work with orphaned children.

5.6 Instruments:

Questionnaire design and piloting

Rutter (2000) outlines the requirements for rigorous determination of the effect of environmental factors on child mental health. He recommends the use of well-validated, sensitive and differentiating measures of both potential risk and protective factors, and of psychological outcomes. This section outlines the instruments used in the questionnaire, which attempt to be both standardised and culturally sensitive.

Consultations on questionnaire items

Consultations were held with researchers and practitioners in order to improve questionnaire design. Particularly helpful were the authors of other orphan mental health studies, or of child studies conducted in the research locations. Drafts of questionnaires were subsequently sent to twelve researchers, and ten replied with comments. Often researchers were able to be more open about methodological difficulties than possible in published papers or theses. A full list of consultations is given in Appendix 12.

Child-friendly questionnaire design

It was important that questionnaires and research tools were appealing to participants, in order to reduce questionnaire fatigue. A large-scale, quantitative study precluded the use

of many participatory techniques such as drama and group activities (Boyden & Ennew, 1997). However, study design included drawing and activities.

Figure 32: Games used in the quantitative interviews



The questionnaire design aimed to make the research an enjoyable and interesting experience for children. Questionnaire layout was designed in order to minimise questionnaire fatigue, and intersperse potentially upsetting items with more light-hearted sections. Jane Roberts (Nuffield College, Oxford) was exceptionally helpful in assisting with item order, graphics and overall design.

Two ‘games’ accompanied standardised questionnaires. Responses for the Revised Children’s Manifest Anxiety Scale (R-CMAS) involved throwing a tennis ball into one of two cups labelled ‘ewe/yes’ or ‘hay/no’. Responses for the Child PTSD Checklist involved throwing a velcro-covered tennis ball at a velcro-marked board (see figure 1). These games were extremely popular with participants. Interviewers reported that they also used the games when privacy was interrupted during interviews, as they allowed children to answer items without being overheard.

Cartoon figures were used to accompany many of the ‘sections’ in the questionnaire. Adapted cartoons of Bart and Lisa Simpson (re-named Buntu and Lindiwe), and of DragonBallZ (a popular cartoon at the time of data collection) were used as vignettes throughout the qualitative and quantitative questionnaires.

Figure 33 Examples of items from quantitative questionnaires



Buntu has been unwell this year with TB. Lindiwe has had stomach upsets.

Have you been unwell this year? _____ what with? _____

Items from the Levonn/Andile cartoon questionnaire accompanied the Child PTSD checklist (full explanations of scaling and the use of pictures from Levonn are given below).

	not	some	Most	all
 Do you get nightmares or bad dreams about what happened?	○	●●	●●●	●●●●

Wherever possible, pictures were used alongside written items, which assisted understanding for participants with poor literacy (especially streetchildren).

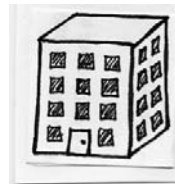
please circle the one which is most like your home



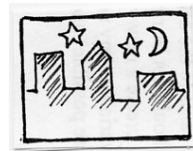
house made of
brick or concrete



shack on its own plot



block of flats



living on the street

Drawing and writing activities were also included, such as the 'Road of Life' (see Appendix 5). Participants were given the option of drawing or writing answers, or having

the interviewer draw or write for them. These activities were extremely popular in both the pilot, qualitative and quantitative studies. Drawings were given as additions to written answers (i.e. 'I want to be a teacher'), and were sometimes drawn by interviewers at child request. As a result, these were not interpretable in a qualitative approach, but were only used to show objects or people as a child-friendly method of data collection. Where children drew a picture which was difficult to understand (i.e. a drawing of a woman in the household), they were asked by the interviewer to describe what the drawing was of, and this was recorded (e.g. 'aunt').

Piloting

Piloting of questionnaires took place in four stages, and versions were piloted with adults before piloting with children

- 1) In the UK, drafts were initially piloted with two Children and Families social workers, who commented on sensitivity and child-friendliness
- 2) Adapted drafts were then piloted with three schoolchildren in the UK (aged 11, 13 and 15). Comments were made regarding length of questionnaire, layout of standardised questionnaires, and games.
- 3) In South Africa, isiXhosa drafts were piloted with two isiXhosa -speaking community workers
- 4) Finally, drafts (in isiXhosa and English) were piloted with 10 children in South Africa: 5 orphaned and 5 non-orphaned. Piloting took place at Cape Town Child Welfare (Guguletu).

Translations

All research materials (questionnaires, information forms and consent forms) were translated and back-translated. Several of the standardised questionnaires (the CDI, RCMAS, SDQ and Child PTSD Checklist) and survey items (such as items from the National Youth HIV and Sexual Behaviour Survey (A. Pettifor et al., 2003)) had already

been translated into isiXhosa for previous studies, and these were also back-translated as a precaution.

Choice of instruments, collaborations and added items

Risk and protective factors

The present study aimed to identify risk and protective factors in children's environments which could potentially mediate adverse outcomes associated with stressful situations (Masten et al., 1999; Rutter, 1999), and which functioned at different levels of the ecological framework (Bronfenbrenner, 1979). It was hypothesised that risk and protective factors may also interact within a cumulative model of risk (Sameroff et al., 1997). Risk and protective factors were compiled from three sources. Firstly, literature review identified factors which had been found to be associated with mental health outcomes in children with some similar experiences to AIDS-orphaned children (bereaved children, refugee children etc) (see Chapter 3 for details of this literature review). Secondly, factors raised in the qualitative study were included (see Chapter 4 for details of qualitative study findings). After synthesis of factors derived from these sources, a list was compiled and items were eliminated, with a prioritisation of factors which were feasible to measure, reduced method overlap, and were policy relevant. Eliminations at this stage included factors which were impossible to measure. For example, there is extensive evidence of the importance of maternal mental health in child psychological outcomes (Bifulco et al., 2002; C. Graham & Easterbrooks, 2000; Spence et al., 2002). However, the cross-sectional study design meant that parental mental health data would not be obtainable for many orphaned children. Even if the study were to measure mental health of children's current caregivers (following Manuel, 2002) this information would be complicated by the sample's inclusion of streetchildren, children in institutions and members of child-headed households¹².

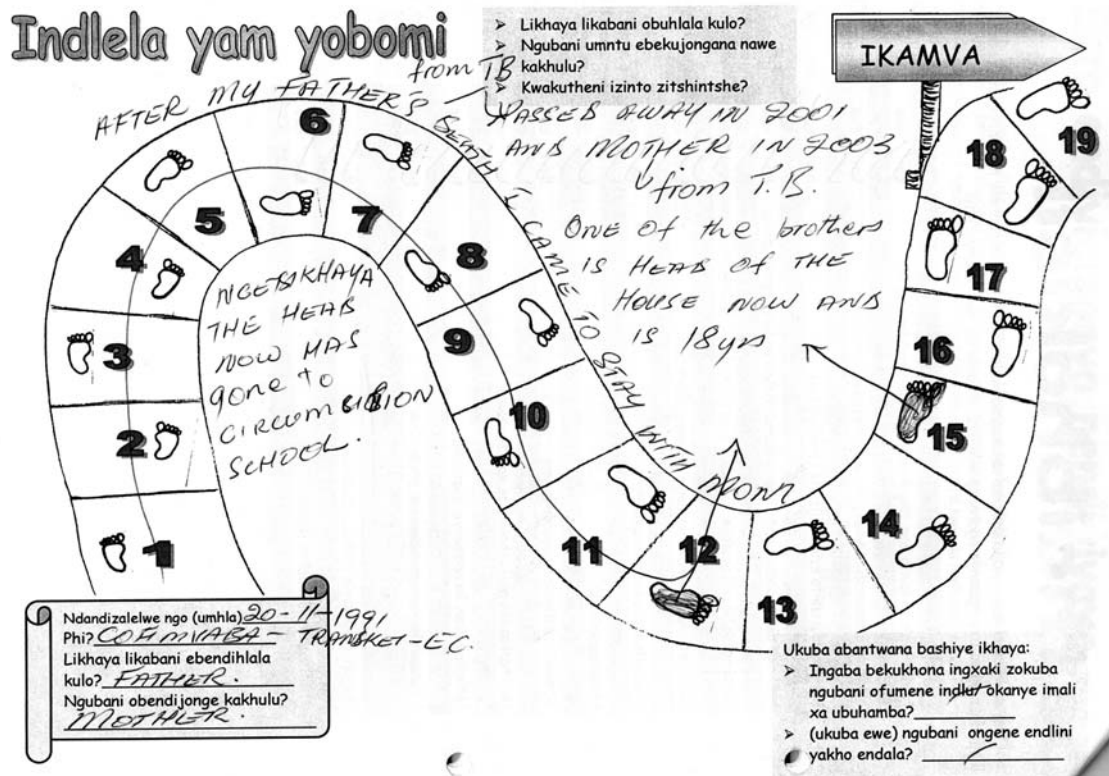
¹² Would the mental health of the oldest child be a 'child' factor, or a 'caregiver' factor?

Thirdly, factors were sent to a number of government agencies and Non-Governmental Organisations, with an invitation to add items which would be particularly useful to their work. A number of items were added. These included an item on caregiver illness contributed by the World Health Organisation, to add to research on mental health outcomes of HIV+ adults and anti-retroviral use. The International Labour Organisation contributed four items on child housework and child paid employment to inform a multi-country study on child labour. The South African Law Commission contributed three items on property-grabbing of homes after parental death. Further items were included on post-bereavement and community support for children (UNICEF New York) and on specific responsibilities of child-headed households (Planned Parenthood Association of South Africa). The aim of including these items was to assist other NGOs working with AIDS-orphaned children, and add to the policy and intervention applicability of the study. This section will detail the source of each item used to measure demographic factors and risk and protective factors. Items have been broadly grouped according to theme. Some games and activities measured a range of factors simultaneously, such as the 'Road of Life', which provided detailed demographic and bereavement information.

Individual/child-level factors

Basic demographic information: Participants identified names, gender, addresses and age. Ethnicity was identified by asking for first language spoken at home (Wild, Flisher, Bhana, & Lombard, 2004). Each child chose their own pseudonym, in order to facilitate understanding of anonymity (Boyden & Ennew, 1997). Age at parental death, area of origin, migration history, number of changes of caregiver and parental death, as well as historical background, were measured using the 'Road of Life' activity. The 'Road of Life' used a social work tool: the 'River of Life' (Buchanan, 2002), adapted for urban township children who may not have seen a river.

Figure 34: Example of a 'Road of Life' page

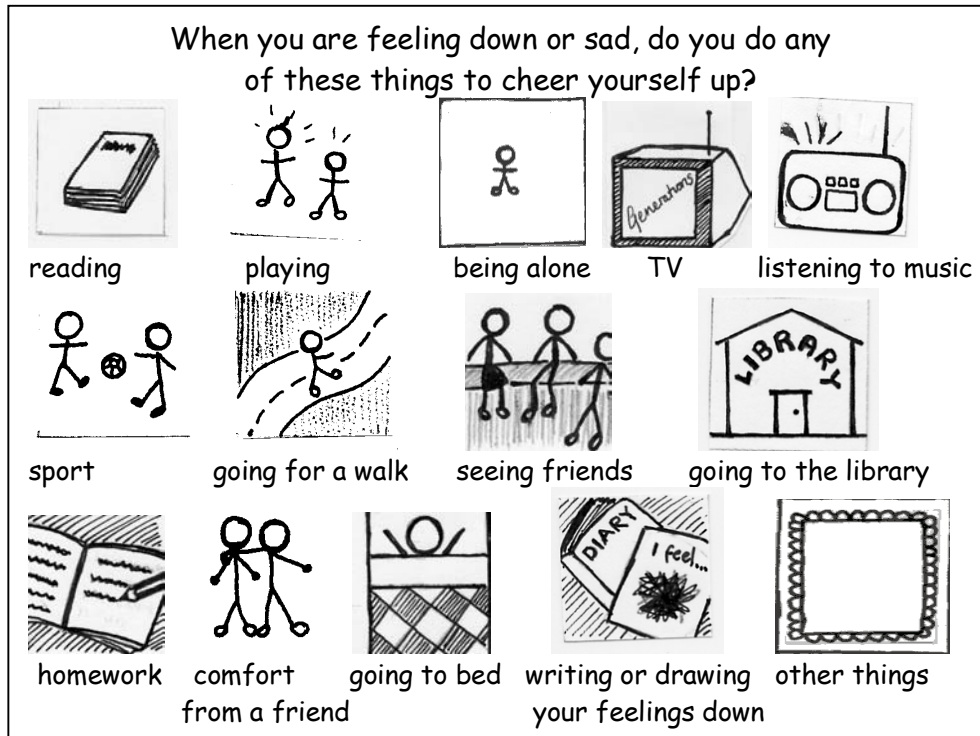


This child was born in 1991, in the Eastern Cape. He is now 15. He lived in his father's house, and was cared for by his mother. His father died from TB in 2001, and he moved to Cape Town with his mother at age 12 (see the coloured-in footprint). His mother died in 2003, also of TB. He now lives in a child-headed household, headed by his 18 year-old brother (who is currently away at circumcision school).

Current health of participant was identified in the qualitative study, and was measured using 2 items asking about illness in the past year ('Buntu has been unwell this year with TB. Lindiwe has had stomach upsets. Have you been unwell this year? What with?'), as well as the Somatic Symptoms subscale from the Child Behaviour Checklist (Achenbach 1991). It was hoped that these items would also allow an opportunity for participants to disclose HIV status if they wished, but very few did so.

Child Coping Factors: A number of potential coping factors were identified in literature review and qualitative data. These included attendance at a place of worship, and religious affiliation. Items were used from the National Survey of HIV: Items 8.10 and

8.11. Coping mechanisms ('when you're feeling sad, do you do any of these things to cheer yourself up?') were identified in qualitative data. A number of options were given, and scores summed.



Further factors included future orientation - degree of optimism about the future, using the National Survey of HIV and Sexual Behaviour among Young South Africans (A. Pettifor et al., 2003):Item 2.4. Future ambitions were asked as a final item, and intended as a light-hearted and positive ending to the questionnaire.

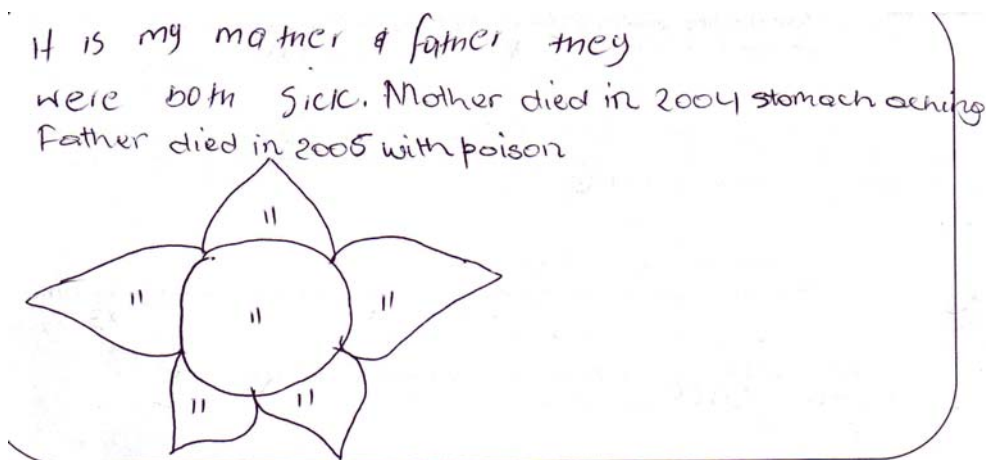


Figure 35: Boy, 17, Langa 'What do you want to be when you grow up?'

Caregiver/Family network factors

Further bereavement factors: Bereavement was measured through three sources (and cross-checked for reliability). These were: information from caregivers, social workers and teachers, the ‘Road of Life’ activity, and a picture activity in the questionnaire (see figures 1 and 11). Items determined presence of multiple bereavement, dates of bereavement and cause of parental death. The qualitative picture activity included discussion of bereavement with interviewers, and the drawing or writing of messages (children often drew flowers, or crosses, or hearts for deceased family members). This was suggested by Professor Lorraine Sherr (University College London), as a sensitive medium for discussing child bereavement. Further factors were measured, namely opportunity to discuss death, and property-grabbing (items contributed by UNICEF and the South African Law Commission respectively). These items were coded according to parental death, sibling death, death of other family members, number of deaths, cause of death/s. More detailed discussion of the verbal autopsy method is given above.

Figure 36: Example of child report of parental death



'It is my mother and father, they were both sick. Mother died in 2004 [with] stomach aching. Father died in 2005 with poison'

Economic factors: Household factors were measured using items from Census 2001 (Statistics South Africa, 2001). Dwelling type was measured using Census categories (H-23a), with added categories of ‘children’s home/shelter’ and ‘living on the streets’. They were then coded according to individual categories (e.g. living on the streets?) and as formal/informal housing. Household possessions and access to services such as electricity were measured using Census 2001 items (H-26-H29). These measured access to working electricity, TV, bath or shower, radio, fridge, running water, phone/cellphone and computer. Food security was measured using self-report of 0-7 days without food in the past week, following studies with AIDS-orphaned children in Tanzania (Makame et al., 2002) and Mozambique (Manuel et al, 2002, unpublished data). The item was worded ‘Buntu and Lindiwe often don’t have enough food in their home. How many days this week did you not have enough food?’ Household employment was assessed by the item: ‘does anyone in your home have a job?’ coded dichotomously, and where possible was corroborated by adult report. Receipt within the household of each of the possible South African social security grants (child support grant, foster care grant, pension, war veterans grant, care dependency grant, disability grant, social relief of distress, and grant in aid) were measured as dichotomous variables and corroborated by caregiver or social worker report. They were then combined to determine household receipt of any grant, and coded dichotomously.

School and employment factors: Information on school enrolment was obtained from school registers or social workers, corroborated by child report and coded dichotomously as ‘currently enrolled/not enrolled’. Information from both teachers and participants determined school grade and ‘highest school grade passed’. This allowed comparison with child’s age to determine years of delay at school (in the South African school system, grade advancement is reliant on passing the previous grade) and was used as a proxy measure for school achievement. Information from children and teachers was also used to ascertain attendance levels (very good/misses some days/poor) and reasons for missing school. Positive affiliation to school was identified as a potential protective factor, and measured using an item from the National Youth Survey of HIV and Sexual Behaviour: Item 8.3 (A. Pettifor et al., 2003). The item was worded: ‘How much do you

like school? By that I mean how much do you enjoy learning and going to classes?’ do not like it at all/do not like it much/like it/like it very much. This was coded as ‘positive affiliation’ (like it/like it very much’) versus negative affiliation. Items relating to child work and housework were devised by the International Labour Organisation, and were presented as part of the section on activities done in an ordinary week



'doing housework'?
How many hours per day?



A job outside the home?
How many hours per day?

Household and caregiving factors: A number of household-level factors were identified in a picture-activity, suggested by Professor Andy Dawes (Human Sciences Research Council). This measured: household overcrowding, existence of kitchen and bathroom in the home, caregiver-child ratio, family size and composition. Factors particular to fostered children were also measured in this activity: where the child sleeps (i.e. fostered children sometimes slept in the kitchen rather than in a bedroom), the presence of a biological child of the same age or under 5 in the household as a potential risk, and placement with siblings as protective. Children reported whereabouts of all siblings using a drawing activity.

Existence of primary caregiver, and relationship of child to primary caregiver, were identified using items from the National Youth Survey of HIV and Sexual Behaviour (A. Pettifor et al., 2003) (items 8.13-8.14) Primary caregiver was identified as the person who ‘stays with you and takes care of you at home’. Relationships of caregiver to children were categorized as the following: biological parent, grandparent, other extended family member (aunts, uncles, cousins, adult siblings etc), non-family member (social worker/careworker, foster carer), living in a child-headed or youth-headed households and living on the streets (including children staying in shelters).

Number of changes of caregiver was measured on the 'Road of life' mapping activity. Age of primary caregiver was asked (due to evidence of more depression amongst elderly carers), but many children did not know the age of their caregivers. Health status of caregiver was measured by child report of illness 'never/rarely/sometimes/very often?'.

Quality of care was measured using the following 5 items: 1) An item on caregiver regulation was identified through reliability analysis as the most discriminative item in a devised caregiver-regulation scale used with South African orphans (Wild et al., 2006, July). 4 further items were derived from the qualitative research stage (Cluver & Gardner, 2007b), and supported by literature review. 2) Children's sense of belonging in the household 'do you feel that you belong with the people that you live with? Yes/somewhat, not at all, 3) Praise for doing something well 'Does someone at home praise you when you have done something well? Often/rarely/never', and 4) caregiver/child activities 'In the past month, has this person helped you with reading or homework, or told stories with you?' yes/no. Intra-household resource distribution was identified in qualitative data and literature as a major concern for orphans, and items measured perceptions of equal access to food, clothes and school fees as other co-resident children.

do you get the same food/clothes/school fees/ school equipment as other children you live with? ☐ I get more ☐ I get less ☐ I get about the same

Children's roles as young carers (particularly in AIDS-affected households) were identified in literature review and qualitative data. Children were asked about current and lifetime caring roles for younger children and for unwell adults in the home.

Trauma items: A devised questionnaire measured child exposure to potentially traumatic items, using cartoon character vignettes. This functioned both to measure specific risk factors (identified by qualitative data/ literature review), and as a 'traumatic experiences questionnaire', commonly used as a precursor to child post-traumatic stress instruments in order to identify a potentially traumatic stressor (Ensink et al., 1997; Heath & Kaminer, 2004; Seedat et al., 2000).

Traumatic events included witnessing of or victimisation by the Western Cape's four most common community crimes: robbery, assault, stabbings and shootings (South African Police Services, 2004). Wording was adapted from the Child Exposure to Community Violence (CECV) Checklist (Richters & Martinez, 1993). Children also

identified any other witnessed or experienced traumas, which were coded into broad categories such as ‘crime’, ‘accidents’ and ‘rape’. Child exposure to trauma was categorised according to exposure/non-exposure, and then by exposure category.

Child report of physical abuse, sexual abuse and domestic violence were measured using items from the Child Exposure to Community Violence (CECV) Checklist (Richters & Martinez, 1993), adapted after consultation with 20 social workers from the Cape Town Child Welfare Society. Physical abuse was defined as being hit with an object likely to cause ‘actual or potential physical harm’ (World Health Organisation, 1999b) i.e. a broomstick, switch, stick or metal piping. Emotional abuse was thought to be too complex to measure by child report alone. Responses were coded according to exposure to any kind of abuse or domestic violence, and then according to type of abuse.

Community-level factors

Stigma: No standardized instruments currently exist to measure AIDS-related stigma amongst orphaned children. A brief stigma scale was devised, based on a) the qualitative stage of this research (Cluver & Gardner, 2007b), b) literature review and c) consultation with local academics currently researching stigma (Deacon, 2006; Maughan Brown, 2004). Participants reported frequency of experiencing teasing, being treated badly and being gossiped about, and the extent to which these events caused distress (not at all/somewhat/very much). Scale values were computed for each participant, with a total possible score of 8.

Community factors: Positive community activities were identified using the qualitative stage of this research, supported by literature review. Items included were: playing a musical instrument, playing with toys or games, playing netball, soccer, swimming or another sport, dancing, socializing with friends, using a computer, reading, and family outings. The total possible score was 13, and participants identified activities which they did at least weekly. Attendance at 4 types of youth club (sports/art or drama/support

group/other) were identified by qualitative data and measured using items from the National Youth Survey of HIV and Sexual Behaviour: (2.8.6).

Bullying was measured with the 9-item, standardised ‘Social and Health Assessment Peer Victimization Scale’ (Ruchkin, Schwab-Stone, & Vermeiren, 2004), used in research with vulnerable children in Cape Town (Ward et al., 2007). This scale is adapted from the Multidimensional Peer Victimization Scale, and showed $\alpha=.82$ in a US validation study (Mynard & Joseph, 2000). Items included; being called names, being hit or threatened and having possessions broken or stolen. This measure generated a total global score of exposure to bullying.

Social Support was assessed using the standardised Social Support Scale (Adolescent Pathways Project, 1992), measuring social support for urban adolescents in each microsystem of family, peers and school. Psychometric properties were acceptable: $\alpha=.63$ in a US study. This scale has been used in a study in Cape Town, although with Coloured rather than Black African children (Van der Merwe & Dawes, 2000). The scale was adapted to replace ‘mother’ and ‘father’ with ‘caregiver’. After piloting the scale was further adapted to combine ‘kids your own age’ and ‘your group of close friends’ as isiXhosa translations of the two categories were too blurred. Perceived community support was requested for inclusion by UNICEF (New York) and was further identified in qualitative data and literature review as potential protective factor. Measurement used an item from the National Survey of HIV and Sexual behaviour among Young South Africans (A. Pettifor et al., 2003):Item 2.5. The scale produced a global score of ‘perceived social support’ plus sub-scores of perceived support from caregivers, peers and school.

Standardised mental health scales

Summary of standardised mental health scales used:

Psychological outcome	Instrument	Number of items	Outcome measure	Author/s
Depression	The Child Depression Inventory – short form	10	Total score	(Kovacs, 1992)
Anxiety	The Revised Children’s Manifest Anxiety Scale	28	Total score	(Reynolds & Richmond, 1978)
Peer Problems	Peer problems subscale of the Strengths & Difficulties Questionnaire	5	Total score (subscale score)	(Goodman, 1997)
Post-traumatic stress	The Child PTSD Checklist	28	Total score Symptom cluster scores (hyperarousal, avoidance, numbing, re-experiencing)	(Amaya-Jackson, 1995)
Delinquency	Delinquency subscale of the Child Behaviour Checklist- Youth Self Report	12	Total score (subscale score)	(Achenbach, 1991)
Conduct Problems	Conduct Problems subscale of the Strengths & Difficulties Questionnaire	5	Total score (subscale score)	(Goodman, 1997)

No comprehensive instruments were known to have been validated and normed in a South African context. Three comprehensive instruments have been used in South Africa. The Diagnostic Interview Schedule for Children (DISC 2.3) has been used with children in Khayelitsha (Robertson et al., 1999) and was found to be diagnostically useful, but was not recommended for use as it was found to be over-long for a township population (Robertson, 2004). The South African Child Assessment Schedule (SACAS) (Barbarin, 1998) is a modified version of the Child Behaviour Checklist (Achenbach & Edelbrock, 1987), and has been both used (Barbarin & Richter, 2001; Barbarin et al., 2001; Van der Merwe & Dawes, 2000) and validated in a South African context. (Barbarin, 1999). However, this is available in parent or teacher report only, and has been translated into Afrikaans and Sotho but not isiXhosa. The SACAS does not include the delinquent subscale of the CBCL. A further scale, the 'Schedule for Affective Disorders and Schizophrenia for School-age Children' (Kiddie-SADS) (M. Kaufman, Birmaher, & Brent, 1997) has been used in South Africa amongst similar populations, (Cooley-Quille et al., 1995; Suliman, 2002) but only in English. This instrument requires interviewers to be a) qualified clinicians and b) extensively trained in administering the K-SADS, which was decided to be both problematic and expensive in the context of this study.

Thus no comprehensive and South-Africa validated scales could be found. Instead, the questionnaire used a number of scales validated in other countries (and subscales of longer validated instruments). Criteria for scales chosen included strong psychometric properties, evidence of successful use (if possible in isiXhosa) in a similar township population, child-friendliness, and comparability with other studies of AID-orphan mental health.

The Child Depression Inventory, the Revised Children's Manifest Anxiety Scale, and the Child Behaviour Checklist (Delinquency) were chosen in collaboration with Dr Lauren Wild (University of Cape Town). At the time of questionnaire design, Wild et al were completing fieldwork of a similar study of orphan well-being in the Eastern Cape. This study had been informed, in turn, by our pilot study in 2003-4 (Cluver & Gardner, 2006). In light of the variability of instruments used in international studies of AIDS-orphaned

children (Cluver & Gardner, 2007a), it was decided that the two South African studies should, as far as possible, parallel mental health scales. This would allow for comparison of outcomes across two provinces. Some minor adjustments were made: for example the Eastern Cape study (Wild et al., 2006, July) used only 6 items of the 12-item CBCL delinquency subscale, and so additional items were included in order to allow comparison with US norms.

The PTSD scale was chosen in collaboration with Dr Soraya Seedat, (Medical Research Council Unit on Anxiety and Stress Disorders, University of Stellenbosch). The MRC unit have conducted a number of high-quality studies of post-traumatic stress amongst Cape Town children (Ahmed, Seedat, Van Niekerk, & Bulbulia, 2004; Seedat et al., 2004; Seedat et al., 2000; Suliman, Kaminer, Seedat, & Stein, 2005). The Child PTSD Checklist was recommended in light of the lack of validated instruments in South Africa, and allowed for comparability with a number of local, school-based community surveys of PTSD. Full details and psychometric properties of instruments used are described below.

Depression:

Depression was measured using **the 10-item short form of the Child Depression Inventory (CDI)** (Kovacs, 1992). This scale was used in the Eastern Cape study (Wild et al., 2006, July) and found Cronbach's alpha of .64. The CDI has also been used in South African populations (Suliman, 2002), including an adapted version that was used in Langa township (one of the study areas) (Heath & Kaminer, 2004). The Heath study conducted a validation of their adapted CDI with the Beck Depression Inventory in a Cape Town school, although this used the English (pre-translated) version. Concurrent validity of the adapted CDI was good: correlating with the BDI for both boys and girls ($r=0.77$, $r=0.84$ respectively). No validation has been conducted with either of the isiXhosa -translated versions of the CDI used by Heath and Kaminer or Wild et al (2006). However, internal consistency for the isiXhosa version of the adapted CDI was very good

(Cronbach's $\alpha = .88$). The CDI was also used in the Family Health Project study of orphan well-being (Forehand et al., 2002).

Kovacs (1992) reports comparable results between the 10-item short form and the full CDI, which is a 27 item, self-report downward extension of the Beck Depression Inventory for adults. (Beck & Beamesderfer, 1974). The CDI is aimed at 7-17 year old children, and was normed in the US. It has also been used in numerous community surveys.

Reliability: Internal consistency is good, with alpha coefficients ranging from .71 to .94. (Kovacs, 1992; Saylor, Finch, & Spirito, 1984) Test-retest reliability has been found to be more variable, ranging from .87 amongst hospitalized children to .38 in a community sample. A review of psychometric properties suggested that the construct measured may be differentially stable over time in different populations (Saylor et al., 1984).

Validity: For content validity, factor analysis of the CDI found correspondence between factor loadings and DSM-IV criteria for multidimensional depression. (Saylor et al., 1984) Studies of the CDI's construct validity report that high CDI scores correspond with self-report of low self-concept, anxiety (Kovacs, 1992) and parent-reported aggression (Kazdin & Petti, 1983). Concurrent validity with the Piers-Harris Self-concept scales was good (.64 $p < .001$). Discriminant validity: The CDI has been found to discriminate clinically depressed and nondepressed psychiatric patients (I. Sandler, Tein, & West, 1994), and to distinguish between clinic-referred and public school children (Kline, Hodges, Siegal, Mullins, & Griffin, 1982; Saylor et al., 1984), although discriminatory power has been found to be poorer in other studies (Fundudis et al., 1991; Kovacs, 1992). Results for criterion (predictive) validity seem largely good (Kazdin & Petti, 1983; Kovacs, 1983).

Anxiety:

Anxiety was measured using **The Children's Manifest Anxiety Scale – Revised (R-CMAS)** (Reynolds & Richmond, 1978) This 28-item scale was used in the Eastern Cape

study (Wild et al., 2006, July). *Reliability*: The RCMAS has been found to have good internal consistency in a number of studies, with Cronbach's $\alpha=.85$, and test-retest reliability was found to be .68 after 9 months (Gerard & Reynolds, 1999; Reynolds & Richmond, 1978). Internal consistency in Wild's study was $\alpha.80$. Inter-rater reliability is not known.

Validity: Content validity was found to be good (Reynolds & Richmond, 1978), as was construct validity (Reynolds & Paget, 1981) across gender, race and IQ (Gerard & Reynolds, 1999). A comparison of psychometric properties of six children's anxiety scales (Muris, Merckelbach, Ollendick, King, & Bogie, 2002) found strong correlations between the R-CMAS and other scales. Discriminant validity was found to be good (Mattison, Bagnato, & Brubaker, 1988; Perrin & Last, 1992), but one study (Dieker et al., 2001) suggests that high correlations with depression may lead to a necessity for caution in using the RCMAS to discriminate between anxiety and depression (Gilroy, 2004). Criterion/Predictive validity was found to be strong (Hadwin, Frost, French, & Richards, 1997). *Standardisation*: Standardisation sample populations for the RCMAS have been large, diverse and representative of US populations (Reynolds & Paget, 1981, 1983; Reynolds & Richmond, 1978). The RCMAS is not known to have been standardised in South Africa. It has been used in another South African study, but with White children in Gauteng province (Jacobs, 1991).

Externalising problems

Externalising problems were measured using two subscales: 1) **the delinquent subscale of the Child Behavior Check-List/Youth Self-Report** (Achenbach, 1991; Achenbach & Edelbrock, 1987). This 12-item subscale includes items such as 'I lie or cheat' and 'I don't feel guilty after doing something I shouldn't'. The Eastern Cape study (Wild et al., 2006, July) used 6 items from this subscale and 3 items from the aggressive behavior subscale in order to measure externalizing problems. The CBCL-YSR is widely used and is aimed at 11-18 year olds. It has been normed on a mixed-ethnicity US population, and

was used in the Family Health Project study of orphan well-being in the USA (Forehand et al., 2002). The scale has been used in South Africa (Barbarin et al., 2001).

Reliability: Internal consistency of the CBCL-YSR full scale ranges between α .71 and .95 (Achenbach & Rescorla, 2001; Song, Singh, & Singer, 1994), test-retest value ranges from .47 to .79 and inter-rater reliability was described as ‘relevant’ (Achenbach, 1991).

Validity: The CBCL-YSR is commonly used as a ‘gold standard’ in testing convergent validity of other instruments, and correlation with the Conners’ Rating Scales-Revised was good (.82) (Achenbach, 1992). Discriminant validity was found to be good in a norming study of Swedish 11-18 year olds (Broberg et al., 2001). Criterion validity was found to be ‘acceptable’, with a 33% false-positive and a 30% false-negative rate (Achenbach, 1991).

2) The 5-item **Conduct Problems subscale of the Strengths and Difficulties Questionnaire (SDQ)** (Goodman, Meltzer, & Bailey, 1998) was also used. The SDQ is well-validated, and has been translated into 51 languages, including isiXhosa (Goodman, Cluver, Tshandu, & Vondani, 2004). *Reliability:* In a norming study with 10,438 children (Goodman 2001) reliability was generally satisfactory, whether judged by internal consistency (mean Cronbach’s α =.73), cross-informant correlation (mean: 0.34), or retest stability after 4 to 6 months (mean: 0.62). SDQ scores above the 90th percentile predicted a substantially raised probability of independently diagnosed psychiatric disorders. The SDQ was used in the pilot study for this research (Cluver & Gardner, 2006).

Peer Problems

The pilot study suggested that peer relationships may be a difficult area for orphaned children. Orphans were less likely to perceive themselves as having no good friends (97%) than non-orphans (65%, p =.002). The scale used in measuring peer difficulties was the 5 item peer problems subscale of the **Strengths and Difficulties Questionnaire**. (Goodman, 1997) (see above for scale properties).

Post-traumatic stress

To date, only two studies have measured Post-traumatic stress amongst children orphaned by AIDS. A non-controlled study in the Congo with 354 orphans found that 39% were experiencing PTSD (Makaya et al., 2002). No further information could be found regarding scales or cut-off scores used. The pilot study for this research used an adapted version of the Impact of Events Scale (IES-8) (Dyregrov & Yule, 1995), with the orphan sample only, and found 73.3% of the orphan group above the cut-off score for PTSD. One item was shared with the non-orphan sample, and this very limited control suggested that PTSD symptoms might have been more common amongst the orphan than non-orphan group. The very limited evidence available suggested that Post-Traumatic stress was a potentially relevant psychological problem for this sample group.

Scales considered for use¹³:

Post-traumatic stress was measured using the 28-item **Child PTSD Checklist** (Amaya-Jackson, 1995). This has been used in a number of studies by the MRC Research Unit on Anxiety and Stress Disorders, including two large-scale school samples in Cape Town (Seedat et al., 2004; Seedat et al., 2000). The Child PTSD checklist has been translated into isiXhosa and was adapted for use in a community survey of child mental health in Langa (Heath & Kaminer, 2004). The study authors recommended using the unmodified full scale (Kaminer 2004, personal communication). This scale was chosen as it has been used more than any other PTSD scale with isiXhosa-speaking, Black African children. The psychometric properties, although unpublished, are largely good.

¹³ A number of PTSD scales have been used amongst children in South Africa. These include the IES-8 (Dyregrov & Yule, 1995), the Child PTSD Checklist (Amaya-Jackson), the Child and Adolescent Trauma Survey (CATS) (March, 1999), Levonn (which measures distress rather than DSM-IV criteria of PTSD) (Richters, Martinez, & Valla, 1990), the K-SADS, (M. Kaufman et al., 1997) and the Children's PTSD Inventory (Saigh, 1998). Psychometric properties of all these scales were considered. In the interests of brevity, only the scale chosen (the Child PTSD checklist) is detailed here.

The scale was accompanied by cartoons from the **Levonn scale** (Richters et al., 1990), which has been used in the local population (Zissis et al., 2000), and was found to be extremely useful with the study population (Robertson, 2004, personal communication), although was not suitable for use in this study as a measurement tool due to lack of correspondence with DSM-IV criteria. The Levonn items were used only as illustrations to accompany the scale. It is not known whether the use of pictures affected the comparability of the scales, as children looked at pictures to a variable extent. For this particular scale, children were also using the Velcro and tennis ball response ‘game’ (see figure 32) so it is unlikely that pictures affected response.

Figure 37: Item using the Child PTSD Checklist and Levonn/Andile

	Do you go over and over what happened in your mind?				

The Child PTSD Checklist rates the degree to which each of the 17 symptoms of PTSD was present during the last month. The scale is derived from DSM-IV criteria (American Psychiatric Association, 1994), and uses a 4-point (Likert) severity scale. The checklist was tested in three US sites (a specialised trauma clinic, with incarcerated adolescents and in an adolescent clinic inpatient sample). All psychometric data reported is unpublished, and largely from conference proceedings (Amaya-Jackson, Newman, & Lipschitz, 2000).

Reliability: Internal consistency was good, with α of .82-.95. Test-retest reliability at one week was $r=.91$, $p<.001$. Inter-rater reliability was not reported. *Validity:* ‘Good construct validity’ is reported (Newman & Amaya-Jackson, 1996). The scale corresponds to DSM-IV diagnostic criteria. ‘Good content validity’ is also reported, but no more information given. Convergent validity has been more extensively reported, and was found to be acceptable with the Beck Depression Inventory $r=.72$ $p=.01$, and the Multidimensional Anxiety Scale for Children (MASC) $r=.42$, $p=.01$. Concurrent validity

for the scale has been established by comparing it with the Clinician-Administered PTSD Scale for Children and Adolescents (CAPS-CA) (Nader et al., 1996) and found correlation of .64 (Newman et al 1998). Discriminant validity was found to be good when compared to diagnostic, clinician-administered interviews KSADS and CAPS. Using a PTSD Checklist symptom threshold of 'most of the time', kappas were .28 and .18 respectively, and using a threshold of 'all the time', kappas were .17 and .22 respectively. Criterion validity found a CAPS mean intensity rating of $r=.64$. In the US, Lipschitz et al used this scale with urban adolescent girls (Lipschitz, Rasmusson, Anyan, Cromwell, & Southwick, 2000). The K-SADS (M. Kaufman et al., 1997) was administered to a sub-set of adolescents, and the study found 87% agreement between diagnoses of current PTSD ($\kappa=.60$).

5.7 Methodological Limitations

Methodological and conceptual limitations are discussed in detail in Chapter 7. In outline, these include lack of standardised scales validated in South Africa, unknown HIV status of participating children, sample group limitations, limitations of child report, and margin of error in the 'verbal autopsy' method of determining cause of parental death. All analyses using clinical cut-offs are to be interpreted with caution, as no validated cut-offs exist for sub-Saharan Africa. For this reason, analyses do not focus primarily on cut-offs, but instead use continuous scores. The probable inclusion of HIV+ children within the sample may also have affected psychological measures.

5.8 Data Entry and data cleaning

Data were entered into SPSS 14. A random subset of 1 in 10 questionnaires was re-checked for accuracy. Where data was missing and could be obtained by telephone (such as sociodemographic data), calls were made to provide missing information.

Data cleaning was completed, using the Tulane University Data Cleaning programme (<http://www.tulane.edu/~panda2/Analysis2/datclean/dataclean.htm>), and specific SPSS data cleaning tutorials.

5.9 Analysis Strategy

Strategies for analysing the data were devised in response to six sets of questions, and aimed to use the most appropriate analyses to address each individual question. All data were analysed using SPSS (Version 14.0) All tests were two-tailed and significance was set at $p < .01$ level because of number of comparisons made.

Strategies for testing variables:

The data were initially approached by testing the first hypothesis – i.e. whether AIDS-orphaned children reported higher levels of psychological problems than other-orphans or non-orphaned children. This was clearly established in Questions 1 and 2 reported in Chapter 6. The analysis strategy then attempted to determine whether any of the environmental variables tested were acting as mediating factors in the relationship between orphanhood status and increased psychological problems. In light of the lack of available evidence concerning environmental mediators in mental health for AIDS-orphaned children, a number of potential factors were measured, in selected spheres of children's lives (Bronfenbrenner, 1979). Variables were grouped thematically, according to the literature review reported in Chapter 3: Basic demographic factors, Child-level factors, Coping factors, Caregiving arrangement factors, Quality of caregiving factors, Community factors, Positive activity factors, Trauma factors, School factors, Social Support, Poverty factors, Stigma factors, Work and Young Carer factors. These groupings inevitably crossed over to some extent – i.e. trauma factors included both household-level traumas such as domestic violence, and community-level traumas such as community violence. Bronfenbrenner's framework groups variables according to areas in a child's life in which interventions can be introduced. Variables in this study were

thus re-grouped according to those potential areas – i.e. poverty-related factors (including school factors as analyses showed that financial reasons were the cause of the vast majority of non-attendance), caregiving-related variables (including both caregiving arrangements, quality of care, abuse within the home and young carer factors) and community-level factors (including community violence, positive community-level activities and community-level stigma). At a policy level, these different groupings are the focus of different types of policy – i.e. anti-poverty policies, household-level interventions, and community safety initiatives. Thus the analytical approach was driven by both theoretical and policy concerns. The lack of primarily theoretically-driven analysis methodology is recognised as a limitation of the study, but p-values were set at $p < .01$ in order to adjust for the multiple comparisons made.

This thesis presents the variables and groups of variables which were considered to be particularly interesting and relevant to policy in South Africa. In addition to the significant mediating variables reported here, a number of other variables were not addressed in this thesis.

1) One particular factor – social support - showed both group differences and associations with mental health outcomes, and will be addressed in future analyses and publications. An outline of initial data on social support suggests the necessity for a nuanced approach to differing findings from different subscales, and future analyses must address these complexities. On the Social Support Scale, children rated levels of support received from a range of sources in 3 ecological contexts: family (caregiver, siblings) school (teacher, principal or assistant principal) and peers (your group of close friends) as well as other identified sources of support. Total scores reflect both the number of sources of support (ie children who were not attending school had no ‘teacher’ or ‘principal’ sources) and the child-perceived levels of support on emotional, instrumental and satisfaction categories. Higher scores reflect stronger social support networks. Overall, children orphaned by AIDS had lower mean scores on the Social Support Scale (mean 39.65 SD 5.04) than children orphaned by other causes (mean 42.21 SD 4.29) ($p < .0001$) and lower scores than non-orphaned children (mean 41.19 SD 5.02) ($p < .039$). There were no

differences between children orphaned by other causes and non-orphaned children. Initial analyses showed strong associations between total social support scores social support and mental health outcomes. Without controlling for socio-demographic co-factors, higher total social support scores were associated with lower reported mental health problems on depression ($p < .001$ $r = -.293^{**}$), anxiety ($p < .001$, $r = -.200^{**}$), peer problems ($p < .001$ $r = -.265^{**}$), PTSD ($p < .001$ $r = -.283^{**}$), delinquency ($p < .001$ $r = -.256^{**}$) and conduct problems ($p < .001$ $r = -.286^{**}$).

Social Support from caregivers: Reported social support from caregivers showed moderate group differences: Children orphaned by AIDS (mean score 8.51 SD 1.14) had slightly lower scores than children orphaned by other means (mean 8.71 SD .85) ($p < .022$) and non-orphaned children (mean 8.68 SD .92) ($p < .043$). There were no differences between children orphaned by other causes and non-orphans. *Social Support from siblings:* Children orphaned by AIDS (mean 7.06 SD 2.59) reported lower levels of perceived social support from siblings than non-orphaned children (mean 7.60 SD 2.32) ($p < .006$) but there were no differences between children orphaned by AIDS and orphaned by other causes (mean 7.24 SD 2.75) or by children orphaned by other causes and non-orphans. *Social Support from schools:* Children orphaned by AIDS (mean score 6.55 SD 1.31) reported less social support from teachers than non-orphans (mean 6.81 SD 1.37 $p < .01$) with no differences between AIDS-orphaned and other-orphaned children, or other-orphans and non-orphans. There were no group differences in reported social support from school principals. These analyses included children who were not attending school. *Social Support from friends:* AIDS-orphaned children (mean score 7.29 SD 1.61) reported less social support from friends than other-orphaned children (mean 8.25 SD 1.27 $p < .001$) and than non-orphaned children (mean 8.20 SD 1.28 $p < .001$). There were no differences between other-orphans and non-orphans. *Social Support from others:* Around half the children in all groups identified support from ‘another person in your life’. Of children who reported an ‘other’ source of support, children orphaned by AIDS (mean 8.61 SD 1.13) reported lower levels of perceived social support from other people in their lives than non-orphans (mean 8.85 SD .662) ($p < .02$). Children orphaned by other causes (mean 8.82 SD .89) fell between two groups and did not differ from either.

2) Some factors showed group differences, but were not associated with mental health outcomes. These included living in a formal or informal dwelling: non-orphans were more likely to live in formal structures (66%) than orphans ($p < .0001$ χ^2 15.7). There were no differences between orphans (AIDS and non-AIDS) in type of dwelling: 53% lived in a formal structure (a house or block of flats) and 40% lived in an informal structure (a shack on its own plot or in the back yard of another dwelling). Living in a formal dwelling was not significantly associated with any psychological outcomes, but was minimally associated with lower anxiety scores ($p < .094$) and higher delinquency scores ($p < .176$). Due to these minimal and inconsistent associations, type of dwelling was not included in multivariate regressions.

3) Some variables did not reflect the factors which they were attempting to measure. For example, access to electricity in the home can be an unreliable measure of poverty as many households illegally 'tap' electricity from public lines or from other households. 93% of children overall had access to electricity (with no differences between groups) and 77% had access to piped water in the home.

2) Some factors were supported strongly by theory, but produced numbers too small for inclusion in analyses. These included children in foster families living with a biological child of the foster family who was the same age as the participant child (Minty, 1999). Only 30 children reported this caregiving arrangement, and this number was too small for inclusion in regressions.

2) Other factors showed group differences and were associated with mental health outcomes (without controlling for other factors), but it was considered that the data collected did not provide enough information to include in major analyses. These included children acting as carers for younger children in the household: Children orphaned by AIDS were more likely to be a carer for younger children (68%) than both children orphaned by other means (49%) ($p < .0001$ χ^2 23.30) and non-orphaned children (53.8%) ($p < .0001$ χ^2 15.06). However, this was measured by a single and over-general

item ‘do you look after a younger child in the home?’, and did not tell us how much time was spent on caring, what roles were performed, how many younger children were cared for, or what relationship those children were to the participant. Other items were poorly worded, i.e. ‘have you ever cared for an unwell adult in your home?’ This item showed group differences (children orphaned by AIDS were more likely to be or have been carers for an unwell adult in their home (62.6%) than children orphaned by other causes (39.4%) ($p < .0001$ χ^2 23.30) and more likely than non-orphaned children (30.2%) ($p < .0001$ χ^2 69.83). Children orphaned by other causes were more likely than non-orphaned children ($p < .03$ χ^2 4.56)) but this item did not tell us when the unwell adult was cared for, how long they were unwell for, what illness they had, or what their relationship was to the child. Nor did the item distinguish between current caring and past caring.

3) some variables did not produce sufficiently reliable data for use. This included ‘age of caregiver’, as many children were not aware of the exact age of their caregiver, and some of the variables attempting to determine circumstances of non-resident parents, of whom children often knew very little information.

4) Some variables showed group differences, but were better approached through another variable. For example, some of the poverty-related variables showed differences according to orphanhood status – i.e. one-way ANOVAs showed differences in access to a phone or cellphone ($p < .001$ $F=9.81$). Children orphaned by AIDS (64.9%) were less likely than children orphaned by other causes (72.2%) to have access to a phone or cellphone ($p < .05$ χ^2 3.7) , and less likely to have access than non-orphaned children (80.2%) ($p < .001$ χ^2 18.8). Children orphaned by other causes were less likely to have access than non-orphaned children ($p < .03$ χ^2 4.4). This variable was an indicator of the increased poverty amongst AIDS-orphaned children. However, the poverty variable of insufficient food was both a stronger indication of increased poverty, and a more realistic area of intervention than cellphone access.

5) a number of variables showed differences between orphans and non-orphans, but not between AIDS-orphaned and other-orphaned children. These included access to household goods and services ($p < .01$). These indicate interesting areas for future analysis,

but were not used in the present thesis due to the fact that they would not function as mediating variables in the difference between AIDS-orphanhood and other-orphanhood.

6) Some factors produced results which required further information in order to be useful. For example, children orphaned by AIDS were more likely to attend a support group than children orphaned by other causes (29.2% compared to 16.2%), but lack of information on children's mental health prior to attending groups, or of the nature of the groups themselves, meant that this variable was not considered suitable for further analyses.

Analyses of Questions 1-6

Question 1: What is the basic demographic composition of the sample? Are there differences between groups on demographic factors?

Basic frequencies and means tests were used to explore sociodemographic characteristics of the sample, such as gender and age. Differences between orphanhood groups on sociodemographic characteristics were assessed using independent sample t-tests, chi-squared tests and one-way ANOVAs.

Question 2: Do AIDS-orphaned children have more mental health problems than other children? Do these persist independently of basic demographic factors?

Firstly, it was necessary to establish relationships between the three key variable groups of: orphanhood status, psychological outcomes and sociodemographic factors. Analyses explored differences between orphanhood groups on psychological scales. These were assessed using independent sample t-tests, Chi-squared tests and one-way ANOVAs. Analyses then explored differences between orphanhood groups on sociodemographic factors, and differences between sociodemographic factors and continuous psychological outcomes, also using independent sample t-tests, Chi-squared tests and one-way ANOVAs.

Secondly, a model was developed in order to test the association of orphanhood status with psychological outcomes, without controlling for sociodemographic factors. Multiple linear regression analyses were used to assess associations between orphan status (orphaned due to AIDS and orphaned due to other causes, compared to non-orphans) with each continuously-scored psychological outcome (depression, anxiety, post-traumatic stress, peer problems, delinquency, and conduct problems).

Thirdly, a model was developed in order to test the association of orphanhood status with psychological outcomes, controlling for relevant sociodemographic factors. Sociodemographic factors that were associated with each psychological outcome at $p < .20$ level were identified as potential co-factors for multivariate models (Hosmer & Lemeshow, 1989). Multiple linear regression analyses were then re-performed, but controlling also for these identified sociodemographic factors.

Fourthly, analyses examined differences between orphanhood groups on proportions of children scoring within the clinical range for each psychological problem. Analyses used standardised clinical cut-offs. Children orphaned by AIDS were compared to other orphans, non-orphans and to norms established in developed countries.

Question 3: Are AIDS-orphaned children poorer than other children? Does poverty mediate differences on mental health between orphan groups?

Firstly, associations between orphanhood status and mental health, whilst controlling for relevant socio-demographic characteristics, were established in the analyses conducted for Questions 1 and 2.

Secondly, this analysis also needed to determine associations between poverty and orphanhood status, and between poverty and mental health outcomes. Differences between orphanhood groups on the four poverty indicators chosen: food security, access to school, receipt of any social security in the household, and any employment in the

household, were assessed using Chi-square tests. Associations between poverty indicators and mental health outcomes were then examined using independent sample t-tests.

Thirdly, analyses explored the potentially mediating effects of poverty on the established relationship between AIDS-orphanhood and psychological problems. As with Question 2, multivariate linear regression analyses were used to assess associations between orphan status (orphaned due to AIDS and due to other causes) with each mental health outcome (depression, anxiety, post-traumatic stress, peer problems, delinquency, conduct problems) and poverty.

Two regression models were created for each psychological outcome. Model 1 shows the final model created in Question 2: associations between orphan status and mental health outcome, adjusting for sociodemographic co-factors that were associated at $p < .20$ with each respective outcome (Hosmer & Lemeshow, 1989). Model 2 takes the analysis a step further, and further adjusts for the four poverty indicators predicted to mediate the association between orphan status and mental health. The four poverty variables were combined and coded as a dichotomous variable. Children were either coded as ‘not poor’ ie having all four variables: (‘attending school and household employment and receiving grant and food secure’), or coded as ‘poor’ ie not having one or more variable. Thus if a child was attending school, someone in the home had a job, and was receiving a grant, but did not have enough to eat at least 5 days a week, they were coded as ‘poor’. This must be understood within the context of overarching poverty affecting the whole sample group in deprived research areas.

Reductions in coefficients between Model 1 and Model 2 were indicative of a mediational effect of poverty on the association between orphan status and mental health outcome. However, it was considered optimal to conduct a formal test of mediation in order to confirm the regression results. Fourthly, after testing that the preconditions were met for mediation (Baron & Kenny, 1986), the Sobel test (Sobel, 1982) was conducted to

determine the potential mediating effect of the combined poverty variables on the relationship between orphanhood status and psychological outcomes.

Question 4: What types of caregiving arrangements are associated with mental health outcomes for AIDS-orphaned children? What other caregiving factors are mediating differences in mental health between orphan groups?

What types of caregiving arrangements are associated with mental health outcomes for AIDS-orphaned children?

Firstly, differences between orphanhood groups on type of caregiving arrangement were assessed using Chi-square tests or one-way ANOVAs. Secondly, associations between psychological outcomes (depression, anxiety, PTSD, peer problems, delinquency and conduct problems) and type of caregiving arrangement were examined, using t-tests and chi-square tests.

Multivariate linear regression analyses (Table 3) were used to assess associations for AIDS-orphaned children between type of caregiving arrangement and psychological outcomes, controlling for age, gender and poverty (food security). AIDS-orphaned children living in different care arrangements were compared to a base variable of non-orphaned children living with a biological parent.

What other caregiving factors are mediating differences in mental health between orphan groups?

Firstly, differences between orphanhood groups on caregiving factors (changes of caregiver, separation from siblings, caregiver illness, caregiver monitoring, positive reinforcement, caregiver-child activities, sense of belonging, intra-household resource allocation, abuse, domestic violence and extent of housework) were assessed using Chi-square tests. Secondly, associations between psychological outcomes (depression, anxiety, PTSD, peer problems, delinquency and conduct problems) and caregiving factors

were then examined, using t-tests and chi-square tests. Caregiving factors which showed both group differences on orphanhood status and were associated with psychological outcomes ($p < .01$) were selected for further analysis.

Thirdly, analyses explored the potentially mediating effects of the selected caregiving factors on the established relationship between AIDS-orphanhood and psychological problems. As with Question 2 and 3, multivariate linear regression analyses were used to assess associations between orphan status (orphaned due to AIDS and due to other causes) with each mental health outcome (depression, anxiety, post-traumatic stress, peer problems, delinquency, conduct problems) and caregiving factors.

Two regression models were created for each psychological outcome. Model 1 shows the final model created in Question 2: namely associations between orphan status and mental health outcome, adjusting for sociodemographic co-factors that were associated at $p < .20$ with each respective outcome (Hosmer & Lemeshow, 1989). Model 2 takes the analysis a step further, and further adjusts for caregiving indicators expected to mediate the association between orphan status and mental health. These were caregiver illness and time spent by the child doing housework.

Two regression models are presented for each outcome. Model 1 examined associations between orphan status and psychological outcome, adjusting for age and gender, Model 2 takes the analysis a step further, and adjusted also for caregiving factors of caregiver illness and child housework.

Fourthly, reductions in coefficients between Model 1 and Model 2 were indicative of a mediational effect of these factors on the association between orphan status and mental health outcome. In addition, a formal test of mediation was conducted in order to confirm the regression results. After testing that the preconditions were met for mediation (Baron & Kenny, 1986), mediating effects associated with caregiving factors were then assessed using the Sobel test (Sobel, 1982) for all psychological outcomes where regression models showed significant change from models 1-2.

Question 5: Do AIDS-orphaned children experience higher levels of bullying, community violence, AIDS-related stigma and less access to sport? Are any of these factors operating on a community level are mediating differences in mental health between orphan groups?

Firstly, associations between orphanhood status and mental health, whilst controlling for relevant socio-demographic characteristics, were established in the analyses conducted for Questions 1 and 2.

Secondly, this analysis also needed to determine associations between community-level factors and orphanhood status, and between community-level factors and mental health outcomes. Differences between orphanhood groups on community factors were assessed using one-way ANOVAs. Associations between community factors and mental health outcomes were examined using bivariate correlations.

Where community-level factors were associated with both mental health outcomes, and orphanhood status, they met criteria (Baron & Kenny, 1986) to be examined as a potential mediating variable between the two.

Thirdly, analyses explored the potentially mediating effects of community-level variables on the established relationship between AIDS-orphanhood and psychological problems. As with Question 3 and 4, multivariate linear regression analyses were used to assess associations between orphan status (orphaned due to AIDS and due to other causes) with each mental health outcome (depression, anxiety, post-traumatic stress, peer problems, delinquency, conduct problems) and community-level factors.

Two models are presented for each outcome. Model 1 shows the analysis conducted in Question 2: associations between orphan status and mental health outcome, adjusting for demographic co-factors that were previously shown to be associated with orphanhood group at $p < .20$. Model 2 further included four community factors as additional

explanatory variables: community violence, bullying, stigma and positive recreational activities.

Backwards elimination was used to identify and omit those community factors that did not contribute significantly to the model, thereby yielding parsimonious models for each outcome (Blalock, 1979). Stigma was retained in each of the models; bullying, trauma and positive activities were eliminated.

Reductions in coefficients between Model 1 and Model 2 were indicative of a mediational effect of stigma on the association between orphan status and mental health outcome (Baron & Kenny, 1986). In addition, a formal test of mediation was conducted in order to confirm the regression results. Fourthly, after testing that the preconditions were met for mediation (Baron & Kenny, 1986), the Sobel test (Sobel, 1982) was conducted to determine the potential mediating effect of stigma on the relationship between orphanhood status and psychological outcomes.

Question 6: Are there any interaction effects between risk factors? Are factors combining to produce a cumulative effect on the mental health of children?

A final set of analyses sought to investigate the possibility of cumulative effects of key predictive factors on mental health. A number of potential analysis methods allow exploration of additive or interactive relationships between independent variables. Stepwise regression and path analysis would have had the advantage of allowing a continuous dependent variable of mental health outcomes. However, stepwise multiple regression was considered inappropriate due to the number of independent variables which were wished to add into the model, and the restriction to additive relationships between variables. Path analysis was not considered suitable due to lack of prior hypothesised model (Asher, 1976; Blalock, 1979). A convenient mode of analysis allowing us to address these concerns for a modest subset of variables, is log-linear analysis. An additional advantage of log-linear is the investigation of both mutual

simultaneous relationships amongst factors, and particular interaction effects, in which variables with separate impact have a much greater impact when combined. These might be expected to indicate a possible cumulative effect of risk factors on mental health.

However, in order to take advantage of the pattern-seeking and interaction-seeking advantages of log-linear, it was necessary to use a dichotomous dependent variable of mental health. Clinical cut-off scores as used in Question 2 (although used with caution as not normed on a South African population) provided a plausible way to proceed.

Firstly, in order to establish the relevance of combining mental health scale outcomes, factor analyses were used on clinical-level cut-off scores. Internalising disorders (depression, anxiety, PTSD) loaded at .79, and externalising disorders (conduct problems, behaviour problems) loaded at .91. Peer problems were excluded from this analysis. The findings of Question 2 showed that internalising disorders were of more concern to this sample than externalising disorders, and thus internalising disorders only were used for subsequent analyses. Secondly, a dichotomous variable was created to determine the existence for children of a clinical-level score in *one or more* of the internalising disorders of depression, anxiety or post-traumatic stress. This constituted the dependent 'mental health' variable for the purpose of log-linear analysis.

Thirdly, in an analysis testing interactions between factors, it was considered helpful to use a broadly population-representative sample in terms of the key factor of orphanhood status. I weighted the sample to reflect South African population proportions of AIDS-orphaned, other-orphaned and non-orphaned children, allowing broad representativeness of other risk factors. Weighting used data from the General Household Survey 2005 (Statistics SA, 2006a) and UNAIDS (UNAIDS, 2006). Within the age group 10-19, approximately 24% of children are orphaned, with 50% of these (12% of all children) orphaned due to HIV/AIDS.

Fourthly, the study wished to identify factors which would potentially contribute to cumulative effects on child mental health. Potential risk and protective factors were

entered into multivariate logistic regressions with orphanhood status, controlling for age and gender, and with the dependent variable of any internalising disorder (I) (ie clinical-level score on one or more of depression, anxiety or PTSD). Backwards-elimination selected eight variables with associations $p < .01$. Three variables were excluded due to: small group size (streetchildren $n=60$) or limited relevance to direct interventions or policy (community support, coping mechanisms). The remaining five variables were coded dichotomously for entry into log-linear analyses, and were the following; food security (F), stigma (S), orphanhood status (V) quality of care (Q) and bullying (B).

Fifthly, the study wished to determine whether there were any interactive effects between sets of factors. Hierarchical loglinear modelling by backwards selection, yielded the following model with sound fit of .398: (F*S*I, V*B*I, S*F*Q, Q*I, V*Q, V*S, V*F, B*Q, S*B). All of these terms were significant at $p < .005$. For the purposes of this analysis, the study attended to the interactions which included 'presence of internalising disorder' (I).

Finally, associations between psychological outcomes and risk factors were then examined, using chi-square tests. For this analysis, significance was set at $p < .01$ level (for regressions) and $p < .005$ level (for log-linear) because of the number of comparisons made.

Summary of analysis strategies

Differences between orphanhood groups on psychological scales, sociodemographic characteristics and risk and protective factors, were assessed using independent sample t-tests, Chi-squared tests and one-way ANOVAs. Multivariate linear and logistic regression analyses were used to assess associations between orphan status (orphaned due to AIDS and orphaned due to other causes, compared to non-orphans) with psychological outcomes (depression, anxiety, post-traumatic stress, peer problems, delinquency, and conduct problems), controlling for sociodemographic, risk and protective factors. Where necessary, backwards elimination was used in order to identify significant variables. Sobel tests were used to determine mediating influences of risk and protective factors on the relationship between orphanhood status and psychological outcomes. In order to explore interactions between risk factors, log-linear analysis was used.

5.10 Dissemination of findings



Figure 38: Feedback session to the Nobantu ‘Women for Peace’ Project, Mfuleni

The overarching goal of this research was to provide policy-makers with an evidence-base on the well-being of vulnerable children. It is an ethical responsibility of applied research in the developing world to ensure that findings are available to relevant stakeholders. Academic papers and a PhD thesis will be largely inaccessible to South African social workers and policy makers. There has also been a high level of interest expressed within South Africa in these findings. Many agencies have shown an eagerness

to use evidence-based practice in their work with AIDS-orphaned children. A number of South African Government departments, Social Services and NGOs requested information sessions, meetings, and easily-comprehensible policy briefing documents on the study findings.

Feedback of study findings was not made to children who had participated in the study. This was partially due to budget constraints: letters of feedback were sent to all children who participated in the pilot quantitative and qualitative stages, but the research budget was insufficient for the postage of 1025 further letters to children. The decision not to feed back on findings to children was also based on an ethical decision. Informing children that they were in a high-risk group for mental health problems may in itself be damaging.

Dissemination strategies included:

- Conversion of findings into four ‘Policy Briefing’ documents (see Appendix 9)
- Publication of papers in peer-reviewed journals. At the time of writing, four papers have been published, and five further papers are in submission or preparation.
- Presentation of findings and discussion with the National Minister for Social Development (Dr Zola Skweyiya) and the National Director General of Social Development (Mr Vusi Madonsela). Parliament, 21 Feb 2007. Subsequent meetings have taken place with the Deputy Director-General of Integrated Development (Ms Vuyelwa Nhlapo) the Chief Director of the Children’s Directorate (Dr Maria Mabetoa) and the Chief Director of the HIV/AIDS Directorate (Dr Connie Kganakga).
- Presentation of findings to Government departments requesting feedback:
- Presentation of findings to the South African AIDS Conference 2007, where it was awarded the Discovery Clinical Excellence Award for ‘Best Oral Presentation’.
- Presentation of findings to the AIDS Impact Conference (July 2007) the Human Sciences Research Council (March 2007) the University of Cape Town AIDS and Society Research Unit (Feb 2007), the University of the Western Cape (June 2007), Oxford University Department of Psychiatry (May 2007), Columbia University HIV

Center for Clinical and Behavioral Studies (August 2007), Yale University Centre for International Research on AIDS (September 2007).

- Presentation of findings as a set of workshops to social workers and community workers at Social Services departments and NGOs
- Presentation of findings to all community agencies, schools and orphan support groups who participated in the study (19 organisations).
- Emailing of policy briefs and papers to a wide range of academics, NGOs and government departments who had requested study findings.

Responses to feedback and published papers

- The National Department of Social Development plan to extend this current study into a national survey of outcomes for AIDS-orphaned children. A brief summary of Ministerial responses to the findings is given in Chapter 7. At the time of writing, the study is being planned with the Directorate-General of Social Development, the Children's Directorate, and the HIV/AIDS Directorate.
- The Department of Social Development has sent study findings and copies of all papers to their national mailing list of organisations and groups working with AIDS-affected children.
- UNICEF (Pretoria) and DFID Southern Africa Programme Directors requested study findings to inform South Africa policies.
- Six schools are planning to initiate services such as feeding schemes or anti-bullying strategies as a result of the study.
- Five NGOs are currently using the policy briefs in their fundraising strategies. This is in response to increasing donor demands for research evidence of areas of need, and effectiveness of services.
- Presentation of findings to academic audiences resulted in debate on targeting of services, and discussions with HSRC and the Children's Institute on documents currently in preparation.
- The Joint Learning Initiative on Children Affected by AIDS (JLICA) have incorporated the study findings into their current project reviewing research.

- UNICEF Swaziland is currently planning a trial of psychosocial support for orphaned children, and is utilizing study findings and methodologies.
- SoulBuddy and Soul City (television programmes for children addressing issues around HIV and AIDS) have used the findings in devising the forthcoming season's episodes and story-lines.

Summary of dissemination:

The study has been more successful than anticipated in terms of dissemination of findings. This may be attributable to the current political climate. Whilst dissemination was time-consuming and costly, it was an essential component of the overall study. It also allowed a level of criticism and debate which has improved the interpretation and policy recommendations presented in Chapters 6 and 7.

5.11 Summary and conclusions

Chapter 5 has outlined the methodology for Stage 4 of the research design. It has explained choices of sample and control groups, and strategies for sampling of children. The chapter described the verbal autopsy method used to determine cause of parental death. Fieldwork methodologies and realities were detailed, including challenges and research constraints. Ethical considerations were an integral part of the research design, and a detailed overview was given of research ethics.

The chapter then described the instruments used for measurement of mental health problems, and for measurement of risk and protective factors in child mental health. Strategies for analysing the data were given, focusing on each of the research questions which will be answered in Chapter 6. Finally, Chapter 5 explained the strategy for dissemination of the study findings, and some of the responses in South Africa to the new evidence provided by this thesis.

Chapter 6 will continue Stage 4 of the research design. It will report findings resulting from the data collection and analysis strategy described in the present chapter.

Chapter 6: Quantitative stage: Results

- 6.1 Introduction and structure
- 6.2 Question 1: Demographic data: overall results
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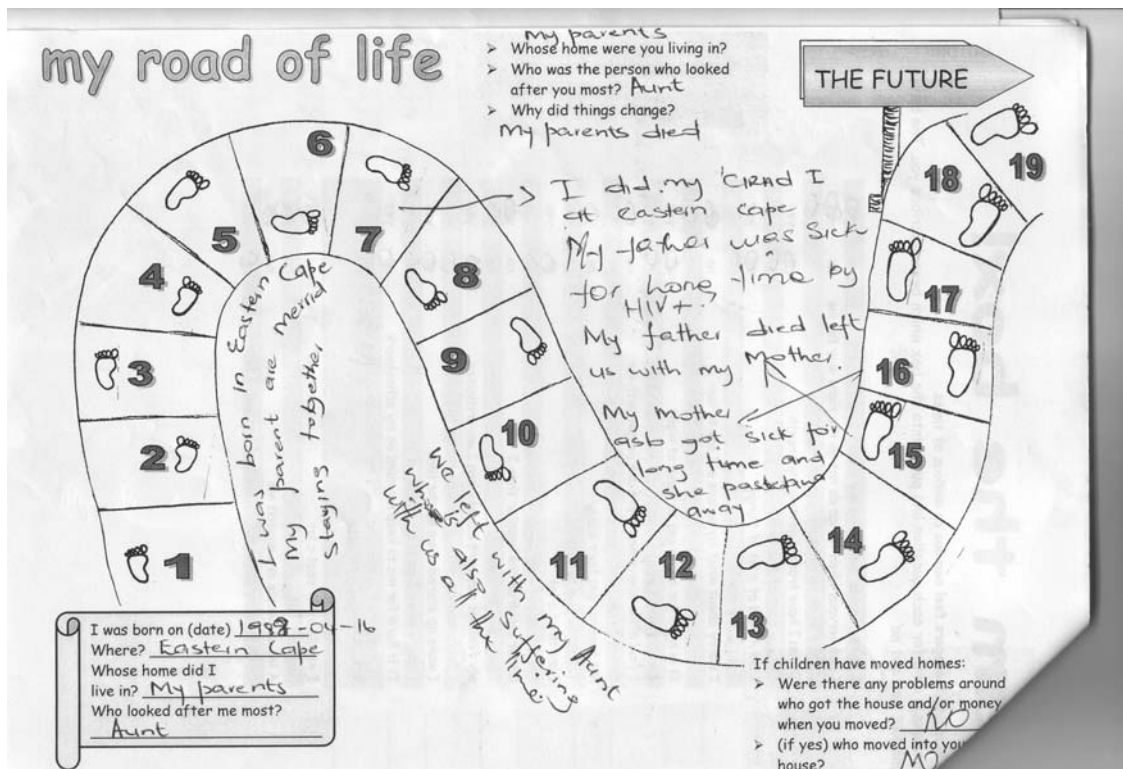
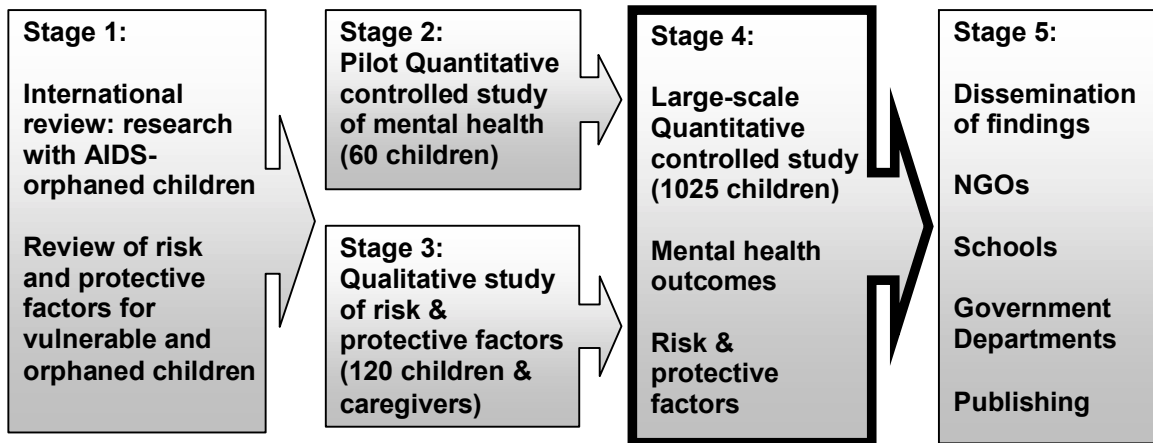


Figure39: Road of Life, Girl, 14, Makhaza.

6.1 Introduction and structure



Chapter 5 described in detail the methodology and analysis strategy for the quantitative stage of the current study (Stage 4 above). This chapter presents the key findings from the quantitative stage. It is divided into six sections, each of which addresses a specific set of questions.

Question 1: What is the basic demographic composition of the sample? Are there differences between groups on demographic factors? (Section 6.2)
Question 2: Do AIDS-orphaned children have more mental health problems than other children? Do these persist independently of basic demographic factors? (Section 6.3)
Question 3: Are AIDS-orphaned children poorer than other children? Does poverty mediate differences in mental health between orphan groups? (Section 6.4)
Question 4: What types of caregiving arrangements are associated with mental health outcomes for AIDS-orphaned children? What other caregiving factors are mediating differences in mental health between orphan groups? (Section 6.5)
Question 5: Do AIDS-orphaned children experience higher levels of bullying, community violence, AIDS-related stigma and less access to sport? Are any of these factors operating on a community level mediating differences in mental health between orphan groups? (Section 6.6)
Question 6: Are there any interaction effects between risk factors? Are factors combining to produce a cumulative effect on the mental health of children? (Section 6.7)

6.2 Question 1: Demographic data: overall results

Question 1: What is the basic demographic composition of the sample? Are there differences between groups on demographic factors?

Summary: Children orphaned by AIDS (mean age 13.7yrs) were older than non-orphans (mean age 13.02 yrs) ($p<.002$), due to increased likelihood of school grade repetition. Gender, language and internal migration showed no group differences. Orphaned children (43%) were more likely to live in informal dwellings than non-orphans (29%, $p<.001$). AIDS-orphans (mean 4.8) and other-orphans (mean 4.6) lived in smaller households than non-orphans (mean 5.2, $p<.003$). AIDS-orphaned children were more likely to be maternally (59%) or doubly (25%) bereaved than other-orphans (28% and 12% respectively), and AIDS-orphans were older at age of first orphanhood (mean 10.1 yrs) than non-orphans (mean 7.8 yrs, $p<.001$).

Table 7 shows differences between orphanhood groups on sociodemographic variables.

Age: AIDS-orphaned children had a mean age of 13.70 (SD 2.52), other orphans had a mean age of 13.38 (SD 2.41) and non-orphans had a mean age of 13.02 (SD 2.01). These differences (Mann-Whitney U test) shows that AIDS-orphaned children were older than non-orphans ($N=665$, $z=-1.46$, $p<.002$), with no other differences between groups. This finding was largely a result of our sampling procedure: orphaned children were matched with non-orphans from the same school grade, and results showed retrospectively that orphaned children were more likely to have had to repeat grades at school than non-orphans. Age was controlled for in all analyses.

Gender: Overall, the sample was 53% male and 47% female. There were no significant differences between groups on gender.

Language and ethnicity: Most children identified the main language spoken at home as isiXhosa (96%), but other languages spoken were: Afrikaans (2%), English (2%), Sesotho (.5%) and isiZulu (.1%). There were no differences between groups.

Ethnic origin of the children was 97% amaXhosa. There were no differences between groups. Almost all non-amaXhosa children were streetchildren (91% - 29 out of 32). These were Coloured (26), Indian (2) and amaZulu (1). The 3 non-amaXhosa non-streetchildren were Coloured (1) and Sesotho (2). When streetchildren were excluded, the sample was 99.7% amaXhosa. Ethnicity was not further analysed due to small size of non-amaXhosa groups.

Household size: AIDS-orphaned children (mean household size 4.8 SD 1.9) did not differ from other orphans (mean 4.6 SD 1.7). However, non-orphans had a larger household size (mean 5.2 SD 2.0) than both AIDS-orphaned children (t (df 666) = 2.99 $p < .003$) and other orphans (t (df 487) = 3.70 $p < .001$).

Dwelling type: Children orphaned by AIDS (43%) and orphaned by other causes (43%) were equally likely to live in informal dwellings (shack made of corrugated iron, plastic etc), rather than formal dwellings (brick or concrete house or flat). Non-orphans were less likely to live in an informal dwelling (29%) than both AIDS-orphaned children ($p < .0001$ χ^2 13.6) and other orphans ($p < .001$ χ^2 10.8).

NB: Streetchildren were excluded from the preceding two analyses due to the changeable nature of their living arrangements: most stayed some nights in shelters or homes (in dormitories of 5-30 beds), and other nights on the streets.

Internal Migration: Child migration is common in Southern Africa, often within an extended family network and adapting to changing financial, educational and caregiving needs (Ansell & Young, 2004). High proportions of children in all orphanhood groups had moved between South African provinces (41%). 58% of participants were born in Cape Town. 35% of children had been born in the neighbouring province of the Eastern Cape, and small numbers had been born in Gauteng (4%), Northern Cape, Kwa-Zulu Natal, Free State and outside South Africa. There were no differences between groups.

Moving between homes: Sixty-six percent of all children had moved between 2 or more different homes (67% of AIDS-orphaned children, 69% of other-orphans and 72% of non-orphans). There were no differences between groups.

Type of bereavement: Amongst AIDS-orphaned children, 59% were maternally bereaved, 66% paternally bereaved and 25% doubly bereaved. Children orphaned by non-AIDS causes were 28% maternally bereaved, 83% paternally bereaved, and 12% doubly bereaved. For 156 orphans, paternal survival and whereabouts were not known. Although it was anticipated that this would affect psychological outcomes, maternal/paternal/double bereavement was not associated with any mental health outcomes (see 6.3) and so was not controlled for in subsequent analyses.

Age at First Orphanhood: AIDS-orphaned children were older at first bereavement (mean 10.1 years SD 3.8) than other orphans (mean 7.8 years SD 4.6) ($p < .0001$, $t(df = 587) = 6.54$). Around 50 children in each group did not know exactly how old they had been when their parent died.

Table 7: Differences between groups on demographic variables

	AIDS-orphaned children (n=425)	Other-orphans (n=241)	Non-orphaned children (n=278)	P value ¹ (χ^2 /F)
Age (mean, SD)	13.7(2.5) ^a	13.4(13.4)	13.0(2.0) ^b	<.001 (MNU test)
Female (%)	50.6 ^a	43.2 ^a	46.4 ^a	ns
amaXhosa ethnicity– overall sample (%)	98.1 ^a	96.7 ^a	96.4 ^a	ns
Household size (mean, SD) ²	4.8(1.9) ^a	4.6(1.7) ^a	5.2(2.0) ^b	<.001 (F 7.50)
Informal dwelling (%) ³	43.0 ^a	43.0 ^a	29.1 ^b	<.001 (χ^2 14.95)
Internal migration (%)	41.4 ^a	44.0 ^a	40.6 ^a	ns
Moved between 2+ homes (%)	66.4 ^a	69.3 ^a	71.6 ^a	ns
Loss of mother (%)	58.6 ^a	28.2 ^b	-	<.001 (χ^2 55.7)
Loss of father (%)	66.1 ^a	83.0 ^b	-	<.006 (χ^2 7.4)
Loss of both parents (%)	24.9 ^a	12.4 ^b	-	<.001 (χ^2 20.8)
Age, first bereavement (mean, SD)	10.1(3.8) ^a	7.8(4.6) ^b	-	<.001

^a ^b ^c Means with different superscripts differ significantly at $p < .01$, tested using Tukey's post-hoc comparisons.

¹ P-value associated with Mann-Whitney-U test, one-way ANOVA or Chi-square test

² Number of cases reduced due to exclusion of streetchildren who moved between shelters and streets. For AIDS-orphaned children, $n=403$; other orphans, $n=223$; non-orphans, $n=265$.

³ Number of cases reduced due to exclusion of streetchildren. For AIDS-orphaned children, $n=403$; other orphans, $n=223$; non-orphans, $n=265$.

6.3 Question 2: Do AIDS-orphaned children have more psychological problems?

Question 2: Do AIDS-orphaned children have more mental health problems than other children? Do these persist independently of basic demographic factors?

A version of the following analysis appears as:

Cluver, L, Gardner, F & Operario, D (2007) *Psychological distress amongst AIDS-orphaned children in urban South Africa*. Journal of Child Psychiatry and Psychology and Allied Disciplines. 48 (8), 755-763.

Summary:

Controlling for socio-demographic factors such as age, gender, formal/informal dwelling and age at orphanhood, children orphaned by AIDS were more likely to report symptoms of depression ($p < .001$), peer relationship problems ($p < .001$), post-traumatic stress ($p < .001$), delinquency ($p < .001$) and conduct problems ($p < .001$) than both children orphaned by other causes and non-orphaned children. Anxiety showed no differences. AIDS-orphaned children were more likely to report suicidal ideation ($p < .05$). Compared to Western norms, AIDS-orphaned children showed higher levels of internalising problems and delinquency, but lower levels of conduct problems.

Background to Question 2:

Research in the developed world has explored effects of bereavement on children, and shows differing mental health effects of parental death from causes such as homicide (Black & Harris-Hendricks, 1992), war (Kaffman & Elizur, 1979) and cancer (Siegel, Karus, & Raveis, 1996). However, despite the magnitude of effects of AIDS on orphanhood worldwide, very little empirical evidence explores psychological consequences of AIDS orphanhood specifically (A. Stein et al., 2005). No published studies to date compare children orphaned by AIDS to children orphaned by non-AIDS causes and non-orphaned children, and so it is difficult to isolate differential effects of AIDS and orphanhood within our understanding of children's responses to bereavement.

Results:

Differences between orphanhood groups on socio-demographic factors are shown in Question 1 and Table 7 above.

Table 8 shows associations between socio-demographic factors and continuous psychological outcomes. Increased age was positively correlated with scores on all scales ($p < .001$). Females reported more depression and anxiety than males ($p < .01$); whereas males reported more delinquency and conduct problems than females ($p < .01$). Smaller household size was associated with peer problems, and internal migration associated with delinquency. Maternal, as opposed to paternal, bereavement, and loss of both parents were not associated with heightened distress on any outcome.

Psychological outcomes when controlling for socio-demographic factors (Table 3):

Two models are shown for each psychological outcome. The unadjusted models show univariate associations between orphan category and psychological outcome. The adjusted multivariate models control for sociodemographic co-factors that were associated with each psychological outcome at $p < .20$ level (Hosmer & Lemeshow, 1989).

Orphanhood groups were also compared to each other, and to norms established in the developed world, regarding proportions of children scoring within the clinical range for each psychological problem (Graph 1).

Depression

When controlling for age and female gender, orphanhood by AIDS was significantly related to higher depression scores. Orphanhood by other causes was not associated with depression in either the unadjusted or adjusted models.

The recommended cut-off score for the full Child Depression Inventory (CDI) is 19 (Kovacs, 1992), identifying the upper 10% of the distribution in a non-clinical sample. Pro-rating for the CDI short form, 17% of AIDS-orphaned children fulfilled clinical criteria for depression, compared to 10% of other-orphaned children and 9% of non-orphans.

An additional item asked respondents to identify suicidal ideation. When controlling for age and female gender, AIDS-orphaned children were more likely than other groups to endorse a conservative threshold of 'I want to kill myself' ($p < .05$).

Anxiety

Orphanhood by AIDS initially was marginally associated with anxiety in the unadjusted model, but the association was completely eliminated in the adjusted model (controlling for age, female gender and type of dwelling). Orphanhood by causes other than AIDS was not associated with anxiety in either unadjusted or adjusted models.

Using a recommended cut-off score of 19 (Stallard, Velleman, Langsford, & Baldwin, 2001) to identify children experiencing clinically significant levels of anxiety, 10% of AIDS-orphaned children, 8% of other-orphaned children and 8% of non-orphans fulfilled clinical criteria for anxiety.

Table 8: Associations between demographic factors and mental health outcomes¹

	Depression (CDI)	p (r ²)	Anxiety (RCMAS)	p (r ²)	Peer Problems (SDQ Peer)	p (r ²)	Post- traumatic Stress	p (r ²)	Delinq- uency (CBCL)	p (r ²)	Conduct Problems (SDQ)	p (r ²)
Age	.157	<.001 (.051)	.127	<.001 (.009)	.144	<.001 (.068)	.174	<.001 (.050)	.201	<.001 (.050)	.118	<.001 (.049)
Gender		<.01		<.01		ns		ns		<.001		<.01
Male (M,SD)	2.72(2.64)	(.078)	11.11(5.31)	(.080)	2.25(2.10)		15.58(13.76)		2.79(2.90)	(-.106)	1.27(1.56)	(-.079)
Female(M,SD)	3.15 (2.85)		11.98(5.21)		2.43(2.15)		17.18(14.71)		2.22(2.43)		1.27(1.56)	
Household Size	-.019	ns	-.003	Ns	-.067	.04 (-.003)	-.059	ns	-.017	ns	-.011	ns
Informal dwelling		ns		Ns		ns		ns		ns		ns
Yes (M, SD)	2.99(2.82)		11.70(5.35)		2.23(2.18)		15.64(14.35)		2.19(2.42)		1.29(1.50)	
No (M, SD)	2.79(2.63)		11.11(5.19)		2.37(2.09)		16.21(13.94)		2.41(2.38)		1.36(1.49)	
Internal Migration		ns		Ns		ns		ns		<.019		ns
Yes (M, SD)	2.97(2.88)		11.54(5.55)		2.29(2.14)		16.24(14.13)		2.28(2.38)		2.29(2.37)	
No (M, SD)	2.88(2.66)		11.53(5.09)		2.36(2.11)		16.44(14.32)		2.69(2.91)		2.69(2.90)	
Moved between 2 or more homes		ns		Ns		ns		ns		ns		ns
Yes (M, SD)	2.97(2.77)		1.54(5.36)		2.27(2.11)		15.84(13.93)		2.42(2.58)		1.36(1.49)	
No (M, SD)	2.86(2.65)		11.47(5.07)		2.47(2.15)		17.28(14.60)		2.72(2.93)		1.47(1.65)	
Mother only death ²		ns		Ns		ns		ns		ns		ns
Yes (M, SD)	3.33(2.99)		11.73(5.68)		2.70(2.09)		18.58(14.90)		2.74(2.85)		1.58(1.60)	
No (M, SD)	3.09(2.70)		11.64(4.79)		2.62(2.14)		18.75(14.68)		2.70(2.70)		1.46(1.53)	
Father only death ²		ns		Ns		ns		ns		ns		ns
Yes (M, SD)	3.23(2.86)		11.88(5.06)		2.70(2.15)		18.96(14.78)		2.70(2.72)		1.49(1.57)	
No (M, SD)	3.28(2.98)		12.52(5.81)		2.43(2.03)		19.34(15.32)		2.54(2.56)		1.47(1.39)	

Death of both parents ²	Ns	Ns	ns	ns	ns	ns
Yes (M, SD)	3.42(3.19)	12.28(5.52)	2.73(2.14)	18.73(14.80)	2.59(2.78)	1.50(1.69)
No (M, SD)	3.16(2.75)	11.54(5.19)	2.66(2.11)	18.67(14.76)	2.76(2.76)	1.52(1.52)
Age at first bereavement	Ns	Ns	ns	ns	ns	ns
	.051	.009	.068	.050	.050	.049

¹ P-values associated with independent sample t-test or bivariate associations.

² Includes only orphaned children.

Peer Problems

Orphanhood by AIDS was significantly associated with peer relationship problems in the unadjusted model, and this association remained significant after controlling for age, household size, and more than 2 moves between homes. Orphanhood by causes other than AIDS was not associated with peer problems in either unadjusted or adjusted models.

Borderline scores for peer problems as 4-5, and abnormal scores above 6, identified scores above the 98th percentile in a British validation study (Meltzer, Gatward, Goodman, & Ford, 2000b). Using the higher cut-off, 14% of AIDS-orphaned children, 9% of other-orphaned children and 8% of non-orphans fulfilled 'abnormal' criteria.

Post-traumatic stress symptoms

Orphanhood by AIDS was significantly associated with PTSD symptoms in both the unadjusted model and in the adjusted model which controlled for age, female gender, household size and number of moves. Orphanhood by causes other than AIDS was moderately associated ($p < .05$) in the unadjusted model, but the association was completely eliminated in the adjusted model.

Following DSM-IV criteria for PTSD, a clinical cut-off was used of 1 re-experiencing, 3 avoidance or numbing and 2 hyperarousal symptoms, and a conservative symptom threshold of 'most of the time' (Erwin, Newman, McMackin, Morrissey, & Kaloupek, 2000). In this sample, 50% of AIDS-orphaned children fulfilled criteria for PTSD, compared to 30% of other-orphaned children and 23% of non-orphans. This can be compared to PTSD prevalence rates of 2-13% in US populations (Cuffe & Addy, 1998; Lipschitz et al., 2000), and 22% in Cape Town community samples (Seedat et al., 2004). In a US study, 25% of AIDS-orphaned children had PTSD (Lester et al., 2006).

Delinquency and Conduct Problems

On the delinquency scale, orphanhood by AIDS, but not orphanhood by other causes, was significantly associated in both the unadjusted and the adjusted model (controlling for age, male gender, type of dwelling, migration and number of moves). On the conduct problems scale, orphanhood by AIDS, but not orphanhood by other causes, was significantly associated in both the unadjusted model and the adjusted model (controlling for age, male gender and migration) .

For the Child Behavior CheckList (CBCL) delinquency scale, a clinical cut-off of 8 for boys and 7 for girls, was found to identify scores $\geq 95^{\text{th}}$ percentile in the US (Achenbach, 1991). Using this cut-off, 7.8% of AIDS-orphaned children, 5% of other-orphaned children, and 5.5% of non-orphans fell within the clinical range. For the Strengths and Difficulties (SDQ) conduct problems scale, an abnormal score of 5 identified children $> 90^{\text{th}}$ percentile in a British normative study (Meltzer et al., 2000b). This cut-off identified 5% of AIDS-orphaned children, 3% of other-orphaned children, and 4% of non-orphans. Thus AIDS-orphaned children showed slightly above-US levels for delinquency, but below-UK levels for conduct problems, with both proportions lower than might be expected in the context of high-violence and high-crime research areas.

Discussion

These analyses provide evidence indicating that AIDS-orphaned children had higher overall levels of psychological difficulties than both children orphaned by other causes and non-orphaned children, and that these associations remained significant when controlling for socio-demographic co-factors such as age, gender and migration. Internalising problems of depression, suicidality, and post-traumatic stress were all higher amongst AIDS-orphaned children, and proportions of AIDS-orphaned children within the clinical range for these scales were high compared to Western-established norms. The same was true for peer-relationship problems. Anxiety showed no group differences, and proportions within the clinical range were comparable to norms. For delinquency and conduct problems, AIDS-orphaned children showed higher scores than other groups.

However, whilst delinquency showed slightly higher proportions within the clinical range than US norms, conduct problems showed lower than UK norms.

Findings of heightened internalising problems are consistent with other studies from Sub-Saharan Africa (Atwine et al., 2005; Bhargava, 2005). Mixed findings for conduct problems also echo inconsistent findings in the literature (Atwine et al., 2005; Poulter, 1996). Only three previous studies, all uncontrolled, had explored post-traumatic stress amongst AIDS-orphaned children (Cluver & Gardner, 2006; Lester et al., 2006; Makaya et al., 2002), and the findings of this study suggest that PTSD is an important area for future research and intervention. Findings correspond to other studies of parentally-bereaved children, which have found emotional and behavioural symptoms, but little evidence of anxiety disorders (Dowdney, 2000).

It was hypothesised that a number of community-level risk factors might raise distress levels in all children, and reduce differences between AIDS-orphaned, other-orphaned and non-orphaned children. Firstly, research localities are marked by social instability and high crime levels. Community-based studies report high overall levels of depression and post-traumatic stress (Ensink et al., 1997). Secondly, within the control group of non-AIDS parental deaths, many were violent or gang-related deaths. Violent parental death has been shown to increase internalising distress (Black & Harris-Hendricks, 1992; Yule & Williams, 1990), and thus was expected to raise distress levels amongst the control group of children orphaned by non-AIDS causes. Thirdly, this study included purposive sampling of streetchildren, child-headed and youth-headed households (both AIDS-orphaned and controls), all high-risk groups for psychological difficulties (Richter & Van der Walt, 1996; Thurman et al., 2006). It was expected that all these factors would reduce group differences, and it is notable that the predictive value of AIDS orphanhood remained significant despite heightened risks for the whole sample.

Table 9. Multivariate associations between orphanhood by AIDS, orphanhood by other causes, and psychological outcomes, controlling for sociodemographic cofactors

	Depression ¹		Anxiety ²		Peer Problems ³		PTSD ⁴		Delinquency ⁵		Conduct Problems ⁶	
	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model
Orphanhood by AIDS	.200**	.179**	.097*	.069	.290**	.261**	.299**	.267**	.144**	.124**	.142**	.130**
Orphanhood by other causes	.035	.029	-.008	-.022	.055	.040	.087*	.073	-.002	-.011	.015	.009
R-Square	.032	.052	.008	.026	.068	.090	.067	.090	.019	.048	.016	.036
R-Square change	.023	.023	.022	.022	.026	.026	.027	.027	.035	.035	.023	.023
F-change	7.64**	7.64**	6.28**	6.28**	8.22**	8.22**	6.56**	6.56**	6.43**	6.43**	7.40**	7.40**

* Denotes significance at the 0.05 level

** Denotes significance at the .001 level

¹ Adjusted model controls for age, gender

² Adjusted model controls for age, gender, informal dwelling

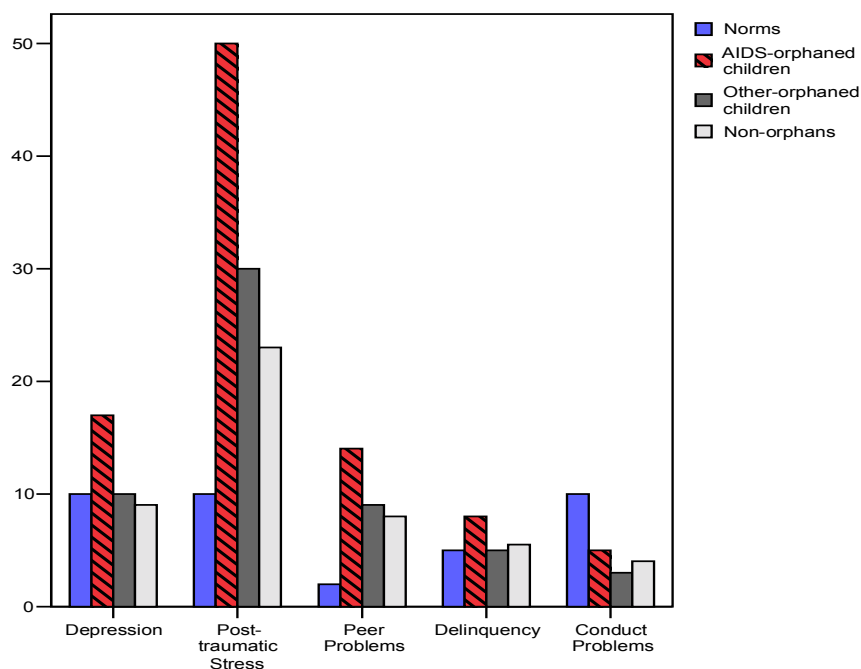
³ Adjusted model controls for age, household size, >2 moves between homes

⁴ Adjusted model controls for age, gender, household size, >2 moves between homes

⁵ Adjusted model controls for age, gender, informal dwelling, migration, >2 moves between homes

⁶ Adjusted model controls for age, gender, migration

Graph 1: Comparing groups on proportions of children with clinical-range scores for psychological problems



Specific limitations of this analysis:

This question highlights a number of limitations which apply to all the following questions, and to the study overall. An important limitation is the unavailability of HIV serology prior to parental death, and poor reliability of local death certificates regarding HIV/AIDS. However, the ‘verbal autopsy’ method has been validated in South Africa, and a conservative threshold was used of 3+ AIDS-defining symptoms. It was also unknown whether parents of control group children may have been HIV-positive but asymptomatic, and with prevalence of up to 28% in study areas, many participants were likely to have AIDS-affected family members (Department of Health, 2005). However, illness amongst families of control children would tend to have the effect of reducing group differences, and yet differences were highly significant.

A further limitation which applies to all the analyses in this chapter is the lack of scales validated in sub-Saharan Africa. Although all scales had been previously used with this population, no standardised psychological scales for this age group have been validated in

Southern Africa. The use of clinical cut-off scores and comparison with western norms (in this question and in question 6) can only provide tentative conclusions in a differing cultural context. Although cut-offs were not locally validated, they are useful in giving some indication of distress levels.

Conclusions:

Generalisation of the findings of this study to other areas and to other groups affected by HIV/AIDS should be made with caution. However, in this sample of children from deprived urban areas in South Africa, orphanhood by AIDS (but not orphanhood by non-AIDS causes) was shown to be independently associated with depression, post-traumatic stress, peer relationship problems and suicidal ideation, and this association remained above and beyond the effects of sociodemographic factors. Evidence for increased externalising problems was also found. Use of clinical cut-offs (whilst not validated in a Sub-Saharan context) show above-expected proportions of clinical-range scores for internalising problems and delinquency, and below-expected proportions for conduct problems. These findings suggest that AIDS-related parental bereavement can contribute to heightened levels of internalising and some externalising distress, beyond that even for other orphans.

The question remains of which mechanisms are driving these differences between AIDS-orphaned, other-orphaned and non-orphaned children. Hypothesised mechanisms include poverty, education, caregiving factors and community factors, including AIDS-related stigma. The following questions will examine these factors as potential mediators of the relationship between AIDS-orphanhood and psychological distress.

6.4 Question 3: Poverty

Question 3: Are AIDS-orphaned children poorer than other children? Does poverty mediate differences in mental health between orphanhood groups?

The following analysis is under review as

Cluver, L, Gardner, F and Operario, D (under review) *Effects of poverty on the psychological health of AIDS-orphaned children.*

Summary:

This analysis examines associations between poverty indicators targeted by South African poverty alleviation programmes, orphanhood status (AIDS orphans, non-AIDS orphans and non-orphans), and psychological problems (depression, anxiety, post-traumatic stress, peer problems, delinquency and conduct problems). Children orphaned by AIDS had lower food security ($p < .001$), access to social security ($p < .001$), lower likelihood of any household member being employed ($p < .001$) and lower access to education ($p < .01$). Food security, access to social security grants, employment in the household and access to school were associated with better psychological health ($p < .01$ on all scales). Poverty indicators mediated associations of AIDS orphanhood with depression (Sobel test, $p < .0002$), conduct problems ($p < .001$) delinquency problems ($p < .00008$), post-traumatic stress ($p < .00007$), and peer problems ($p < .0003$).

Background to Question 3:

Psychological problems are influenced and exacerbated by poverty: Research with children in high-income countries has found poverty and parental unemployment to be associated with internalizing problems and post-traumatic stress (Radke-Yarrow & Brown, 1993; Sund et al., 2003), and good school attendance to be associated with better outcomes (Masten et al., 1999). Poverty-related stressors may be particularly relevant for AIDS-orphaned children: familial AIDS illness is closely and causally related to increased poverty, food insecurity and unemployment (Booyesen, 2002). AIDS-orphaned children have also been shown to have lower school enrollment and attendance (Gray et al., 2006). In the qualitative stage of this project (Chapter 4), orphaned children and caregivers identified food security, school attendance and access to social security as

major factors that they considered important in child psychological health (Cluver & Gardner, 2007b).

South Africa increasingly recognizes the multidimensional nature of child poverty (Noble et al., 2006) and has launched a series of poverty alleviation programmes. As well as being valuable in their own right, these might potentially improve psychological outcomes for AIDS-orphaned children. The extent to which poverty-alleviation programmes reach intended beneficiaries is variable (Goldblatt, Rosa, & Hall, 2006).

Question 2 showed that children orphaned by AIDS presented heightened psychological distress compared to other groups. But AIDS-orphaned children are also likely to be poorer, and to experience lower access to school and social grants than other children. It is important to disentangle the effects of poverty from those of AIDS orphanhood, and to determine whether effects of AIDS orphanhood on mental health are diminished when controlling for poverty-related factors. Specific aims are: 1) to examine associations between orphanhood, poverty, and psychological distress in this sample; 2) to assess whether poverty mediates the association between AIDS-orphanhood (compared to orphanhood by other causes and non-orphanhood) and psychological outcomes; and 3) based on this empirical understanding, to draw conclusions about how targeted poverty alleviation programmes could potentially improve the psychological well-being of orphaned children.

Poverty indicators used in this analysis:

Four indicators of poverty were used: food security, access to school, receipt of any social security grant in the household, and any adult employment in the household. Each poverty indicator represented the focus of a particular poverty alleviation programme in South Africa. Information on school attendance and enrolment were obtained from school registers or social workers, corroborated by child and coded dichotomously as ‘currently enrolled/not enrolled’. Food security was measured as number of days (0-7) without food in the past week, following studies with AIDS-orphaned children in Tanzania (Makame

et al., 2002) and Mozambique (Manuel et al, 2002, unpublished data). Following the UN definition of ‘food security’ as constant and adequate nutrition (UNESCO, 1996) and in recognition of poor overall food security in the research area (Cousins, 2004), an ‘acceptable’ threshold was set of ‘at least 5 days in the past week with sufficient food’, and coded dichotomously as ‘secure/not secure’. Household employment was assessed by: ‘does anyone in your home have a job?’ coded dichotomously, and where possible was corroborated by adult report. Extensive evidence shows South African social grants benefiting the household as a whole, rather than the individual recipient (i.e. child, pensioner, disabled person) (Duflo, 2003). Consequently, the study measured household access to any social security transfer. Receipt within the household of each of the possible social security grants available in South Africa (child support grant, foster care grant, pension, war veterans grant, care dependency grant, disability grant, social relief of distress, and grant in aid) were coded as dichotomous variables and corroborated by caregiver or social worker report. They were then combined to determine household receipt of any grant, and coded dichotomously.

Results

Associations between AIDS orphanhood and poverty (Table 10)

Access to school. Overall school attendance was high. In the sample as a whole, 24 children were not enrolled in school. However, AIDS-orphaned children were less likely to be enrolled than non-orphaned children. Children orphaned by other causes (3%) did not differ from either group. The major reason stated for non-enrolment was inability to afford school fees, uniform, or transport (88% of AIDS-orphaned and 40% of other-orphaned children). Fifteen percent of non-attenders were streetchildren (who comprised 6.5% of the overall sample), although specialist schooling was available to this group. Small numbers reported non-attendance due to caring for siblings, pregnancy, illness or choice. No participants in the study had completed school, and so there were no cases of non-attendance due to school completion.

Food Security. In the sample as a whole, 136 children did not have enough to eat for at least 5 days in the past week. AIDS-orphaned children were less likely to report food security than children orphaned by other causes ($p < .001$, $\chi^2 63.1$) and non-orphans ($p < .001$, $\chi^2 61.2$).

Social Security Grants. All participants lived in poor households eligible for means-tested grants, thus receiving a grant was not an indicator of greater poverty within this sample. However, grant uptake was variable, with 389 children receiving no grant in the household. AIDS-orphaned children were less likely to live in a household accessing any social security transfer (46%) than both children orphaned by other causes (61%) ($p < .001$, $\chi^2 13.30$), and non-orphaned children (65%) ($p < .001$, $\chi^2 24.5$). There were no differences between children orphaned by other causes and non-orphans.

Household employment. In the sample as a whole, 250 children lived in households where nobody had a job. Children orphaned by AIDS were less likely to live in a household where anyone had a job than children orphaned by other causes ($p < .001$, $\chi^2 7.1$), who were less likely to do so than non-orphans ($p < .001$, $\chi^2 17.3$).

Associations between poverty-related factors and mental health outcomes (Table 11)

Access to school, food security, employment in the household and receipt of any social security were each associated with lower scores on depression, anxiety, peer problems, post-traumatic stress, delinquency and conduct problems (Table 11).

Table 10: Differences between orphanhood groups on poverty variables

	Children orphaned by AIDS (n=425)	Children orphaned by other causes (n=241)	Non-orphaned children (n=278)	<i>p-value</i> ¹
Attending school (%)	93.9 ^a	97.1 ^b	98.2 ^b	<.01
Food security 5+ days/week (%)	65.4 ^a	78.0 ^b	91.4 ^c	<.001
Any employment in household (%)	50.1 ^a	59.8 ^b	77.3 ^c	<.001
Any social security transfer (%)	45.9 ^a	60.6 ^b	64.7 ^b	<.001
Receiving Child Support or Foster Care Grant (eligible children only) ⁴	20.6 ^a	19.4 ^a	19.4 ^a	ns
Formal dwelling (%) ⁵	53 ^a	53 ^a	66 ^b	<.001

^{a b c} Different superscripts reflect statistically different means ($p < .01$), tested using post-hoc comparisons

¹ P-value associated with one-way ANOVA or Chi-square test.

² Number of cases reduced due to exclusion of streetchildren who moved between shelters and streets. For AIDS-orphaned children, n=403; children orphaned by other causes, n=223; non-orphans, n=265.

³ Number of cases reduced due to exclusion of streetchildren. For AIDS-orphaned children, n=402; children orphaned by other causes, n=221; non-orphans, n=261.

⁴ Number of cases reduced due to eligibility criteria of grants. For children orphaned by AIDS, n=343; children orphaned by other causes, n=138; non-orphaned children, n=108.

⁵ Number of cases reduced due to exclusion of streetchildren who moved between shelters and streets. For children orphaned by AIDS, n=402; children orphaned by other causes, n=221; non-orphaned children, n=261.

Table 11: Associations between poverty-related factors and mental health outcomes¹

	Depression M (SD)	<i>p</i> (<i>t</i>)	Anxiety M (SD)	<i>p</i> (<i>t</i>)	Peer Problems M (SD)	<i>p</i> (<i>t</i>)	Post- Traumatic Stress M (SD)	<i>p</i> (<i>t</i>)	Delinquency M (SD)	<i>p</i> (<i>t</i>)	Conduct Problems M (SD)	<i>p</i> (<i>t</i>)
Attending School		<.01 (5.8)		<.01 (3.6)		<.01 (4.1)		<.01 (6.7)		<.01 (5.9)		<.01 (6.2)
Yes	2.82 (2.69)		11.41(5.17)		2.28 (2.12)		15.74 (13.76)		2.42 (2.57)		1.34(1.49)	
No	5.38 (3.15)		14.53(7.08)		3.69 (1.73)		31.10 (17.81)		5.11 (4.50)		2.89(2.27)	
Food security in past week		<.01 (9.4)		<.01 (10.2)		<.01 (10.0)		<.01 (16.3)		<.01 (8.7)		<.01 (7.8)
≥5 days	2.50 (2.59)		10.66(5.23)		1.99 (2.04)		12.78 (12.24)		2.14 (2.51)		1.20 (1.43)	
<5 days	4.36 (2.79)		14.56(4.23)		3.51 (1.98)		28.23 (14.02)		3.84 (2.93)		2.09 (1.75)	
Any employment in household		<.01 (6.3)		<.01 (3.2)		<.01 (5.5)		<.01 (5.6)		<.01 (3.9)		<.01 (3.5)
Yes	2.51 (2.57)		11.04(5.12)		2.06 (2.07)		14.46 (12.87)		2.20 (2.43)		1.25 (1.47)	
No	3.64 (2.91)		12.22(5.61)		2.84 (2.15)		19.71(16.31)		2.87 (2.80)		1.61 (1.62)	
Any social security transfer in household		<.01 (4.6)		<.01 (2.6)		<.01 (5.1)		<.01 (5.5)		<.01 (5.4)		<.01 (4.1)
Yes	2.57 (2.61)		11.14(5.45)		2.03 (2.08)		14.22 (13.76)		2.11 (2.56)		1.22 (1.53)	
No	3.37 (2.86)		12.03(5.02)		2.71 (2.12)		19.05 (14.35)		3.02 (2.77)		1.62 (1.55)	

¹ P-value associated with independent sample t-test.

² Number of cases reduced due to eligibility criteria of grants. For children orphaned by AIDS, n=343; children orphaned by other causes, n=138; non-orphaned children, n=108.

Mediational effects of poverty-related factors on associations between AIDS-orphanhood and psychological outcomes (Table 12 and Figure 40)

Table 12 presents multivariate models demonstrating (model 1) the direct association between orphanhood status and each psychological outcome (controlling for demographic co-factors), and (model 2) associations between poverty-related factors, orphanhood status, and each psychological outcome. Each outcome is considered separately.

Depression. Controlling for age and gender, orphanhood by AIDS was significantly related to higher depression (model 1), but this association was eliminated in the adjusted model 2 which controlled for school access, food security, household employment and access to social security. Orphanhood by other causes was not associated with depression in either model.

Anxiety. Controlling for age and gender, orphanhood by AIDS, or by other causes, was not associated with higher anxiety, in the unadjusted model 1 or adjusted model 2, which controlled for poverty-related factors.

Peer Problems. Controlling for age, household size and more than 2 moves between homes, orphanhood by AIDS was significantly associated with higher peer relationship problems (model 1). In the adjusted model 2 which controlled for poverty-related factors, the association remained significant but was weakened. Orphanhood by other causes was not associated with peer problems in either model.

Post-traumatic stress. Controlling for age, gender, household size and more than 2 moves between homes, orphanhood by AIDS was significantly associated with higher post-traumatic stress symptoms (model 1). In the adjusted model 2 which controlled for poverty-related factors, the association remained but was weakened. Orphanhood by other causes was not associated with post-traumatic stress in either model.

Delinquency. Controlling for age, gender, internal migration and two or more moves between homes, orphanhood by AIDS was significantly related to higher delinquency (model 1), but this association was completely eliminated in the adjusted model 2 which controlled for poverty-related factors. Orphanhood by other causes was not associated with delinquency in either model.

Conduct Problems. Controlling for age, gender and internal migration, orphanhood by AIDS was significantly related to higher conduct problems (model 1), but this association was completely eliminated in the adjusted model 2 which controlled for poverty-related factors. Orphanhood by other causes was not associated with conduct problems in either model.

Table 12. Multivariate associations between orphanhood by AIDS, orphanhood by other causes, and psychological outcomes, controlling for sociodemographic cofactors and poverty-related variables

	Depression ¹		Anxiety ²		Peer Problems ³		PTSD ⁴		Delinquency ⁵		Conduct Problems ⁶	
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
Orphanhood by AIDS	.178**	.071	.070	-.026	.260**	.165**	.267**	.130**	.111*	.010	.123*	.034
Orphanhood by other causes	.018	-.029	-.021	-.063	.039	.002	.074	.020	-.009	-.048	-.011	-.044
R-Square	.060	.139	.029	.119	.091	.158	.091	.276	.063	.146	.037	.103
R-Square change	.082		.095		.071		.187		.084		.070	
F-change	21.59**		23.54**		18.24**		56.25**		21.99**		17.47**	

* Denotes significance at the 0.05 level ** Denotes significance at the .001 level

Note: Model 1 adjusted for sociodemographic co-factors, described below. Model 2 adjusted for poverty indicators: attending school, food security for ≥ 5 days in past week, employment in household and any social security transfer in household.

¹ Model 1 controls for age, gender.

² Model 1 controls for age, gender.

³ Model 1 controls for age, household size, >2 moves between homes.

⁴ Model 1 for age, gender, household size, >2 moves between homes.

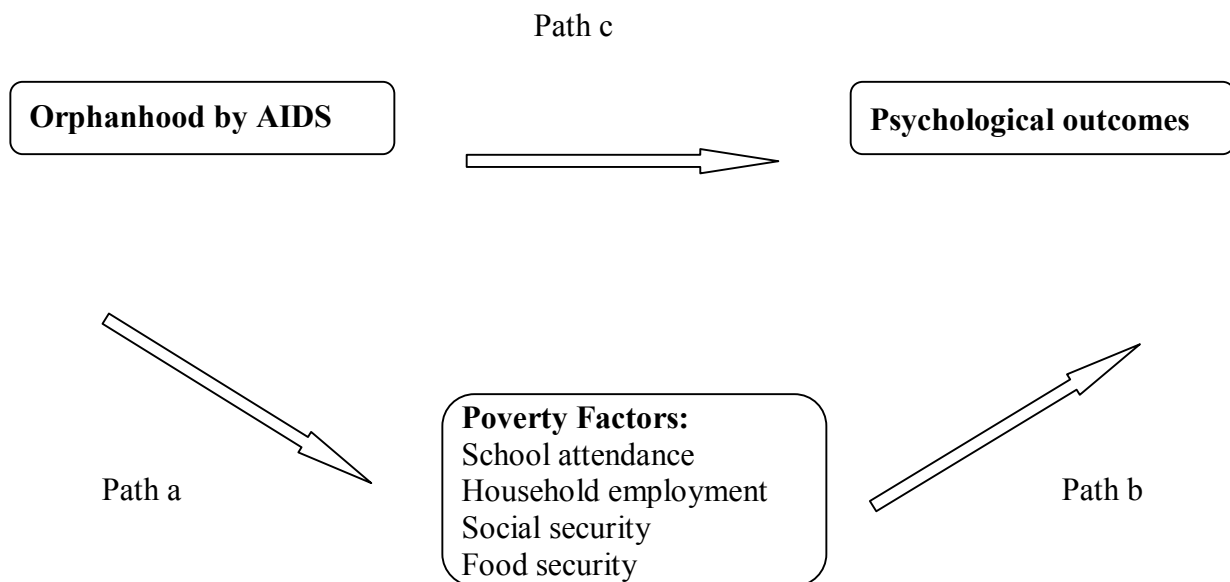
⁵ Model 1 controls for age, gender, migration, >2 moves between homes.

⁶ Model 1 controls for age, gender, migration

Formal tests of mediation: Effects of poverty-related factors on associations between AIDS-orphanhood and psychological outcomes

Analyses directly tested whether the combined presence of the four poverty alleviation factors measured [school access, food security, household employment and access to social security] mediated the association of orphanhood by AIDS and psychological outcomes (Figure 40) using the Sobel test (Sobel, 1982). Results showed that poverty variables mediated the association of AIDS orphanhood with depression ($p < .0002$), peer problems ($p < .0003$) PTSD ($p < .00007$), delinquency ($p < .00008$) and conduct problems ($p < .001$).

Figure 40: Mediation model for poverty-related factors



Discussion

This analysis has identified poverty-related factors that mediate the association between AIDS-orphanhood and psychological problems. It explored the effects of school access, acceptable food security, household employment and household receipt of any social security transfer as factors that contribute to fewer psychological problems. At the same time they are potential targets for prevention or alleviation of these problems. When combined, these 'protective factors' were shown to eliminate differences between AIDS-orphaned and other groups on symptoms of depression, conduct problems and delinquency. For peer relationship problems and post-traumatic stress, group differences were reduced but remained significant.

On all poverty-related variables, AIDS-orphaned children were disadvantaged compared to other groups. Children orphaned by AIDS had higher school dropout and higher food insecurity, while their households had lower employment than other groups. These outcomes may be associated with familial AIDS illness, for example use of household income on medical expenses for the AIDS-unwell person. They may also reflect increased vulnerability to AIDS amongst the very poor. AIDS-orphaned children were less likely to live in a household receiving any state grant, which appears to reflect lower access to state support rather than non-eligibility. Low grant uptake among eligible groups in South Africa has been connected to administrative delays and poor knowledge of the social security system. Further obstacles to grant uptake for AIDS-orphaned children include child migration between regions and households, deaths of grant recipients and insufficient numbers of social workers to process foster care grants (Giese et al., 2003).

Evidence from the wider field of child mental health suggests that poverty (which seems to be a mechanism for the impact of AIDS-orphanhood on mental health) may itself impact on psychological well-being through a range of mechanisms (Rutter, 2003). These include poverty's impact on caregiving, discrimination and education, which then affect

mental health outcomes. It is important that future research examines these mechanisms further.

Conclusions

The post-apartheid South African government has implemented a range of poverty-alleviation policies aimed at improving well-being of deprived families. There is growing evidence of the positive effects of such policies on child well-being, such as improved school enrolment among recipients of the Child Support Grant (Case, Hosegood, & Lund, 2005). This study suggests that programmes that improve access to school for poor children, employment within households, food security, and transfer of social grants have the potential to alleviate psychological distress and inequalities for AIDS-orphaned children, in addition to their intrinsic value in reducing poverty. AIDS-affected families may be both more in need of, and less likely to access, such state support. With this evidence of potentially far-reaching effects of state programmes on the well-being of AIDS-orphaned children, it is important to ensure that this vulnerable group has access to the benefits of such effective policies.

6.5 Question 4: Caregiving

Question 4: What types of caregiving arrangements are associated with mental health outcomes for AIDS-orphaned children? What other caregiving factors are mediating differences in mental health between orphan groups?

Summary:

This analysis explored associations of i) types of caregiving arrangement and ii) other caregiving factors (eg abuse and caregiver illness) with psychological problems and AIDS-orphanhood status. Living on the streets was associated with heightened delinquency ($p < .05$) and PTSD ($p < .01$) for AIDS-orphaned children, independent of age, gender and poverty. Living with grandparents was associated with lower anxiety ($p < .01$), and there were no differences between other types of family care. Poor quality of care, abuse, domestic violence, separation from siblings and changes of caregiver were all associated with psychological problems for children generally. AIDS-orphaned children reported more caregiver illness and excessive housework, and these factors mediated associations between distress and AIDS-orphanhood. Caregiver illness mediated the relationship with depression (Sobel test, $p < .007$), peer problems ($p < .008$), PTSD ($p < .0003$), delinquency ($p < .03$) and conduct problems ($p < .004$). Hours of child housework mediated the relationship with peer problems ($p < .00005$), PTSD ($p < .0002$) and delinquency ($p < .02$).

Background to Question 4:

Orphaned children in South Africa have traditionally been absorbed into the extended family, but the HIV/AIDS pandemic is placing financial and personal strain on such informal arrangements, with increased numbers of children living in foster care, child-headed households and on the streets.

Other caregiving factors reflecting quality of care, including changes of caregiver, separation from siblings, caregiver illness, caregiver monitoring, positive reinforcement, caregiver-child activities, abuse and child housework, are major predictors of children's emotional and behavioural outcomes (Rutter, 2000). It is useful to provide reliable evidence on which to base decisions regarding placement of AIDS-orphaned children, and support of caregivers. However, little is known about impacts of different caregiving arrangements on AIDS-orphaned children. Only one other known study tests associations

between caregiving arrangement and psychological problems for AIDS-orphaned children. In Uganda, unstandardised scales were used with 193 children, all receiving sponsorship. No differences were found between orphans living with parents, grandparents, other relatives and child-headed households (Sengendo & Nambi, 1997).

Uncontrolled studies of child-headed and youth-headed households suggest poor psychological outcomes (Thurman et al., 2006), but current policy debates focus on these arrangements as preferable to abusive foster care or property-grabbing of family homes (Mhangwana, 2004). Studies of streetchildren find associations with psychological problems (Richter & Van der Walt, 1996), but no studies were found of AIDS-orphaned streetchildren.

A number of other caregiving factors were hypothesised as potential risks for AIDS-orphaned children. Multiple caregiver changes predicts psychological problems amongst fostered and refugee children (Meltzer et al., 2003). Placement of orphaned siblings and psychological distress has been examined in two studies: in Zambia, sibling dispersion was associated with greater distress in an urban, but not a rural sample (Nampanya-Serpell, 1998). In Tanzania, sibling dispersion was not associated with any outcomes (Makame et al., 2002). Many AIDS-orphaned children are cared for by surviving HIV+ parents or elderly grandparents. In three African studies, caregiver illness was associated with poorer orphan mental health (Chatterji et al., 2005; Nampanya-Serpell, 1998). Caregiver illness may lead to children acting as young carers, and contribute to psychological distress.

Caregiver monitoring of children is protective for behavioural outcomes (O'Connor, 2002). An unpublished study suggests that this is true for AIDS-orphaned children (Wild et al., 2006, July) and amongst non-orphaned, AIDS-affected children (Dutra et al., 2000). Positive reinforcement and carer-child activities are protective for children generally (Gardner et al., 2006), and were associated with fewer problems amongst Tanzanian AIDS-orphaned children (Makame et al., 2002). Qualitative and quantitative research suggests that sense of belonging and equal sharing of household resources may

be protective for fostered AIDS-orphaned children (Bhargava, 2005; Cluver & Gardner, 2007b). Abuse and domestic violence have established negative impacts on child mental health. There is no known evidence of higher abuse rates amongst AIDS-orphaned children, although children living outside their direct biological family may be at higher risk for abuse (Richter et al., 2004). Studies in South Africa have shown heightened levels of domestic violence in AIDS-affected families (Jewkes et al., 2003).

Specific aims of this analysis are the following: Firstly, to examine associations between orphanhood status, type of caregiving arrangement (ie living with relatives or on the streets) and other caregiving factors (ie caregiver monitoring, abuse). Secondly, to examine associations between psychological outcomes, type of caregiving arrangement and other caregiving factors. Thirdly, to examine the extent to which caregiving factors mediate associations between AIDS-orphanhood (compared to orphanhood by other causes and non-orphanhood) and psychological outcomes.

Caregiving indicators used in this analysis

Caregiving arrangements: Primary caregivers were identified using items from the 2003 South African National Youth Survey of HIV and Sexual Behaviour; as the person who ‘stays with you and takes care of you at home’ Type of caregiving arrangement amongst AIDS-orphaned children and other-orphans were categorized as: living with surviving biological parent, grandparent, other relative, non-relative, living in a child-headed/youth-headed household and living on the streets.

Other caregiver factors were measured. Number of caregiver changes was reported as number of deaths of primary caregiver, or of children moving to live with a new caregiver, or of a new caregiver moving into the home after caregiver death. Sibling dispersion was measured by the existence of siblings under age 18 who lived in a separate household from the child participant. Caregiver health status was reported as unwell never/rarely/sometimes/very often. This was coded dichotomously as ‘very often unwell’ versus all others.

Positive caregiving was measured by five items. Caregiver monitoring was measured using the most discriminative item for psychological outcomes in a devised caregiver-regulation scale used with South African AIDS-orphaned children (Wild et al., 2006, July). This asked ‘how much does your caregiver *really* know what you do with your free time?’ and was coded dichotomously as ‘high monitoring’ (‘knows a lot’) and ‘low monitoring’ (‘knows a little’/‘does not know’). Positive reinforcement was measured by frequency of praise for the child by ‘someone at home’. It was divided into ‘high’ (‘often’) and ‘low’ (‘rarely’ or ‘never’) and coded dichotomously. Caregiver-child activities were measured by past-month help with homework, reading, or telling stories, and coded dichotomously. Areas particularly relevant to orphans included children’s sense of belonging in the family, which was divided into ‘yes’ and ‘somewhat’ or ‘not at all’ and coded dichotomously. Intra-household resource allocation was measured by children’s perception of allocation of food, clothes and school fees, compared to other co-resident children. This was divided into ‘positive’ (‘I get more’ or ‘I get about the same’) and ‘negative’ (‘I get less’) and coded dichotomously.

Negative caregiving was measured using 9 items. Child report of physical abuse, sexual abuse and domestic violence was measured using 7 items from the Child Exposure to Community Violence (CECV) Checklist (Richters & Martinez, 1993), which was adapted after consultation with 20 social workers in Cape Town. Physical abuse was defined as being hit with an object likely to cause ‘actual or potential physical harm’ (WHO, 1999a) ie a broomstick, stick or metal piping. Emotional abuse was thought to be too complex to measure by child report alone and in a study of this type. Items were combined and exposure to any kind of abuse or domestic violence was coded dichotomously as ‘yes/no’. Extent of child housework was measured through items devised by child labour researchers at the Institute of Child Health, and was coded as ‘minutes of housework per weekday’. In order to additionally explore ‘excessive housework’, a conservative cut-off score was applied of ‘3+ hours of housework per day’, based on the South African Department of Labour definition of excessive child work (2003).

Results

Group differences on type of caregiving arrangement (Table 13)

AIDS-orphaned children were less likely to be cared for by a surviving biological parent than other orphans ($p < .001$, $\chi^2 35.3$), and were more likely to be cared for by a grandparent, other extended family or living in a child-headed or youth-headed household ($p < .001$). Streetchild numbers were purposely matched across the 3 groups, as no reliable data is available on the streetchild population. Children cared for by non-relatives included those looked after by step-parents, foster parents and neighbours, but numbers were too small (23) for inclusion in further analyses.

Descriptive associations between type of caregiving arrangement and psychological distress (Table 14)

As a very preliminary descriptive analysis (without controlling for socio-demographic factors), each type of caregiving arrangement was compared with all others, looking at associations amongst AIDS-orphaned children only ($n=425$). Without controlling for age, gender or poverty, living with a grandparent was associated with less anxiety. Living with a biological parent showed higher post-traumatic stress and delinquency than other caregiving arrangements. Living with a grandparent showed lower scores on all psychological scales. Children living in a child-headed or youth-headed household showed higher anxiety. Living on the streets showed higher anxiety, PTSD, delinquency and conduct problems.

Effects of type of caregiving arrangement for AIDS-orphaned children (Table 15)

Previous analyses (Question 2) showed that, when controlling for age and gender, orphanhood by AIDS was associated with significantly more psychological problems of depression, peer problems, PTSD, delinquency and conduct problems ($p < .001$). Therefore this analysis focused on AIDS-orphaned children in particular. Multivariate linear regressions were used to explore the effects of different types of caregiving arrangement on mental health outcomes for AIDS-orphaned children. Analyses

controlled for age, gender and poverty (number of days with enough to eat), then simultaneously controlled for all types of caregiving arrangement, with a comparison variable of non-orphaned children who lived with a parent. Controlling for age, gender and poverty, there were almost no differences between types of family care. AIDS-orphaned children living with grandparents showed less anxiety ($p<.01$). However, children living on the streets showed higher post-traumatic stress ($p<.05$) and higher delinquency ($p<.01$).

Group differences on other caregiving factors (Table 13)

Descriptive properties of caregiving factors are described in Table 13. One-way ANOVAs showed that primary caregivers of AIDS-orphaned children were more likely to be unwell 'very often' than other-orphans ($p<.001$, $\chi^2 2.52$) or non-orphans ($p<.001$, $\chi^2 18.21$). Data were not systematically collected on cause of caregiver illness, but 60% of often-ill caregivers of AIDS orphans were surviving parents, suggesting AIDS-related illness. 20% were aunts or uncles, and 14% grandparents. AIDS-orphaned children did more housework per day than non-orphans ($p<.001$, $\chi^2 5.11$) and other orphans ($p<.001$, $\chi^2 4.97$) and were more likely to report excessive housework (>3 hours per day) than non-orphans ($p<.001$, $\chi^2 13.3$) and other-orphans ($p<.001$, $\chi^2 9.9$). There were no group differences on other caregiving factors.

Associations between other caregiving factors and psychological distress (Table 14)

For other caregiving factors, preliminary analyses examined associations amongst all children. Without controlling for age and gender, children who had experienced more than 2 changes of primary caregiver reported more anxiety, PTSD and delinquency. Sibling dispersion was associated with more delinquency. Having a primary caregiver in poor physical health and greater duration of reported housework per day were associated with more problems on all scales. High caregiver monitoring and presence of carer-child activities was associated with fewer problems on all scales. Positive reinforcement and equal allocation of household resources were associated with less depression, anxiety,

peer problems, PTSD and delinquency. A sense of belonging in the home was associated with less depression, anxiety and PTSD. Abuse or domestic violence was associated with more depression, delinquency and conduct problems.

Mediating effects of caregiver illness and child housework (Table 16)

Only two caregiving-related factors showed both differences between orphanhood groups and significant associations with psychological health: namely caregiver illness and amount of child housework. Model 1 shows associations between AIDS-orphanhood and psychological outcomes when controlling for age and gender, Model 2 shows psychological outcomes when further controlling for caregiver illness and hours of child housework (Table 10). In Model 1 AIDS-orphanhood was significantly related to more depression, peer problems and PTSD. For anxiety, delinquency and conduct problems, significance was at the $p < .05$ level in Model 1, but this association was reduced to non-significance in Model 2 which additionally controlled for caregiver illness and housework. For depression, significance was at the $p < .001$ level in Model 1, but this association was reduced to the $p < .05$ level in Model 2, which controlled additionally for caregiver illness and child housework. For PTSD and peer problems, significance was at $p < .001$ in Model 1, and remained so in Model 2, although associations were weakened (PTSD β from .35 to .26, peer problems β from .28 to .20). These results suggest that caregiver factors mediate the relationship between AIDS-orphanhood and mental health, and the strength of this relationship was then tested using the Sobel test.

Mediational analyses using the Sobel test (Figure 41) showed that caregiver illness significantly mediated the relationship between AIDS-orphanhood (vs other-orphanhood and non-orphanhood) and depression ($p < .007$), peer problems ($p < .008$), PTSD ($p < .0003$), and conduct problems ($p < .004$). It had a moderately significant effect on delinquency ($p < .03$). Hours of child housework mediated the relationship between AIDS-orphanhood (vs other-orphanhood and non-orphanhood) and both peer problems ($p < .00005$) and PTSD ($p < .0002$) and had a moderately significant effect on delinquency ($p < .02$).

Table 13: Differences between groups on type of caregiving arrangement and caregiving-related variables

Type of caregiving arrangement ²	Children orphaned by AIDS (n=425)	Children orphaned by other causes (n=241)	Non-orphaned children (n=278)	P value ¹
Caregiver biological parent (%)	32.5 ^a	56.0 ^b	74.1 ^c	<.001
Caregiver grandparent (%)	20.5 ^a	8.3 ^b	9.7 ^b	<.001
Caregiver other extended family (including siblings over 25) (%)	33.2 ^a	20.3 ^b	8.3 ^c	<.001
Caregiver non-relative	1.9	3.3	1.8	<.386
Child/Youth-headed household (%)	7.3 ^a	5.4 ^b	1.1	<.001
Streetchildren (matched numbers)	5.4 ^a	7.5 ^a	6.5 ^a	Numbers matched
Caregiving-related factors				
>2 changes of caregiver (%)	6.3 ^a	6.6 ^a	3.6 ^b	<.218
Separated from siblings (%) ³	21.1 ^a	25.3 ^a	19.9 ^a	<.320
Caregiver very often unwell ² (%)	13.6 ^a	7.1 ^b	4.0 ^c	<.001
High caregiver monitoring ² (%)	84.1 ^a	91.5 ^a	82.9 ^a	<.011
High positive reinforcement (%)	92.9 ^a	90.4 ^a	87.1 ^a	<.035
Caregiver-child activities ² (%)	90.4 ^a	94.0 ^a	89.5 ^a	<.163
High sense of belonging (%)	91.5 ^a	90.0 ^a	90.6 ^a	<.798
Intra-household resource allocation (positive, %)	86.1 ^a	88.8 ^a	89.1 ^a	<.398
Abuse/Domestic violence (%)	18.6 ^a	19.5 ^a	25.2 ^a	<.093
Housework/day-mins (mean, SD)	85.90(58.39) ^a	62.54(47.10) ^b	61.83(57.16) ^c	<.001
>3 hrs housework/day (%)	25.2 ^a	14.7 ^b	13.7 ^c	<.001

^{a, b, c} Different superscripts reflect statistically different means ($p < .01$), tested using post-hoc comparisons

¹ P-value associated with one-way ANOVA or Chi-square test. The group of children orphaned by unknown causes was excluded from this analysis.

² Number of cases reduced due to some children lacking primary caregiver. For AIDS-orphaned children, n=416, for other orphans, n=235, for non-orphans, n=276 ³ Number of cases reduced due to some children lacking siblings under 18. For AIDS-orphaned children, n=375, for other orphans, n=221, for non-orphans, n=261

Table 14: Associations between caregiving factors and mental health outcomes¹

AIDS-orphaned children only												
	Depression (CDI)	p (t)	Anxiety (RCMAS)	p (t)	Peer Problems (SDQ Peer)	p (t)	Post- Traumatic Stress Symptoms	p (t)	Delinquenc y (CBCL)	p (t)	Conduct Problems (SDQ)	p (t)
Surviving biological parent ²												
Yes (mean, SD)	3.77 (2.89)	<.253 (-1.1)	12.69 (4.32)	<.082 (-1.7)	3.13 (1.98)	<.400 (-.84)	24.56 (14.57)	<.001 (-3.5)	3.46 (2.80)	<.012 (-2.5)	1.77 (1.56)	<.290 (-1.1)
No (mean, SD)	3.42 (2.90)		11.73 (5.53)		2.94 (2.12)		19.13 (15.18)		2.72 (2.79)		1.60 (1.55)	
Grandparent ²												
Yes (mean, SD)	2.72 (2.51)	<.003 (2.9)	9.68 (5.07)	<.001 (4.8)	2.55 (2.02)	<.023 (2.3)	13.89 (13.60)	<.001 (4.9)	1.82 (2.00)	<.001 (4.3)	1.08 (1.31)	<.001 (3.9)
No (mean, SD)	3.74 (2.96)		12.65 (5.06)		3.12 (2.08)		22.67 (15.07)		3.25 (2.91)		1.80 (1.58)	
Other extended family ²												
Yes (mean, SD)	3.64 (2.88)	<.409 (-.69)	11.96 (5.02)	<.713 (-.47)	3.24 (2.28)	<.108 (-1.8)	19.67 (13.31)	<.417 (1.2)	2.62 (2.63)	<.103 (1.7)	1.63 (1.37)	<.826 (.55)
No (mean, SD)	3.38 (2.94)		11.77 (5.02)		2.88 (2.00)		20.94 (15.45)		3.10 (3.04)		1.60 (1.60)	
Child-headed or Youth-Headed Household ²												
Yes (mean, SD)	4.26 (2.63)	<.149 (-1.4)	14.58 (7.16)	<.005 (-2.8)	2.94 (1.61)	<.852 (.19)	25.90 (19.81)	<.056 (-1.9)	3.32 (3.07)	<.453 (-.75)	2.16 (1.85)	<.057 (-1.9)
No (mean, SD)	3.48 (2.92)		11.84 (4.96)		3.01 (2.11)		20.48 (14.71)		2.93 (2.79)		1.61 (1.52)	
Streetchild ²												
Yes (mean, SD)	4.17 (3.99)	<.276 (-1.1)	14.77 (4.71)	<.011 (-2.5)	3.00 (1.93)	<.995 (.01)	27.91 (16.02)	<.022 (-2.3)	6.35 (4.68)	<.001 (-6.2)	2.74 (2.16)	<.001 (-3.5)
No (mean, SD)	3.50 (2.83)		11.89 (5.19)		3.00 (2.08)		20.47 (15.05)		2.76 (5.34)		1.59 (1.49)	

Table 15. Multivariate associations between AIDS-orphanhood and psychological outcomes, adjusting for type of caregiving arrangement² and controlling for sociodemographic co-factors

	Depression ¹	Anxiety ¹	Peer Problems ¹	PTSD ¹	Delinquency ¹	Conduct Problems ¹
Age	.116**	.028	.089*	.091**	.137**	.074*
Gender	.073*	.063	.043	.068*	-.057	-.045
Days with food	-.246**	-.343**	-.310**	-.464**	-.241**	-.196**
Biological parent (β)	.010	-.170	-.181	-.048	-.007	-.051
Grandparent (β)	-.037	-.230**	-.148	-.138	-.119	-.124
Other extended family (β)	.036	-.163	-.114	-.093	-.088	-.051
Child-headed or youth-headed household (β)	.037	-.008	-.114	.002	-.017	-.025
Living on the streets (β)	.071	.061	-.039	.111*	.212**	.114

* Denotes significance at the .05 level

** Denotes significance at the .01 level

¹ Controlling for age, gender and food security

² Comparator was 'non-orphans living with a biological parent'

Table 16. Multivariate associations between orphanhood by AIDS, orphanhood by other causes, and psychological outcomes, controlling for age, gender, caregiver illness and minutes of child housework per day

	Depression ¹		Anxiety ²		Peer Problems ³		PTSD ⁴		Delinquency ⁵		Conduct Problems ⁶	
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
Orphanhood by AIDS	.161**	.124*	.094*	.050	.278**	.207**	.351**	.269**	.128*	.071	.121*	.077
Orphanhood by other causes	.006	-.006	-.040	-.034	.066	.048	.077*	.057	.005	-.010	-.003	-.016
R-Square	.049	.067	.028	.051	.089	.150	.129	.216	.047	.087	.025	.048
R-Square change		.020		.026		.063		.089		.042		.026
F-change		8.81**		10.55**		29.63**		45.76**		18.42**		11.01**

* Denotes significance at the .05 level

** Denotes significance at the .01 level

Model 1 adjusted for age and gender.

Model 2 adjusted for caregiving factors which showed group differences: caregiver illness and housework

Discussion

AIDS-orphaned children experience higher levels of psychological problems than other children. This relationship between AIDS-orphanhood and poorer mental health is mediated by the type of caregiving arrangement they live in, by having a frequently-unwell caregiver, and by the amount of housework they do.

For AIDS-orphaned children, there was no association between mental health and living with a surviving biological parent, extended family, or in a child-headed or youth-headed household. AIDS-orphaned children living with grandparents showed less anxiety. Living on the streets was associated with more psychological problems, independent of age, gender and poverty.

In a developed world context, it would be expected that biological parents would be (in the absence of abuse or other extreme stressors) the best option for primary caregivers. However the findings of few differences between types of family care in this sample may reflect a number of factors. Firstly, African family structures do not presuppose biological parents to be sole carers of children (Ankrah, 1993), and mutable caregiving arrangements within families may mean that extended family care is common for many children at various points in their lives. The finding may also reflect the effects of mediating factors which are shown elsewhere in this chapter. For example, surviving parents of AIDS-orphaned children are likely to be HIV+ themselves, and frequent caregiver illness has been shown to be negatively associated with child well-being. Other caregiving arrangements may reflect greater financial security, such as living with a pension-receiving grandparent, and poverty-related factors are strong mediators of mental health amongst AIDS-orphaned children.

Amongst children generally, all quality of caregiving factors measured showed associations with psychological health. However, on most measures of caregiving quality, there were no group differences, suggesting that quality of care may not be the mechanism by which AIDS-orphanhood is influencing mental health in this case. Only

caregiver illness and amount of child housework showed both group differences between orphanhood groups and significant associations with psychological problems. Caregiver illness significantly mediated differences between AIDS-orphaned children and other groups on depression, peer problems, PTSD and conduct problems. Extent of housework significantly mediated differences on peer problems and PTSD. Both factors had a significant partial mediation effect on delinquency scores.

In summary, these findings suggest that, with respect to mental health outcomes, living on the streets is the least desirable care option for AIDS-orphaned children. Living with grandparents is associated with lower anxiety. Aspects of care such as caregiver regulation of children's activities and allocation of resources, such as food and school fees, suggested comparable care levels amongst AIDS-orphaned children and other groups. This supports arguments that family care of orphans is generally good (Meintjies et al., 2003). However, AIDS-orphaned children did more housework, and were more likely to have caregivers who were frequently unwell. Findings thus suggest some caregiving mechanisms by which orphanhood may possibly be linked to mental health. Living with an unwell caregiver may be a direct consequence of parental death by AIDS (i.e. that the remaining parent is HIV+, or that a grandparent becomes the primary caregiver). In the orphan sample, severity of caregiver illness and duration of child housework were highly correlated ($p < .001$ $r = .298$), and it is likely that this reflects AIDS-orphaned children taking on greater household and care responsibilities in situations of financial strain and adult illness (Bauman et al., 2006). Findings of this study suggest that interventions to improve health of caregivers (i.e. anti-retroviral medication for HIV+ surviving parents), and interventions supporting young carers (i.e. increased support for Home-Based Care), have the potential to reduce some negative impacts of AIDS orphanhood.

Limitations of this analysis

An important limitation of this particular analysis is the retrospective study design, which does not allow distinction of psychological distress experienced before orphanhood, or at

different stages during orphanhood (A. Stein et al., 2005). For example, poor psychological health amongst streetchildren may have preceded living on the streets. The use of cross-sectional data limits the capacity of this study to determine direct causality between risk factors and mental health outcomes. For example, characteristics of children or families may contribute to differing caregiving arrangements. Analyses did attempt to control for potentially relevant factors such as poverty, and thus suggest that caregiving may be an independently important environmental risk (Rutter, 2005).

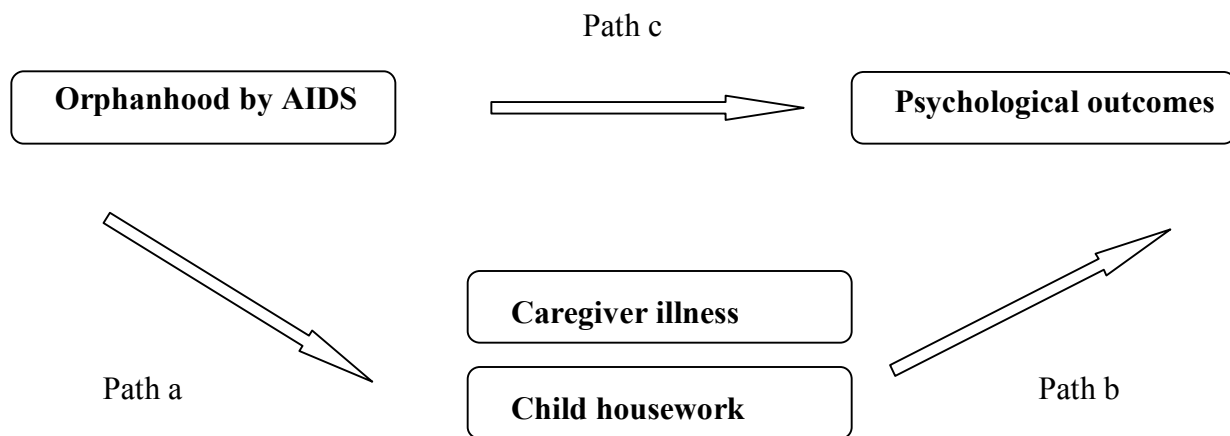
The cross-sectional design of the study also only measures current caregiver illness. Thus it precludes the measurement of previous effects of caregiver illness, where the unwell caregiver has died. There may be trauma for children associated with the illness and death of parents (particularly for double orphans where both parents have already died) which is therefore not identified through a cross-sectional study such as this one. This is an important limitation of the study, and particularly relevant to questions around caregiver illness in the context of AIDS-orphanhood as an ongoing process. Future research studies could usefully approach caregiving from a longitudinal pre-post orphanhood perspective. This would then allow measurement of the impact of parental illness by AIDS (one or both parents), parental death by AIDS, subsequent illness of surviving parents, and subsequent deaths. Further issues for measurement would be the longitudinal impact of interventions such as provision of ARVs for unwell caregivers. This has been found in Kenya to improve school attendance and nutritional status amongst children (Graff Zivin, Thirumurthy, & Goldstein, 2006). A further limitation is the small numbers of sampled children cared for by non-relatives, and the lack of children in orphanages or children's homes. These groups merit further research.

Conclusions

This analysis aims to provide evidence for professionals and policy-makers in making decisions regarding caregiving of AIDS-orphaned children. Preventative interventions to decrease numbers of AIDS-orphaned children becoming homeless have potential to mitigate negative psychological outcomes. Reducing caregiver illness and child housework

also have the potential to alleviate psychological distress. Thus programmes such as healthcare for caregivers, and support for young carers, may have positive consequences beyond their intrinsic value.

Figure 41: Mediation Model for caregiving-related factors



6.6 Question 5: Community factors and stigma

Question 5: Do AIDS-orphaned children experience differences in factors which operate on a community level, i.e. higher levels of bullying, community violence, AIDS-related stigma and less access to sport? Are any of these factors mediating differences in mental health between orphan groups?

A version of the following analysis is in press as:

Cluver, L, Gardner, F & Operario, D (in press) *AIDS-related stigma: Effects on mental health of AIDS-orphaned children*. Journal of Adolescent Health.

Summary:

This analysis explores the mediating effects of stigma and other factors operating on a community-level, on associations between AIDS orphanhood and mental health. AIDS-orphaned children were more likely to experience stigma (55%) than other orphans (27%) and non-orphans (17%, $p < .001$). AIDS-orphaned children (mean 6.10) reported less weekly positive activities than other orphans (mean 6.82) and non-orphans (mean 6.29, $p < .001$). There were no reported group differences on bullying or community violence. All community-level risk factors were associated with poorer psychological outcomes. Multivariate analyses controlling for age and gender showed that experience of stigma significantly mediated associations between AIDS orphanhood and poor psychological outcomes ($p < .0001$)

Background to Question 5:

In the South African context of high population proportions of orphans, interventions aiming to alleviate mental health problems may be more feasible at a community, rather than individual level (Foster, Levine, & Williamson, 2005; Richter et al., 2006). Indeed, evidence from the wider field of child mental health suggests that childhood psychological problems are predicted by risk factors that operate to some extent at the level of the whole community as well as at an individual level (Rutter, 2005). It is important to identify risk factors which are influenced by community norms and resources, and which are thus potentially able to be addressed by group or community-level interventions. Analyses tested factors which can operate at a community-level, including bullying, stigma, community violence and lack of opportunities for positive

recreational activities (Barnes & Cheng, 2006; Deater-Deckard, 2001; Sherr et al., 1992; Strode & Barrett Grant, 2001). Each of these community risk factors has been reported amongst AIDS-orphaned children in South Africa. In the qualitative stage of this research (Chapter 4) participants identified bullying, AIDS-related stigma, witnessing or experiencing community violence, and lack of sports and other activities as factors they considered important in their psychological health. Whether these factors mediate the association between AIDS-orphanhood and mental health outcomes has not yet been examined quantitatively.

High levels of AIDS-related stigma and discrimination have been reported amongst affected communities in South Africa, ranging from subtle rejection to physical assault and rare cases of murder of HIV+ people (Skinner & Mfecane, 2004). There is increasing qualitative evidence that AIDS-orphaned children suffer from 'courtesy stigma' (Goffman, 1963) associated with parental death (Murphy, Roberts et al., 2002; Strode & Barrett Grant, 2001; Van Wyk, 1998). In Rwanda and Zimbabwe, AIDS-orphaned children reported high levels of stigma (Foster et al., 1995; Thurman et al., 2006). Qualitative research in South Africa reports AIDS-orphaned children exposed to bullying, teasing and discrimination from basic social services and education (Giese et al., 2003; Nelson Mandela Children's Foundation, 2001). AIDS-orphaned children in Cape Town have identified specific types of stigma including gossip, taunting and verbal abuse of surviving HIV+ parents (Cluver & Gardner, 2007b; Ferreira et al., 2001).

Experience of stigma can reduce levels of social support and increase a sense of isolation for already-vulnerable groups. There is strong empirical evidence for associations between stigma and poor psychological health amongst other stigmatised groups (Link, 1987). Theories of the processes by which stigma impacts on mental health are often focused on stigma related to homosexuality or of the labelling of mental illness itself. These processes include actual experiences of rejection, culturally-induced expectations of rejection (resulting in reduced confidence and impaired social functioning), and efforts at coping with stigma (such as secrecy or social withdrawal) (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). Sen's theories of internalised shame associated with the

stigma of poverty (Sen, 1983), may reflect evidence of internalised stigma and its effects on self-esteem and depression (Corrigan & Watson, 2002). No known studies explore associations of AIDS-related stigma and mental health amongst non-infected but AIDS-affected children. However, there is evidence of associations between AIDS-related stigma and psychological distress amongst HIV+ adults (Green & Smith, 2004; L. Kahn, 2004; Skinner & Mfecane, 2004), and with poor self-worth amongst children in AIDS-affected families (Strode & Barrett Grant, 2001).

Further hypothesised risks to orphans' mental health are the high levels of bullying and of community violence in poor, urban settlements. Violent environments can lead to trauma and learned delinquent behaviour, and studies show associations between levels of experienced violence and psychological problems amongst South African children (Barbarin et al., 2001; Seedat et al., 2000). A potential protective factor is positive recreational activities, such as sport. Activities are frequently part of child-focussed community interventions, aiming to improve peer relationships and provide opportunities for achievement. Limited evidence from the developed world suggests associations between positive recreational activities and better psychological outcomes (Strong et al., 2005).

Specific aims of this analysis are the following: 1) to examine associations between orphanhood and community risk factors; 2) to examine associations between community risk factors and psychological outcomes; 3) to examine the extent to which community-level factors mediate associations between AIDS-orphanhood (compared to orphanhood by other causes and non-orphanhood) and psychological outcomes.

Measures used for this analysis

Community-level factors: Bullying was measured with the 9-item Social and Health Assessment Peer Victimization Scale (Ruchkin et al., 2004), used in recent research in Cape Town (Ward et al., 2007). This scale is adapted from the Multidimensional Peer Victimization Scale (Mynard & Joseph, 2000), and showed $\alpha=.82$ in a US validation

study. Items included; being called names, being hit or threatened and having possessions broken or stolen. Bullying events were scored on a 4-point Likert scale, ranging from 'not at all' to 'more than four times' in the past year.

Exposure to community trauma was measured by self-report of past-year experience of witnessing or having been a victim of the study area's four most commonly-reported community crimes: robbery, assault, stabbings and shootings (South African Police Services, 2004). The fifth category was witnessing or experiencing any further trauma, and these were coded into broad categories such as 'violent crime', 'accidents' and 'rape'. Wording was adapted from the Child Exposure to Community Violence (CECV) Checklist (Richters & Martinez, 1993). Number of exposure events was summed, with the total possible score of 5.

No standardized instruments currently exist to measure AIDS-related stigma amongst orphaned children. A brief 4-item stigma scale was devised, based on items from the Berger Stigma Scale for HIV+ Youth – Revised (Wright, Naar-King, Lam, Templin, & Frey, 2007). This was adapted for non-infected orphans using a) reports from qualitative interviews with 120 children and caregivers (Cluver & Gardner, 2007b), b) literature review (ie. ACCESS, 2002; Siyam'kela, 2004; Van Brakel, 2004) and c) consultation with local academics currently researching stigma (Deacon, 2006; Maughan Brown, 2006). Participants reported frequency of experiencing teasing, being treated badly and being gossiped about, because of the illness of a family member. Children reported both the frequency of events (never/sometimes/very often), and the extent to which these events caused distress (not at all/somewhat/very much). Scale reliability was good, with $\alpha = .83$ for stigmatizing events, and $\alpha = .88$ when including extent of distress. Scale values were computed for each participant, with a total possible score of 8.

A measure of access to positive community activities was devised from the qualitative stage of this study (Chapter 4), during which an item asked about activity preferences amongst South African orphaned children and caregivers (Cluver & Gardner, 2007b). Items included were: playing a musical instrument, playing with toys or games, playing

netball, soccer, swimming or another sport, dancing, socializing with friends, using a computer, reading, and family outings. There were 13 possible activities, with a score range of 0-13, where activity participation was defined as performing at least weekly.

Results

Differences between orphanhood groups and community risk factors (Table 17)

Overall levels of bullying and experience of community traumas were high, but showed no group differences. Significant group differences on stigma and positive activities were observed. One-way ANOVAs and t-tests showed that AIDS-orphaned children reported significantly more stigma than other orphans ($p < .001$, $t = 5.8$) and more stigma than non-orphans ($p < .001$, $t = 11.2$), and that non-AIDS orphans reported more stigma than non-orphans ($p < .001$, $t = 4.5$). AIDS-orphaned children were more likely to report experience of any stigma (55% of AIDS-orphaned children compared to 27% of other-orphans and 17% of non-orphans, $p < .001$, $\chi^2 = 83.2$). AIDS-orphaned children and other orphans reported significantly fewer positive activities than non orphans ($p < .001$, $t = -4.3$, -2.8 respectively).

Associations between community risk factors and psychological outcomes (Table 18)

Being a victim of bullying, community violence and stigma were each associated with higher scores on depression, anxiety, peer problems, post-traumatic stress, delinquency and conduct problems ($p < .001$ – see Table 18 for details), with the exception of community violence, which was not associated with peer problems (Table 18). Greater number of positive activities was associated with lower scores on depression, anxiety, peer problems and post-traumatic stress, but not on conduct or delinquency problems.

Table 17: Group differences on community factors

	Children orphaned by AIDS (n=425)	Children orphaned by other causes (n=241)	Non-orphaned children (n=278)	P value ¹
Bullying ^{2,3} (mean, SD)	13.65 (5.39) ^a	13.34 (4.67) ^a	14.30 (5.39) ^a	<.080
Name-calling or swearing (%)	35.8	38.6	45.0	<.901
Causing troubles with friends (%)	30.9	33.6	38.8	<.487
Stealing child's possessions (%)	40.7	41.7	50.4	<.074
Making fun of child (%)	35.8	38.3	50.4	<.050
Intimidation by standing close or touching	25.5	26.2	32.0	<.011
Punched, kicked or beat child up	31.8	33.2	29.3	<.693
Hurt child physically in some way	26.0	23.0	24.5	<.095
Broke or damaged possessions	31.6	26.1	28.4	<.317
Refused to talk to child	28.0	27.8	35.3	<.111
Community traumas ⁴ (mean, SD)	1.65 (1.32) ^a	1.89 (1.38) ^a	1.82 (1.35) ^a	<.055
Robbed in the past year (%)	46.4	39.8	28.4	<.001
Assaulted outside the home (%)	12.7	12.9	14.4	<.746
Witnessed shootings (%)	30.4	34.9	31.4	<.261
Witnessed stabbings (%)	39.2	52.5	50.7	<.001
Stigma (mean, SD) ⁵	2.39 (2.57) ^a	1.20 (2.22) ^b	.54 (1.37) ^c	<.001
Teased about family illness (%)	39.4	20.7	7.9	<.001
Treated badly (%)	38.0	19.5	6.5	<.001
Gossiped about (%)	48.3	22.0	13.3	<.001
Upset 'very much' by stigma (%)	31.7	18.8	9.1	<.001
Positive activities ⁶ (mean, SD)	6.10 (2.02) ^a	6.82 (2.28) ^a	6.29 (2.27) ^b	<.001

^a, ^b, ^c Different superscripts reflect statistically different means ($p < .01$), tested using post-hoc comparisons

¹ P-value associated with one-way ANOVAs.

²Number of cases reduced due to missing data. For children orphaned by AIDS, n=408; children orphaned by other causes, n=235; non-orphaned children, n=275.

³Measured using the SAHA Bullying scale ⁴Measured as number of reported traumas

⁵Measured using a devised stigma scale. ⁶Measured as number of reported weekly activities.

Community-level factors mediating associations between AIDS-orphanhood and psychological outcomes (Table 19).

Table 19 presents multivariate models demonstrating (a) the direct association between orphanhood status and each psychological outcome (controlling for demographic co-factors), and (b) associations between community factors, orphanhood status, and each psychological outcome. Each outcome is considered separately. Backwards elimination found that bullying, community trauma and number of positive activities did not contribute significantly to the models, but that stigma did contribute significantly. Mediation effects of stigma on the association between orphanhood group and psychological outcomes (Figure 42) were also tested, where there was a significant change from models 1-2.

Depression: Controlling for age and gender, orphanhood by AIDS was significantly related to higher depression ($\beta=.182$, $p<.001$) (model 1), and this association was eliminated when stigma was accounted for in the adjusted model ($\beta=.053$, $p<.159$). Orphanhood by other causes was not associated with depression in either the unadjusted or adjusted models. Sobel tests showed that stigma fulfilled criteria for full mediation (Baron & Kenny, 1986) between AIDS-orphanhood and depression.

Anxiety: Controlling for age and gender, orphanhood by AIDS was not associated with anxiety ($\beta=.074$, $p<.06$). The adjusted model, controlling for stigma, also showed no relationship ($\beta=-.069$, $p<.073$). Orphanhood by other causes was not associated with anxiety in either the unadjusted or adjusted models. As no relationship was shown, further tests of mediation were not conducted.

Peer Problems: Controlling for age, household size, more than 2 moves between homes, orphanhood by AIDS was significantly associated to higher peer relationship problems ($\beta=.260$, $p<.001$). When stigma was included, the association remained significant but

was weakened ($\beta=.103$, $p<.005$). Orphanhood by other causes was not associated with peer problems in either the unadjusted or adjusted models.

Post-traumatic stress: Controlling for age, gender, household size, more than 2 moves between homes, orphanhood by AIDS was significantly associated to higher post-traumatic stress ($\beta=.272$, $p<.001$), but this association was eliminated when stigma was accounted for ($\beta=.041$, $p<.202$). Orphanhood by other causes was not associated with post-traumatic stress in either the unadjusted or adjusted models. Sobel tests showed that stigma fulfilled criteria for full mediation between AIDS-orphanhood and PTSD ($p=0$).

Delinquency: Controlling for age, gender, internal migration and two or more moves between homes, orphanhood by AIDS was significantly related to higher delinquency ($\beta=.132$, $p<.001$), but this association was eliminated when stigma was accounted for ($\beta=-.007$, $p<.849$). Positive activities did not have a significant association with delinquency. Orphanhood by other causes was not associated with delinquency in either the unadjusted or adjusted models. Sobel tests showed that stigma fulfilled criteria for full mediation between AIDS-orphanhood and delinquency.

Conduct Problems: Controlling for age, gender and internal migration, orphanhood by AIDS was significantly related to higher conduct problems ($\beta=.149$, $p<.001$), but this association was eliminated in when stigma was accounted for ($\beta=.032$, $p<.405$). Positive activities did not have a significant association with conduct problems. Orphanhood by other causes was not associated with conduct problems in either the unadjusted or adjusted models. Sobel tests showed that stigma fulfilled criteria for full mediation between AIDS-orphanhood and conduct problems ($p=.000$).

Table 18: Correlations between community factors and mental health outcomes¹

	Depression (CDI)	Anxiety (RCMAS)	Peer Problems (SDQ Peer)	Post- Traumatic Stress	Delinquency (CBCL)	Conduct Problems (SDQ)	p (r)
Victim of bullying scale	.29 <.001 (.29**)	.47 <.001 (.47**)	.33 <.001 (.33**)	.46 <.001 (.46**)	.36 <.001 (.36**)	.39 <.001 (.36**)	<.001 (.36**)
No of community traumas	.14 <.001 (.13**)	.24 <.001 (.24**)	.19 <.041 (.04**)	.24 <.001 (.24**)	.27 <.001 (.26**)	.23 <.001 (.24**)	<.001 (.24**)
Stigma total score	.36 <.001 (.36**)	.38 <.001 (.37**)	.47 <.001 (.64**)	.64 <.001 (.34**)	.38 <.001 (.39**)	.32 <.001 (.32**)	<.001 (.32**)
No of positive activities	-.18 <.001 (-.18**)	-.12 <.001 (-.13**)	-.14 <.001 (-.13**)	-.14 <.001 (-.14**)	-.01 <.648 ns	-.04 <.223 ns	<.223 ns

¹ P-value associated with chi-squared tests.

* = correlation significant at the .05 level, ** = correlation significant at the .001 level

Table 19. Multivariate associations between orphanhood by AIDS, orphanhood by other causes, and psychological outcomes, controlling for sociodemographic cofactors and AIDS-related stigma

	Depression ¹		Anxiety ²		Peer Problems ³		PTSD ⁴		Delinquency ⁵		Conduct Problems ⁶	
	Model1	Adjusted Model	Model1	Adjusted Model	Model1	Adjusted Model	Model1	Adjusted Model	Model1	Adjusted Model	Model1	Adjusted Model
Orphanhood by AIDS	.182**	.053	.074	-.069	.260**	.103*	.272**	.041	.132**	-.007	.149**	.032
Orphanhood by other causes	.032	-.009	-.005	-.049	.038	-.001	.074	.016	.020	-.023	.023	-.014
Stigma		.339**		.390**		.435**		.634**		.386**		.309**
R ²	.053	.153	.027	.159	.091	.248	.099	.432	.066	.191	.038	.119
Change R ²		.100		.132		.157		.333		.125		.082
F Change		109.92**		141.67**		181.98**		506.80**		143.34**		86.16**

* Denotes significance at the 0.05 level

** Denotes significance at the .001 level

Model 1 controlling for sociodemographic variables associating p<.2 with each outcome:

¹ Model 1 controls for age, gender

² Model 1 controls for age, gender

³ Model 1 controls for age, household size, >2 moves between homes

⁴ Model 1 controls for age, gender, household size, >2 moves between homes

⁵ Model 1 controls for age, gender, migration, >2 moves between homes

⁶ Model 1 controls for age, gender, migration

Model 2 controls for sociodemographic variables, and experience of AIDS-related stigma

Non-orphaned children are absent from table 3, due to inclusion as a base category in regressions

Discussion

Experience of AIDS-related stigma was shown to strongly mediate the association between AIDS-orphanhood and psychological outcomes of depression, post-traumatic stress, conduct problems and delinquency. For peer relationship problems, group differences were reduced but remained significant. For AIDS-orphaned children, other community factors did not explain psychological outcomes above and beyond the impact of orphanhood, and did not reduce associations of orphanhood and psychological problems. These findings suggest that intervention programmes aimed at the reduction of stigma for orphans may have the potential to alleviate psychological problems associated with the impacts of AIDS-orphanhood.

This analysis provides the first quantitative exploration of stigma amongst AIDS-orphaned children in South Africa. It finds higher levels of reported stigma amongst AIDS-orphaned children than other children. This is supported by prior qualitative research with AIDS-orphaned children, suggesting stigma-related distress (Strode & Barrett Grant, 2001). Stigma research has previously typically focused on HIV-infected children and adults (Emlet, 2005; Green & Smith, 2004), although there is general evidence of stigma directed at HIV/AIDS-affected families (ie. Green & Smith, 2004; Kalichman & Simbayi, 2003).

This analysis provides evidence that AIDS-related stigma is an important mediating factor in psychological well-being for AIDS-orphaned children. But stigma reduction is a complex and difficult area. No known studies evaluate effects of stigma reduction strategies on AIDS-orphaned children. Reviews of strategies aiming to reduce stigma towards HIV-infected people suggest positive results of legal protection and provision of anti-retroviral medication, both of which may reduce public fears of HIV (Klein, Karchner, & O'Connell, 2002). A review of 21 studies notes the paucity of quality research on stigma reduction (especially in the developing world), but finds impacts of community interventions including provision of information around HIV, counselling, group desensitisation towards HIV and contact with HIV+ people (L. Brown, Macintyre,

& Trujillo, 2003). These strategies may or may not also reduce stigma towards AIDS-orphaned children, but should be evaluated for such potential effects.

Limitations of the analysis

The stigma scale used did not ask directly about stigma related to HIV/AIDS. Instead, items asked about experienced stigma due to ‘illness’, which in the context of urban South African townships was a proxy term for HIV/AIDS-related illness. In an environment of low disclosure and high secrecy around HIV/AIDS, asking directly about AIDS-related illness would have resulted in children afraid to admit experience of AIDS-related stigma. However, the far higher proportions of reported stigma amongst AIDS-orphaned children (55%, compared to 27% of other orphans and 17% of non-orphans) suggest that the scale was tapping the correct construct.

Stigma items in this study referred to illness of ‘someone in your family’, and high HIV prevalence in study areas (around 28%) means that children in both the AIDS-orphaned and control groups were likely to have HIV-affected or AIDS-unwell family members (Department of Health, 2005). However, experience of AIDS-related stigma amongst control children as well as amongst AIDS-orphaned children would have had the expected effect of reducing group differences, and group differences remained significant.

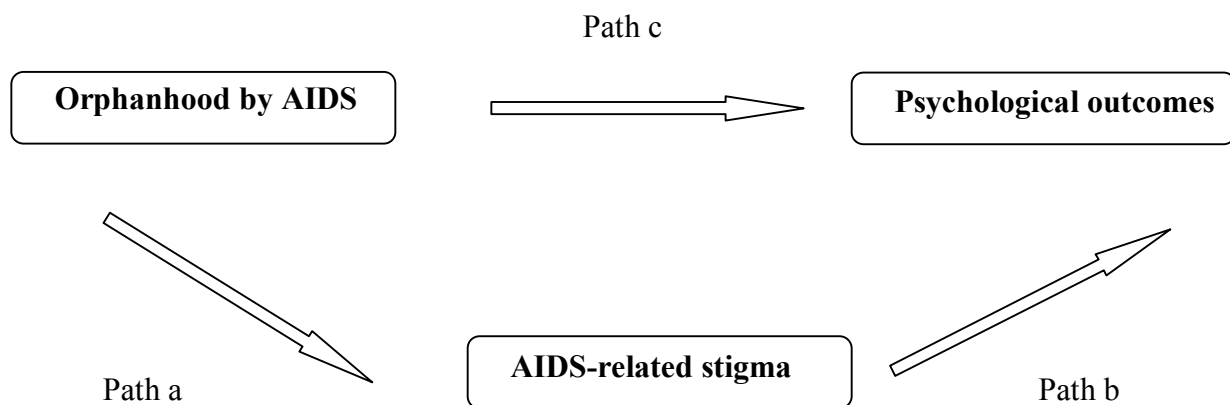
A final limitation is the risk of method overlap. Children who were more depressed, traumatized or had conduct problems may have felt more isolated and threatened, and thus perceived higher levels of stigma than other children. However, children’s experience of stigma can only be measured by self-report, and perceived stigma is inherently at least partially subjective. In order to limit method overlap, items focused as much as possible on actual specific acts of harassment (such as being teased) reflecting the stigma of AIDS. The nature of the sample also precluded the use of alternative (i.e. caregiver or teacher) informants for mental health outcomes: 6% of AIDS-orphaned children did not attend school, and class sizes of 50-70 were judged to limit teacher

capacity to report child psychological problems. The use of caregiver report would have introduced systematic bias of poorer reporting for children living on the streets, in child-headed households, and with very unwell or distressed caregivers (Berg-Nielsen, Vika, & Dahl, 2003). In terms of the risk of method overlap, it may be that some psychological problems are more likely to influence perceptions of stigma. For example, depression and peer problems may be conceptually closer to stigma than post-traumatic stress.

Conclusions

Whilst some factors addressable at a community level, such as reducing bullying and exposure to community trauma, and increasing positive activities, have potential to improve child mental health more generally, AIDS-related stigma was shown to be particularly relevant to AIDS-orphaned children, and to have strong predictive effects on psychological outcomes. This has implications for policy and interventions concerning groups of vulnerable children. Paradoxically, evidence of heightened stigma mediating the association of AIDS-orphanhood and mental health problems may suggest that interventions should be cautious about isolating or focusing on AIDS-orphaned children in particular, and thereby exposing them to further stigma. This is discussed in more detail in the following chapter.

Figure 42: Mediation Model for stigma



6.7 Question 6: Interactions between risk factors

Question 6: Are there any interaction effects between risk factors? Are factors combining to produce a cumulative effect on the mental health of children?

A version of this analysis is currently under review as:

Cluver, L and Orkin, M (under review) *Cumulative risk and AIDS-orphanhood: Interactions of stigma, bullying and poverty on child mental health in South Africa.*

Summary:

Analyses assessed interactions of risk factors with AIDS-orphanhood status and children's likelihood of experiencing clinical-range psychological problems. Logistic regressions and hierarchical log-linear modelling with backwards selection were used to identify factors with significant effects and interactions between factors.

Food insecurity, AIDS-related stigma and bullying all independently increased children's likelihood of clinical-level disorder. When combined, poverty and stigma produced strong interaction effects, and raised likelihood of disorder from 19% to 83%. High levels of bullying interacted with AIDS-orphanhood status to raise likelihood of disorder from 37% to 76% amongst AIDS-orphaned children.

With thanks for collaboration and statistical assistance to Professor Mark Orkin

Background to Question 6:

Previous analyses in Questions 1-5 have established the existence of a number of risk factors for children's mental health, including poverty, caregiver illness and AIDS-related stigma. However, research in the developed world suggests that a key risk factor such as poverty largely affects child mental health through its impact on other risk factors (Rutter et al., 1998), and that the highest risks for child psychological problems arise from cumulative combinations of stressful or negative experiences (Fergusson & Lynskey, 1996). Empirical work with adult populations has found that cumulative prevalence of lifetime stressors account for much of variance in depression (Turner & Lloyd, 1995). Studies with children, beginning with Rutter's Isle of Wight study (Rutter, 1979b), have found evidence of a linear model of cumulative effects of multiple stressors on child internalising and externalising problems (Appleyard et al., 2004).

Theories of cumulative disadvantage have hypothesised that the examination of risk factors in isolation (for example studying the effects of maltreatment whilst controlling for partner violence, family stress and low SES) does not reflect the common co-occurrence of these factors (Cicchetti & Lynch, 1993), and that there is potential for particular pairs or groups of risk factors to interact. However, these studies have all taken place in the developed world, and have explored risk factors which are known to co-occur. No known studies have empirically explored interactions of risk factors in the lives of AIDS-orphaned children, or interactions between AIDS-orphanhood, risk factors and child mental health.

It was important, then, to identify the simultaneous relationships among the main concomitant variables relating to mental health (ie stigma, extreme poverty), differentiated, if appropriate, by AIDS-orphanhood status. One option was to test individual hypotheses of interactions amongst pairs or groups of risk factors. But the lack of sufficient available evidence on the relationship between risk factors for AIDS-orphaned children would have resulted in poorly-evidenced hypotheses. Another option was to test simultaneously the potential for interactions amongst a number of factors which have previously been shown to be risks for child mental health in this sample.

A convenient mode of analysis allowing us to address these concerns for a modest subset of variables is log-linear analysis. An additional advantage of log-linear is the investigation of both mutual simultaneous relationships amongst factors, and particular interaction effects, in which variables with separate impact have a much greater impact when combined. These might be expected to indicate a possible cumulative effect of risk factors on mental health.

Measures used in this analysis

Not all of the factors used were ones that had been identified as mediating factors in the relationship between AIDS-orphanhood and mental health outcomes. It was broadly hypothesized that there was potential for factors which were particularly problematic for

AIDS-orphaned children (such as stigma) to interact with more general risk factors (such as bullying). As described in Chapter 5, 52 potential factors were initially entered into multivariate logistic regressions with orphanhood status, controlling for age and gender, and using a dependent variable of any internalising disorder (i.e. a clinical-level score on one or more of depression, anxiety or PTSD). Backwards-elimination selected five variables with associations $p < .01$; food security, stigma, orphanhood status, quality of care and bullying.

Bullying was measured with the 9-item, standardised ‘Social and Health Assessment Peer Victimization Scale’ (Ruchkin et al., 2004). Scale values were divided between above-median (‘more bullied’; $>12/36$) and below-median (‘less bullied’; $<12/36$). A brief, 4-item stigma scale was devised, and is detailed in Question 5. ‘Stigma’ was defined as endorsement of one or more experiences of stigma. Food insecurity was coded as ‘food insecure’ when children lacked food one or more days per week. Quality of care was measured by five variables; frequency of praise for the child, extent of caregiver monitoring of child, frequency of caregiver-child activities such as help with homework, child’s sense of belonging in the home, and sharing of resources between children in the home. Each factor was coded according to ‘acceptable/unacceptable’ levels, and quality of care was coded as good where levels were acceptable on all five variables.

Results

Using the weighted sample, around one third (301 of 973) of children reported having insufficient food at home for one or more days per week. Around one fifth (220) children reported any experience of AIDS-related stigma. There was no difference in proportions of AIDS-orphaned, other-orphaned and non-orphaned children who were above the median score for being bullied. Overall rates of disorder were 9.7% for depression, 9.8% for anxiety and 27% for PTSD, reflecting similar estimates for South Africa as a whole (Kleintjies et al., 2006), and also reflecting proportions found in low income areas in the Western Cape (Seedat et al., 2000; Zissis et al., 2000). 31% of children showed one or more internalising disorder.

Two-way interaction effects: Log-linear analyses identified a number of two-way effects. Amongst these, the only factor interacting with likelihood of disorder was quality of care. Half (46%) of children reporting poor care showed clinical-range scores in at least one disorder. Only one quarter (24%) of children who reported good care showed a clinical-level disorder ($p < .001$, $\chi^2 53.0$). However, and reassuringly, orphaned children did not report poorer quality of care than non-orphans, with good care reported by 67% of AIDS-orphaned children, 73% of other-orphans and 60% of non-orphans. Other two-way effects showed that orphanhood was associated with increased likelihood of food insecurity (50% of AIDS-orphaned children and 47% of other-orphans, compared to 26% of non-orphans, $p < .001$, $\chi^2 39.2$). AIDS-orphaned children were more likely to report experience of stigma (55% of AIDS-orphaned children compared to 27% of other-orphans and 17% of non-orphans, $p < .001$, $\chi^2 83.2$). Stigma and bullying also showed a two-way interaction effect, with 70% of stigmatised children also bullied, compared to 41% of non-stigmatised children ($p < .001$, $\chi^2 61.1$).

Three-way interaction effects: Two three-way interaction effects related to likelihood of disorder. The first three-way interaction (disorder in relation to stigma and food insecurity) is displayed in Table 15 and Graph 2. The second three-way interaction (disorder in relation to bullying and AIDS-orphanhood status) is displayed in Table 20 and Graph 3.

Figure 5 shows that, amongst all children, the group showing the lowest proportion of disorder were those who were not stigmatised and who had no days without food in the past week (18.8% with disorder). The group showing the highest proportion of disorder were those who were stigmatised and experienced food insecurity (83.2% with disorder). Each of these factors independently is associated with an increase in proportion of clinical disorders. Food insecurity itself (in the absence of stigma) increased the proportion to 33.5%. Stigma itself (in the absence of food insecurity) increased the proportion to 53.3%.

The other three-way effect shows the interaction between disorder and bullying for different categories of orphanhood (Table 21 and Graph 2). There is a low level of disorder amongst non-orphans (12%), but this is heightened four-fold for high levels of bullying (51%). For other-orphans, the level of disorder is 27% with no or low levels of bullying, and this nearly doubles to 47% for high levels of bullying. Among AIDS-orphaned children, proportions with disorder is initially high in the absence of bullying (38%) and nearly doubles to an extremely high 76% when exposed to high levels of bullying.

Discussion

This study demonstrates the strong interactive effects between poverty, AIDS-related stigma, bullying and mental health of children in South Africa. The cumulative effect of two factors - food insecurity and stigma - increased proportions of children with internalising disorders from 19% to 83%. Bullying was associated with substantial rises in mental health problems for all children. For AIDS-orphaned children whose initial rates of disorder were high (38%), being bullied was associated with very high disorder rates of 76%.

Risk factors of stigma and food insecurity were shown to interact with AIDS-orphanhood, and bullying interacted with experience of stigma. Whilst causal directions cannot be determined through cross-sectional data, these findings suggest that there are some risk factors which are part of the experience of AIDS-orphanhood, or mechanisms by which AIDS-orphanhood impacts on mental health. Further, this study finds that these risk factors interact to produce a cumulative negative effect on child mental health. Stigma, bullying and extreme poverty are linking together to intensify the vulnerability of AIDS-orphaned and AIDS-affected children.

Theories of risk mechanisms may help us to understand possible processes by which these interactions are taking place. For example, Sen's conceptualisation of absolute poverty includes both discrimination and internalised stigma (Sen, 1999). There is anecdotal and qualitative evidence of stigma associated with increased poverty amongst

AIDS-affected families, and there is also evidence of stigma towards HIV+ people, but little exploration of how these two forms of stigma may interact. There is strong evidence of negative effects of bullying on child mental health, but we need to understand more about whether bullying takes different forms for different groups of children, and whether some groups are particularly susceptible to psychological distress as a result of being bullied.

The evidence shown here of cumulative interactive effects suggest that interventions addressing one risk factor, such as food insecurity, may potentially both improve mental health outcomes, and reduce the impact or incidence of other risk factors. Services aimed at reducing risk of psychological disorder may need to work on a number of different levels, such as school-based anti-bullying strategies, nutrition schemes, and community-based stigma-reduction.

Limitations of this analysis:

Many of the limitations detailed for Questions 1-5 are also relevant to this analysis. Additionally, the use of cross-sectional data prohibits causal explanations in this question; i.e. this study cannot tell us the direction of the relationship between being bullied and having an internalising disorder. The causal hypotheses presented above rely on evidence from wider literature, and require empirical testing. Furthermore, as with all the questions in this chapter, the cross-sectional design does not allow us to determine the effects of programmes addressing risk factors such as stigma, bullying and food insecurity, only to suggest the potential effects of reducing these risks. Intervention effects must be established using rigorous evaluation methods.

Conclusions:

Poverty, stigma and bullying have striking interactive effects in heightening likelihood of child psychological disorder in the context of AIDS. It is essential that interventions are provided to alleviate these risk factors.

Table 20: Associations between food insecurity, AIDS-related stigma and risk of disorder¹

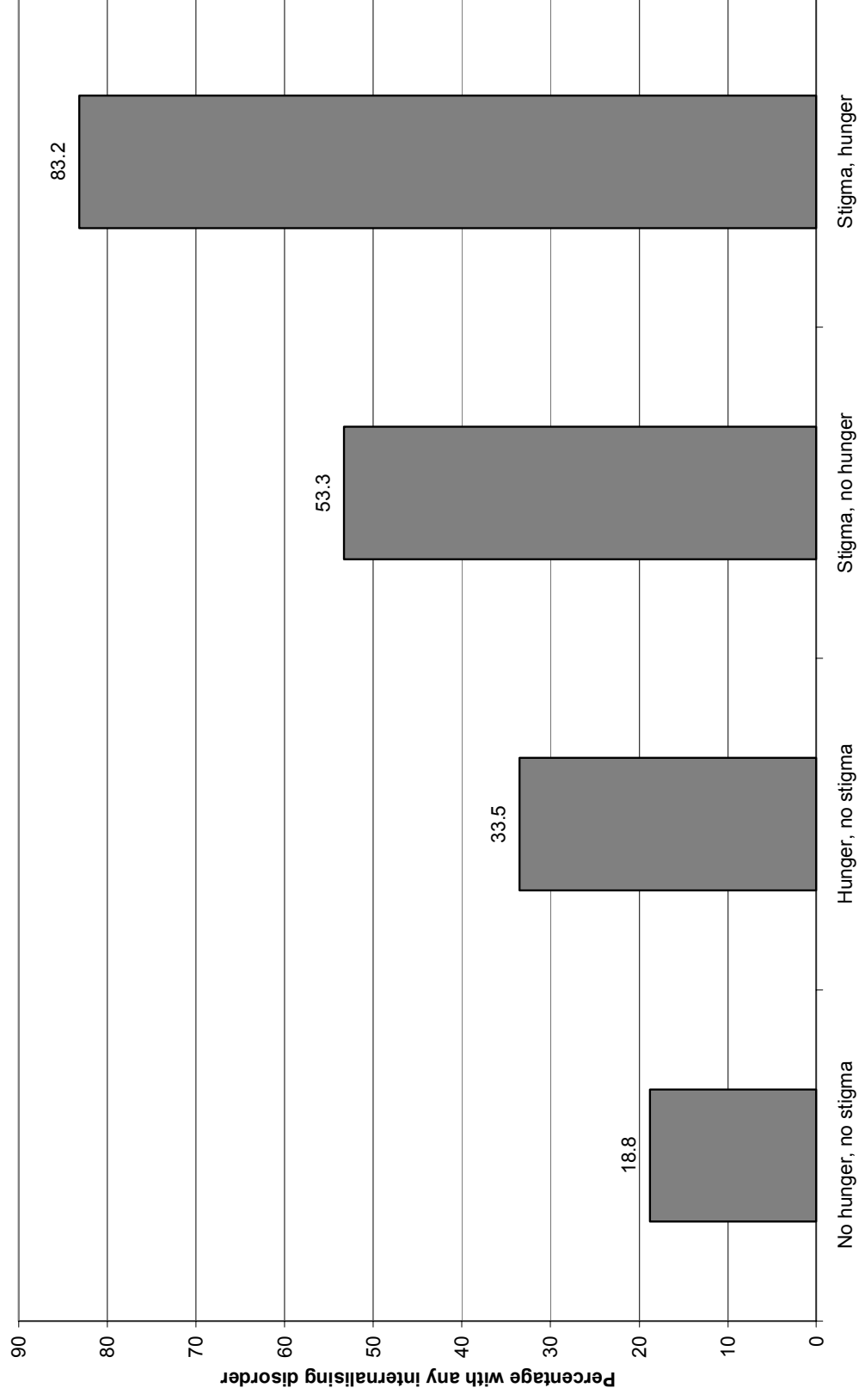
	Food Secure		Food Insecure	
	No stigma (%)	Stigma (%)	No stigma (%)	Stigma (%)
No disorder (%)	81.2	46.7	66.5	16.8
Disorder (%)	18.8	53.3	33.5	83.2
Total	100.0	100.0	100.0	100.0
N	565	107	188	113

Note: 'Disorder' defined as presence of clinical-level score on one or more of: Child Depression Inventory, Revised Children's Manifest Anxiety Scale and Child PTSD Checklist.

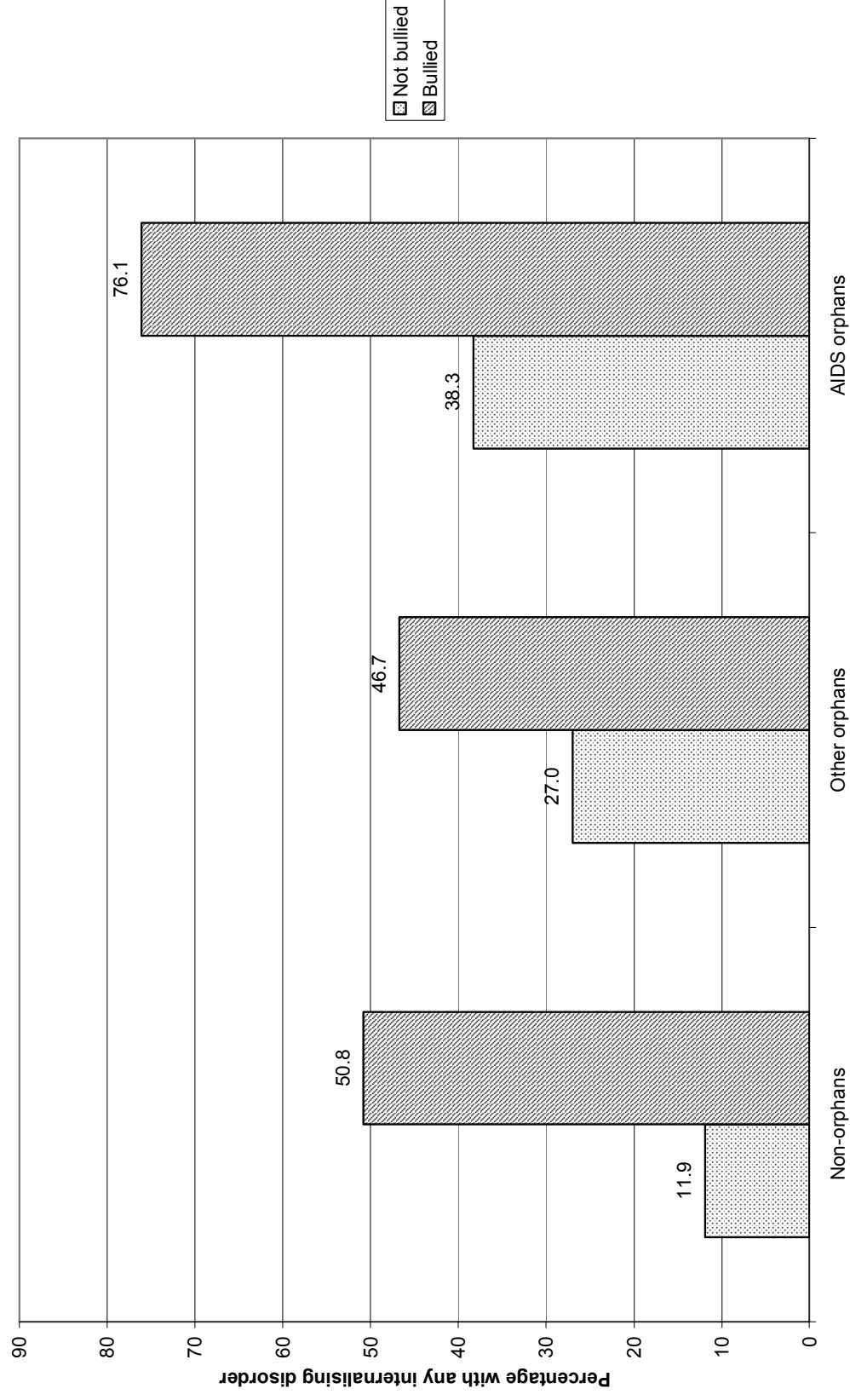
Table 21: Associations between bullying, AIDS-orphanhood and risk of disorder

	More bullied			Less bullied		
	With disorder (%)	Without disorder (%)	Total N (weighted)	With disorder (%)	Without disorder (%)	Total N (weighted)
AIDS-orphaned children	76.1	23.9	46	38.3	61.7	60
Other orphans	46.7	53.3	45	27.0	73.0	63
Non-orphans	50.8	49.2	319	11.9	88.1	354
Total %	53.2	46.8	100	17.2	82.8	100
N (weighted)	218	192	410	82	477	477

Graph 2 Interaction among Disorder, Stigma and Hunger



Graph 3: Interaction among Disorder, Orphanhood, Bullying



6.8 Summary and conclusion

This study has addressed six sets of questions regarding the mental health of AIDS-orphaned, other-orphaned and non-orphaned children in an urban African sample. Question 1 established basic demographic differences between groups. Question 2 showed that AIDS-orphaned children were at heightened risk of psychological problems than other children. Following from this finding, questions 3-6 explored factors in children's lives which may be mediating the relationship between orphanhood status and mental health.

Question 3 established that AIDS-orphaned children in this sample were poorer and had less access to education or grants. These factors had strong mediating effects on mental health. Question 4 established a relationship between type of caregiving arrangement and mental health outcomes for AIDS-orphaned children. It further established strong mediating values of caregiver illness and child housework on mental health of AIDS-orphaned children. Question 5 highlighted the heightened levels of AIDS-related stigma reported by AIDS-orphaned children, and the strong mediating value of this stigma on mental health.

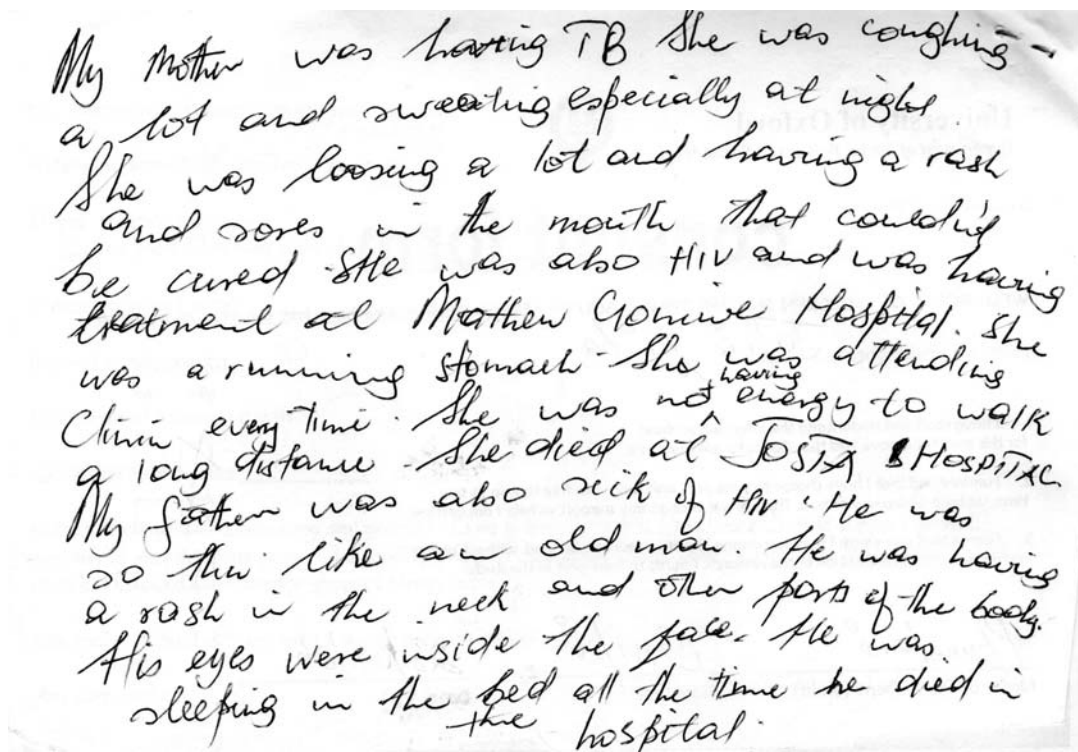
Finally, Question 6 explored possible interaction effects between risk factors. Food insecurity and stigma were found to interact to produce a cumulative effect on likelihood of experiencing an internalising disorder. Being a victim of bullying raised likelihood of disorder for all orphanhood groups, and interacted with AIDS-orphanhood to raise likelihood of disorder to high levels.

This chapter has presented the primary findings of the current study. In the process of analysing the data, it became increasingly clear that these findings have relevance for policy and practice. The data given in the current chapter have implications for responses to AIDS-orphanhood on a range of levels, from social work practice regarding placement of children, to national-level policy regarding provision of social security. It is important to be extremely cautious about the extrapolation of policy implications from research

findings (especially epidemiological research findings). However, South African government and NGOs were insistent that policy guidance was necessary. Therefore, Chapter 7 will detail the limitations of the present study and implications for theory, before cautiously interpreting the findings into policy recommendations and recommendations for future research. Finally, the thesis will conclude with the most recent plans, developed in collaboration with South Africa's Minister of Social Development and senior officials from his department, for a scaling-up of the current study into a nationally-representative survey.

Chapter 7. Policy Implications and Conclusions

- 7.1 Summary of findings
- 7.2 Limitations of the study
- 7.3 Theoretical implications
- 7.4 Policy implications of study findings
- 7.5 Recommendations for future research
- 7.6 Background and plan for national survey
- 7.7 Conclusions



My mother was having TB. She was coughing a lot and sweating especially at night. She was losing a lot and having a rash and sores in the mouth that couldn't be cured. She was also HIV and was having treatment at Matthew Goniwe Hospital. She was a running stomach. She was attending clinic every time. She was not having energy to walk a long distance. She died at Josta Hospital. My father was also sick of HIV. He was so thin like an old man. He was having a rash in the neck and other parts of the body. His eyes were inside the face. He was sleeping in the bed all the time. He died in the hospital.

Figure 43: Girl, 17, Makhaya (Khayelitsha)

'My mother was having TB. She was coughing a lot and sweating especially at night. She was losing a lot [of weight] and having a rash and sores in her mouth that couldn't be cured. She was also HIV and was having treatment at Matthew Goniwe Hospital. She was a running stomach. She was attending clinic every time. She was not having energy to walk a long distance. She died at Josta Hospital. My father was also sick of HIV. He was so thin like an old man. He was having a rash in the neck and other parts of the body. His eyes were inside the face. He was sleeping in the bed all the time. He died in hospital.'

This final chapter of the thesis was developed in conjunction with the responses within South Africa to the study findings given in Chapter 6. In the dissemination stage of the study I initially presented only study results without extrapolation into policy. However, NGOs and the South African government consistently demanded a considered presentation of possible policy responses to the implications of the findings. The Minister of Social Development and senior officials within the department proposed a national-level survey in order to inform large-scale intervention. This resulted in the development of a research proposal which is currently being planned to start in April 2008. For these reasons Chapter 7 now goes further than the originally-intended discussion of study limitations, theoretical implications and recommendations for future research. This chapter will also present detailed (cautious) suggestions for policy implications and the most recent proposal, developed with the Department of Social Development, for the scaling-up of the present study.

7.1 Summary of findings

Derived from the Greek ‘ορφανος’, the word ‘orphan’ has been defined as ‘bereaved’ or ‘bereft’¹⁴. This study sought to examine scientifically what bereavement means for orphans in today’s South Africa, in order to be able to suggest interventions and services. This study also sought to be able to judge from evidence whether a new cause of bereavement, the HIV/AIDS pandemic, carries special implications for policy alternatives.

1) Findings suggest that AIDS-orphaned children do have more psychological problems than children orphaned by other causes, and than non-orphans. Differences remained when controlling for sociodemographic factors such as age, gender, age at orphanhood and type of dwelling. AIDS-orphaned children reported more symptoms of depression, peer problems, post-traumatic stress, conduct problems and delinquency than other

¹⁴ Noah Webster, Universal Dictionary: ‘Orphan, noun, (Greek Orphanos, later Orphos; Latin Orphus, bereaved.) A child bereaved of parents. Cleveland, Ohio and New York City, the World Publishing Company, 1940. p1150.

children. They were more likely to report suicidal ideation. There were no differences for symptoms of anxiety.

2) Our sample groups were compared with Western norms for proportions of children with clinical-level scores for each psychological problem. Although no norms have been validated in South Africa, proportions of children in the clinical range on a weighted version of our sample, suggest that this is a useful comparison (see Chapter 5). By these Western norms, AIDS-orphaned children are much more likely to have clinical level scores for depression, peer problems and post-traumatic stress, compared to other-orphaned and non-orphaned children. They are slightly more likely to have clinical level scores for delinquency, but less likely to have clinical-level scores for conduct problems. Children orphaned by non-AIDS causes and non-orphaned children showed similar proportions with clinical-level scores to Western norms.

3) Poverty-related factors have strong mediating effects on these differences in mental health. AIDS-orphaned children were less likely to have food security, to attend school, to live in a household where anyone was receiving a grant, or to live in a household where anyone had a job. When these four factors were controlled for, group differences in psychological problems were eliminated for depression, conduct and delinquency problems. This suggests that much of the variance amongst orphanhood status and some mental health problems can be accounted for by the greater poverty levels experienced by AIDS-orphaned children.

4) Caregiving arrangements also have important mediating effects. AIDS-orphaned children living on the streets reported more symptoms of post-traumatic stress and delinquency, independent of age, gender and levels of food security. AIDS-orphaned children living with grandparents showed lower anxiety. There were no other differences between different types of adult family care (ie child-headed households, other extended family). The group of children living with non-family members was too small for analysis. This provides evidential support to recommendations such as found in Richter, Foster and Sherr (2006), of the importance of supporting families to care for children. However, further research is needed to compare outcomes for institutionalised children in this context.

5) AIDS-orphaned, other-orphaned and non-orphaned children generally reported good caregiver monitoring, sense of belonging in the home, sharing of household resources, praise, and caregiver-child activities. For all orphans, worse mental health was associated with having many changes of caregiver, separation from siblings, and living in a home with sexual abuse, physical abuse or domestic violence. There were two caregiving factors in which AIDS-orphaned children differed from other orphans. Caregivers of AIDS-orphaned children were more likely to be very often unwell (often surviving HIV+ parents or elderly grandparents) and AIDS-orphaned children did more housework. Controlling for these two factors eliminated the likelihood of higher scores for AIDS-orphaned children in delinquency and conduct problems, and had strong mediational effects on other psychological problems. This suggests that caregiver illness and young caring may be important mechanisms by which AIDS-orphanhood impacts on child mental health.

6) The study aimed to identify risk factors which are influenced by community attitudes and resources, and which may be able to be addressed by group or community-level interventions. Factors were tested which can operate at a community-level, including bullying, stigma, community violence and lack of opportunities for positive recreational activities. Exposure to community violence, bullying and lack of positive activities were associated with worse mental health for children generally, but were not associated with the differences in mental health experienced by AIDS-orphaned children. AIDS-orphaned children also reported very high levels of AIDS-related stigma. Experience of stigma fully mediated the relationship between AIDS-orphanhood and mental health. When controlling for AIDS-related stigma, the differences between orphanhood groups were eliminated for symptoms of depression, post-traumatic stress, delinquency, and conduct problems. The very strong findings related to stigma must be interpreted cautiously due to potential method overlap. However, they do indicate the importance of reducing AIDS-related stigma, and the potential effects of that stigma on the families of HIV-affected people.

7) Risk factors were explored which increased the likelihood of AIDS-orphaned children reporting clinical-level scores on any internalising disorder. Log-linear analyses

identified interactions between these risk factors. AIDS-related stigma and food insecurity interacted to produce a cumulative effect on likelihood of disorder, and increased proportions of children with clinical scores from 19% to 83%. Being a victim of bullying interacted with AIDS-orphanhood status to increase risk of disorder from 38% to 76%. AIDS-orphaned children were more likely to be stigmatised and to experience food insecurity. Stigmatised children were more likely to be bullied. These findings suggest that stigma, bullying and extreme poverty are linking together to intensify the vulnerability of AIDS-orphaned and AIDS-affected children. These findings support the findings amongst other groups of children, of cumulative risk effects of multiple stressors (Rutter, 1999).

7.2 Limitations of the study

Rutter (2000) requires that research articulates carefully and fully the assumptions upon which the chosen research design rests, and makes explicit the extent with which problems and limitations have been dealt. This study presents a number of limitations. These include practical, methodological and conceptual limitations.

Lack of validated scales:

Although all standardised instruments had been previously used with this population, no standardised psychological scales for this age group have been validated in South Africa (Flisher, 2007). For this reason, continuous scores were mostly used, although analysis also includes use of clinical cut-off scores which have been established in developed world contexts. These comparisons can only provide tentative conclusions regarding proportions of children within the clinical range. In order to test the relevance of the western cut-offs to the South African context, I weighted the sample to reflect population proportions of AIDS-orphaned and other-orphaned children (the weighting procedure is described in Chapter 5). Overall rates of disorder were 9.7% for depression, 9.8% for anxiety and 27% for PTSD, 3.8% for conduct problems and 4.8% for delinquency. These reflect both broad prevalence estimates for South Africa (Kleintjies et al., 2006), and proportions found in low income areas in the Western Cape (Seedat et al., 2000; Zissis et

al., 2000). Therefore, although cut-offs were not locally validated, these comparisons suggest that they are useful in giving some indication of distress levels.

Establishing cause of parental death:

A limitation in this study is the unavailability of HIV serology prior to parental death, and poor reliability of local death certificates regarding HIV/AIDS. However, the ‘verbal autopsy’ method used has been validated in South Africa (Hosegood et al., 2004), and this study used a conservative threshold of three or more AIDS-defining symptoms to determine death by AIDS. Where there was any doubt, symptoms were blind-reviewed by two of three independent medical practitioners.

Contamination of control groups:

The study sought to distinguish effects of AIDS-orphanhood from orphanhood more generally. In order to reduce contamination of controls, children in the control groups whose parents disclosed HIV+ status, or whose parents were observed to be AIDS-unwell, were excluded from the sample. Nevertheless, it was unknown whether parents of control group children may have been HIV-positive but asymptomatic, and with prevalence of up to 28% in study areas, many participants were likely to have AIDS-affected family members (Department of Health, 2005). However, illness amongst families of control children would tend to have the effect of reducing group differences, and yet differences between AIDS-orphaned and other children were highly significant.

HIV status of children:

A further limitation is unknown HIV-status of child and adolescent participants. Rates of testing in South Africa, and in the research area, are extremely low (Kalichman & Simbayi, 2003). It was very unlikely that the sample included any children who had been peri-natally infected, as survival rates into adolescence (before the 2004 rollout of anti-retroviral medication) were minimal (Newell et al., 2004). Children who were AIDS-unwell or who disclosed HIV+ status were excluded. However, HIV-prevalence for Western Cape adolescents is estimated at 2-6%, implying that a small proportion of

participants may have been infected post-natally, with potential neurocognitive effects of even asymptomatic HIV. The potential for HIV+ status was highest amongst the group of streetchildren interviewed, most of who engaged in transactional sex.

Reliance on youth report:

Ideally, multiple informants are used when assessing children's psychological distress (Dishion, French, & Patterson, 1995). There are a number of reasons why this was not possible in this study. A major methodological consideration in reliance on youth self-report was the difficulty in obtaining reliable caregiver report for sub-groups within this sample. The pilot study originally intended to interview primary caregivers as well as children (Cluver & Gardner, 2006), but found this impossible for many orphans. These included children who were living with new and unknown foster parents, children living with extremely ill or dying caregivers, streetchildren living in shelters and child-headed households. Options for these groups of children would include having no caregiver report or having reports from caregivers who may have been likely to further underestimate symptoms (Berg-Nielsen et al., 2003). Thus, the use of caregiver report would have potentially introduced a systematic bias of poorer reporting for some of the most vulnerable groups of children.

This systematic bias would have also applied to obtaining teacher report for children who were not attending school. Teacher report has been used in other studies of child mental health. However, township schools are characterised by large class sizes and very little teacher time to complete questionnaires. Cape Town Child Welfare uses teacher-completed questionnaires on child functioning for state foster care assessments, and quality of teacher report has been found to be very variable. Finally, a recent (unpublished) study on teacher perceptions of orphan's psychological needs in South Africa found a high level of variation in teacher perceptions of psychological status of orphans, according to teacher's gender, age and attitude to HIV/AIDS.

It is recognised that a reliance on child/youth self-report of symptoms is not ideal in determining mental health problems (Goodman & Scott, 1997). There is evidence of carer/child discrepancies in reporting symptoms of all the psychological problems

investigated in this study. This study used, where possible, teacher, caregiver or social worker report for validation of socio-demographic information such as school attendance, grant receipt and parental death. However, psychological measurements in this study relied on child self-report, due largely to the serious methodological difficulties in identifying and accessing caregivers for some subgroups of orphaned children (see Chapter 5 on caregiver consent).

There may also be method overlap in using a single informant to report risk factors such as stigma and mental health state. Where possible, risk factors were measured by indicators which minimised the risk of biased reporting (such as school enrolment and number of days in the past week when there was not enough food in the home), but some factors such as stigma are inherently complex in their relationship to particular disorders such as depression. As with report of symptoms, the use of caregivers to report risk factors risked systematic bias for children with no caregiver or compromised care.

Cross-informant reliability:

How much do non-parent caregivers know? Studies from South Africa with fostering grandmothers (Ferreira et al., 2001), as well as the findings from the qualitative stage of this study, suggest that non-parent carers are aware that children orphaned by AIDS are experiencing emotional distress. However, these studies are general and qualitative, and do not ask about specific disorders. Nor do they compare adult report with any measures from the children. Only one study of AIDS-affected children was found comparing caregiver and child report of psychological symptoms, and found agreement to be low (Forehand et al., 2002). Thus there is very limited evidence available on the level of cross-informant agreement for mental health outcomes of orphaned children.

International evidence suggests that parents report fewer depressive symptoms in their children than do children themselves (Angold et al., 1987; Barrett et al., 1991). However, studies have also found parents to report higher levels of depressive symptoms than children (Ivens & Rehm, 1988; Kazdin & Petti, 1983) and others have found a combination of under-and over-reporting (Berg-Nielsen et al., 2003). Studies comparing foster carer and child report of child mental health are largely available from the

developed world (Mount, Lister, & Bennun, 2004), but differences in foster care processes suggest a lack of generalisability to the South African context. Cross-informant agreement of teachers, parents and children has been found to be low for multi-informant scales such as the CBCL and CDI (Achenbach et al., 1987).

Externalising symptoms tend to be reported in higher levels by parents than by children (Angold et al., 1987; Edelbrock, Costello, Dulcan, & Kalas, 1986). In a meta-analysis of the CBCL Parent-Report and Youth Self-Report, average correlation between adolescents and their parents was found to be low (0.28) (Achenbach et al., 1987), and this is in common with other multi-informant instruments of child externalising problems. Post-Traumatic Stress symptoms also differ between child and caregiver reports. Studies show poor recognition of PTSD symptoms amongst children by parents (Handford, Mayes, & Mattison, 1986; Hurt et al., 2001; Sack, Angell, Kinzie, & Rath, 1986). Research generally relies on child report of symptoms for PTSD (Ensink et al., 1997; Fletcher, 2002; Greenwald, 2002; Pynoos, Goenjian, & Tashjian, 1993; Richters & Martinez, 1993; Seedat et al., 2004; Stallard, Velleman, & Baldwin, 1999; Winje & Ulvik, 1998; Yule, 1992; Yule et al., 2000; Zissis et al., 2000), especially when participants have experienced the death of, or separation from, their parents (Black & Harris-Hendricks, 1992; L. Freeman, Schaffer, & Smith, 1996; Pfeffer et al., 1997; Stoppelbein, 2000). The extensive evidence of cross-informant discrepancies suggest that child self-report (and especially report by older children) is a valid measure of psychological difficulties.

Caregiver distress:

Studies indicate that depressed (both non-clinically and clinically) or anxious parents report that their children display inflated levels of both internalising symptoms (Berg-Nielsen et al., 2003; Najman et al., 2000) and externalising symptoms (Brody & Forehand, 1986; Fergusson, Lynskey, & Horwood, 1993). In poor areas of Cape Town, studies have found high levels of depression amongst mothers (Cooper et al., 2002) and amongst grandmothers caring for orphaned children (Ferreira et al., 2001). Evidence also shows heightened depression and anxiety amongst HIV+ mothers (Brandt, 2007). In this context, such evidence suggests that parent report may itself be biased by the stresses experienced by adult carers.

Sample group limitations:

The study is limited to Black African, urban, isiXhosa-speaking children (apart from a few of the streetchildren who had migrated from other parts of South Africa). This limits the generalisability of the study findings. This was partly guided by practical difficulties in recruitment of non-Black groups. In the pilot quantitative stage of this study (Cluver & Gardner, 2006), efforts were made to recruit children from a representative range of population groups in the Western Cape. However serious difficulties were presented in recruiting children from the Coloured and White populations, which both had very low HIV-prevalence at the time of fieldwork (Department of Health, 2005).

Methodological considerations also guided the sampling strategy. In the qualitative and large-scale quantitative stages of the research, it was decided to focus sampling on one ethnic group. This was due to considerations of race as a potential confounding factor in the analysis stage. In the Western Cape, Black African, Coloured and White populations (especially those in the poorer areas) live in separate areas, and differ in language, cultural practices, social mores and approaches to care of children. Subdivision of AIDS-orphan, other-orphan and non-orphan groups into more than one racial and cultural category would have potentially confused findings. Further, it would have complicated the matching of children across the three groups of AIDS-orphaned, other-orphaned and non-orphaned children.

The choice of a Black African sample group was based on the following considerations: 1) Black Africans comprise 79% of the current South African population (Statistics SA, 2006a); 2) Black Africans are the population group most affected by HIV/AIDS both in South Africa, and in the Western Cape (Shisana et al., 2005); 3) Black African children are most likely to be orphaned within the South African population than children in any other ethnic group (Anderson & Phillips, 2006). 4) 89% of Black Africans in the Western Cape are isiXhosa-speaking: 1,073,951 of 1,207 429 in Census 2001 (Statistics South Africa, 2003). In terms of generalisability and relevance to the current orphanhood situation in South Africa, this study chose the most appropriate sample group in terms of ethnicity, within the Western Cape.

However, it is likely that HIV prevalence in some other population groups will rise. In terms of future patterns of orphanhood, it is desirable that the Coloured, White and Indian populations, and rural populations, are also included in orphan research. In terms of current patterns of orphanhood, it is also desirable to include in research non-isiXhosa speaking groups of Black Africans, such as isiZulu, Sepedi and Tshivenda speakers.

Limitations of a quantitative study:

Any quantitative study, using structured or semi-structured measurement tools, risks the omission of variables which have not been hypothesized or included in the study design. In this study, there are two main areas which risk omission. Firstly, not all mental health outcomes were measured. Disorders such as schizophrenia were excluded due to late onset in adolescence and potential for confusion with amaXhosa cultural interpretations of psychosis (Ensink & Robertson, 1999; Mzimkulu & Simbayi, 2006). Greater focus was given to internalising than externalising disorders, following international evidence which indicated that emotional problems were more prevalent amongst AIDS-orphaned children than behavioural problems (Cluver & Gardner, 2007a). Disorders in the hyperactivity and attention deficit spectrum were not included, due to indications in the pilot study of low relevance of these disorders to our sample group (Cluver & Gardner, 2006). Therefore, it is possible that some relevant disorders were omitted in this study.

Secondly, this study risked omission of risk and protective factors which were not included in the questionnaire. Extensive efforts were made to include all relevant factors: literature review of studies with AIDS-orphaned children, literature reviews of studies with other orphaned children (Chapter 3), and a qualitative study of 120 children and caregivers (Chapter 4). However, questionnaires had to be of a length suitable for children to complete (Robertson et al., 1999), and thus limits on the number of items may have led to omission of relevant factors. For example, individual-level factors such as IQ have been shown to influence children's resilience (Rutter, 1985). However, IQ levels were not easily measurable in this study and were thus excluded. Further, during the study design stage, factors were prioritized by their relevance to policy and interventions. For example, characteristics of the deceased parent may have been important to child

psychological health, but were not immediately modifiable by public policy or intervention, and were thus excluded from measurement in this study. Finally, potentially relevant factors such as intra-family stigma were not explored, as they were considered too complex for a quantitative study.

Limitations of a cross-sectional study:

There were limitations in the research design, which was retrospective with respect to bereavement, and cross-sectional, limiting capacity to determine whether AIDS-orphaned children experienced distress prior to orphanhood. Longitudinal study design with AIDS-orphaned children in South Africa is complicated by high levels of mobility and internal migration (Ansell & Young, 2004). However, there is potential for the future development if longitudinal data in demographic surveillance areas such as the Africa Centre for Health and Population Studies, Agincourt Health and Demographic Surveillance System, and longitudinal datasets such as Birth to Twenty (J. Pettifor et al., ongoing). Two longitudinal studies to date (both USA-based) have measured psychological outcomes for children before and after parental death (Forehand et al., 2002; Rotheram-Borus et al., 2004).

Four key limitations of the cross-sectional design are detailed at this point. Firstly, some risk and protective factors may have been highly relevant, but were unable to be measured due to the single-time point measurement. These included a number of parental factors which could only be measured prior to parental death, such as mental health state of deceased parent, early patterns of caregiving and parent-child relationship. Exploration of the mediational effect of these factors would require a longitudinal study of children pre- and post-orphanhood.

Secondly, in interviewing children only post-orphanhood, this study is unable to discriminate stages of high risk for emotional distress during the progression of parental illness and death. For example, particularly stressful periods may include parental HIV diagnosis, disclosure, parental illness or late-stage AIDS-illness. It is notable that time since orphanhood was not associated with any mental health outcomes. Children

bereaved in the past 6 months were excluded due to acute bereavement reactions and sensitivity of questionnaire items.

Thirdly, the cross-sectional study design does not allow us to determine causal mechanisms between AIDS-orphanhood, mental health outcomes and risk factors. For example, living on the streets was shown to mediate the effect of AIDS-orphanhood on likelihood of mental health problems. However, the study could not tell us the extent to which being AIDS-orphaned had contributed to the fact that children were living on the streets (ie rejected by families due to parental AIDS-illness, living on the streets due to multiple familial deaths). It was also unable to tell us whether mental health problems were results or precursors to children becoming streetchildren.

Fourthly, the cross-sectional design limits capacity to determine effects of reducing risk factors. For example, this study showed strong mediating influences of poverty on the relationship between AIDS-orphanhood and mental health. This strongly suggests that reduction of poverty has the potential to improve mental health amongst AIDS-orphaned children. However, it does not prove that reduction of poverty will have a causal effect of reducing already-existing mental health problems amongst orphans. Furthermore, it does not necessarily follow that poverty-reduction measures (such as school feeding schemes) would necessarily reduce likelihood of mental health problems, just that these are potentially important targets for intervention.

This study could not determine the effects of interventions. However, it aimed to provide indications of areas in which interventions could helpfully be focused. In order to determine causal relationships, and the effect of interventions in reducing psychological distress amongst orphans, rigorous intervention trials are required. One such trial is currently being planned in Kwa-Zulu Natal, with community-based randomized controlled evaluations of a range of interventions (Richter & Aber, 2007).

Rutter examines the evidence for environmental mediation effects, and research design requirements needed to provide rigorous tests of such effects (Rutter, 2005). He concludes that, whilst genetic influences play a major role in moderating environmental effects, environmental risks are both real and important. He highlights both family-level

and wider risks, such as socio-economic status and access to services. In cross-sectional studies, Rutter emphasizes the importance of controlling for other characteristics of individuals which may be associated with outcomes. The current study controlled for socio-demographic factors which were associated with orphanhood, and thus aimed to increase reliability of mediational analyses.

Limitations of cross-cultural psychology:

A broader and more conceptual, limitation of this study is the potential difficulties of using western psychological constructs and measurements in a different cultural context. This is part of much wider debates around the classification of mental illness per se, the tensions between western and non-western health systems, and post-colonial power relationships. The following discussion will touch only briefly on these contested and complex areas.

Kleinman (Kleinman & Good, 1985) and Kirmayer (et al., 1993) outline dangers of using Western psychological definitions in a non-Western context. They advocate, instead, the use of indigenous categories of dysfunction and distress. For children in particular, there is ongoing and unresolved debate around the use of western categories of trauma and distress (Dowdney et al., 2006), including the classification of post-traumatic stress disorder amongst children in the developing world (Boyden & Mann, 2000; Dowdney et al., 2006). In South Africa, several difficulties have been highlighted in using Western psychological or psychiatric constructs (Mzimkulu & Simbayi, 2006). These include the individualistic approach of Western mental health, which may have limited relevance in the context of African notions of community or 'ubuntu' (Mkhize). Mkhize further argues that research should take into account the availability of resources to address mental health problems: for example the lack of qualified mental health professionals willing or able to work in poor areas. Anthropological studies have highlighted the importance of beliefs around bewitchment in local understandings of HIV and AIDS (Stadler, 2007).

Swartz (2002) reports potential confusion for Black and Coloured Africans in the medicalisation of mental health, which is often conceptualized rather in spiritual, supernatural or theological terms. Responses to mental illness may also be framed in

terms of traditional beliefs and by traditional healers instead of western doctors (Ensink & Robertson, 1999). Indigenous or ‘culture-bound’ syndromes are a much-debated area in cross-cultural psychiatry, and are located within wider debates of emic versus etic and positivist versus relativist viewpoints (Bhui, Mohamud, Warfa, Craig, & Stansfeld, 2003; Cheng, 2001; Kleinman & Kleinman, 1985). In South Africa, there are arguments for the necessity of locating ‘psychological universals’ within African conceptualisations of psychopathology (Mkhize), and especially spiritual or magical causes of illness.

In Cape Town’s deprived settlements, a number of studies have explored the relationship between Western psychological and Black African conceptualizations of mental distress. Findings suggest methodological difficulties in the use of traditional definitions. In Khayelitsha, adults reported a range of, often somatic, manifestations of mental illness which differed from western symptomology (MacGregor, 2004). Ensink & Robertson (1996) interviewed traditional healers in Khayelitsha about classification of commonly-known children’s syndromes such as *Amafufunyana* (possession or bewitchment) and *ukuthwaza* (the process of becoming a healer, often including symptoms similar to psychosis). The study found that symptoms are not tightly or consistently circumscribed in these categories, and concluded that ‘an epidemiological approach is unlikely to be either feasible or valid’ p40). Swartz, also in Cape Town, found that labelling of African indigenous syndromes was primarily utilised by indigenous healers rather than lay people (Swartz, 2002). Furthermore, a study in Guguletu township (another of my research sites) found that it was not appropriate to inquire directly about indigenous syndromes, as respondents became anxious and were afraid to discuss phenomena such as possible bewitchment (Robertson et al., 1999). These studies suggest that the measurement of indigenous syndromes must be approached with caution, whilst recognising the importance of traditional approaches to health in South African society.

There are several arguments for the applicability of western psychological measurements in a South African context. Firstly, as practitioners, our objective is a reduction in children’s suffering. With such an objective, questions of indigenous versus western culture become less important. They are replaced by the questions of whether children are experiencing emotional difficulties, and how most effectively we can reduce those difficulties (Dyregrov, Gupta, Gjestead, & Raundalen, 2002). With caution, and with

sensitivity towards cross-cultural differences, it is possible to measure the extent of adverse child reactions. Further, it is possible to stringently evaluate the effects of any interventions, whether traditional, societal, or within western models (Dowdney et al., 2006).

Secondly, South African society is not able to be clearly compartmentalized into 'African' and 'Western'. Life in the urban townships of the Western Cape is a complex interplay of cultures. Influences include the legacy of apartheid health services, rural Eastern Cape, Sesotho and amaZulu culture, American media, traditional beliefs around health, and government messages around health, HIV and AIDS. Many township residents work in Cape Town, or in White or Coloured areas, and travel between areas is frequent. Many Black African townships (such as Langa) are in close proximity to areas inhabited by other racial groups. These factors suggest that a categorisation of urban Black African isiXhosa-speakers as distinct from Western culture would not accurately represent the more multifaceted reality.

Cross-cultural aspects were considered carefully in the study design stage. Extensive consultation was conducted with social workers at Cape Town Child Welfare, community-based organisations (Sinako Youth Clinic, Vukhuzakhe Orphan Project, Yizani drop-in centre, Elukhuselweni Halfway House) and academic experts such as Professor Brian Robertson (Ensink & Robertson, 1999), Professor Leslie Swartz (Swartz, 2002) and Dr Julie Carter (Carter et al., 2005). The qualitative stage aimed to identify risk and protective factors which may have been specific to local culture.

One issue that emerged from these stages was the importance of measuring somatic symptoms of emotional distress. The relevance of somatic symptoms in diagnosing psychopathology is a complex and contested area (De Gught & Fischler, 2002; Kirmayer et al., 1993). Evidence for the prevalence of somatisation of psychiatric symptoms amongst Black Africans is widespread but disputed (Okulate et al., 2004; Swartz, 2002). No studies could be found which explored somatising symptoms amongst Black South African children, but a recent anthropological study with adults in Khayelitsha found evidence of a range of manifestations of mental illness, including somatic symptoms such as whole body ache, waist-ache and painful neck veins (MacGregor, 2004). In

recognition of the potential relevance of somatisation, this study used a somatic symptoms scale from the Child Behaviour Checklist (Achenbach, 1992). However, this was largely unsuccessful, producing high scores across all groups, and correlating with no other scales. The failure of this measure was probably due to the confounding factors of inadequate sanitation, nutrition and healthcare, which resulted in all poor children reporting high levels of symptoms such as vomiting, diarrhoea and rashes. For example, 'Problems with eyes' was frequently endorsed on the somatic symptoms scale, but when elaborated on by children, was almost always related to the non-affordability of glasses for vision problems. It is likely that children in South Africa do experience some somatic symptoms of psychological distress, but that these were overshadowed by effects of poverty and limited access to healthcare.

Some further aspects of cross-cultural psychology were not predicted in the research design stage. These included bewitchment and witchcraft, which were frequently reported as both causes of parental death and as causes of children's distress. A small number of children also reported possession by 'tokoloshes' (demons). However, these factors were unable to be explored as risk factors, as they were volunteered by participants, and not measured amongst all respondents. It is suggested that these aspects be considered for inclusion in future research.

Factors for future analysis as indicated by this thesis:

A number of factors in children's lives were addressed in the questionnaire, but were not reported in the 6 major analyses of this thesis. These are important areas for future analyses and future research. One factor in particular will be analysed using this dataset: that of perceived social support (from caregivers, peers, school and others). Initial analyses showed group differences in total social support scores, and in some of the social support subscales, and associations between social support and mental health outcomes. It is important to be aware of the risks of method overlap with self-perceived social support (as with stigma), but this is an important and necessary area for analysis.

Other factors were indicated by this dataset to have relevance for orphan mental health, but require more sensitive or detailed measurement in future research projects. They

include the following: children acting as young carers for younger children in the household, children acting as a young carer for an unwell adult in the household (in the past or currently), access to services in the home, access to support groups and counselling, and age of caregiver.

Suggestions for improvements in future research:

There are a number of improvements which could be made in future research on the same topic. Firstly, future research could attempt to address the limitation of unknown HIV status of child participants, by including anonymous HIV testing. This was not included in the present study due to cost implications and ethical complexities. However, anonymous testing has been successfully included in studies such as those in the Africa Centre and Agincourt. Secondly, anonymous testing would also take place with surviving parents and with other caregivers of children, in order to determine whether HIV status of caregivers affected child mental health. Thirdly, it is important to establish as clearly as possible the HIV status of deceased parents. In the continuing absence of reliable clinical records, an alternative to the verbal autopsy method would be the use of a longitudinal dataset, using a clinical sample of HIV+ parents, and following the children through to post-bereavement. This would have its own limitations – for example it would limit the sample to HIV+ parents who are aware of their status and are seeking treatment – but the longitudinal design would allow information regarding mental health and environmental factors for children at various stages of parental illness and death.

Study findings in the context of study limitations:

How reliable are the findings of this study in the context of the limitations presented by the sample group studied, and the research context? A number of the methodological limitations were inherent in any community study of AIDS-orphanhood in South Africa. These included the lack of psychological scales validated in South Africa, lack of clinical data to determine cause of parental death, contamination of the control groups (who were likely to have had other family members infected with HIV/AIDS) and reliance on youth report to prevent systematic bias of poor caregiver reporting for vulnerable groups.

Whilst these do present questions around the reliability of findings, the potential effects of these limitations are mitigated, as discussed below:

Standardised scales: The study largely used continuous mental health scores. Where western-established cut-offs were used, proportions of children in the clinical range for the population-weighted sample were close to estimates for the South African population, suggesting that these may be viable tests of psychological problems in a South African context.

Cause of death: The use of the verbal autopsy method (whilst necessarily having a margin of error) allowed a clinically-based determination of parental symptoms. A high number of orphaned children were excluded from the sample (more than 10% of orphans) due to lack of clarity regarding symptoms, or symptoms of only one or two of AIDS-defining illnesses. When results from this group were analysed, they typically fell between the AIDS-orphaned and other-orphaned groups in scores for psychological problems, stigma, and socio-demographic factors. This suggests that the excluded group represented some AIDS-orphaned and some other-orphaned children.

Contamination of control groups: In South Africa, it would be impossible to find a control group of children within low-income areas, who were not affected by AIDS in some way. But it is important that the control groups in a South African study are representative of the reality of the current situation. All poor children now grow up in the context of HIV and AIDS, and it is important to distinguish whether AIDS-orphanhood adds another level of vulnerability in this already-vulnerable context.

Reliance on youth report: This study aimed to include children living in a range of caregiving arrangements relevant to the situations of AIDS-orphaned and other-orphaned children in South Africa. This necessarily included child-headed and youth-headed households, children living on the streets and children living with very unwell caregivers. In these circumstances, caregiver and teacher report is not reliable or possible for many children. However, the study used standardised scales with strong psychometric properties, which had all been previously used with similar populations in the Western Cape. Where inter-rater reliability was tested (see Chapter 5), it showed good inter-rater

and cross-time reliability for child report. Thus I argue that these particular limitations were inherent to studying the particular sample group of AIDS-orphaned and other-orphaned poor children, and that as far as possible the limitations of youth self-report were mitigated through the study design.

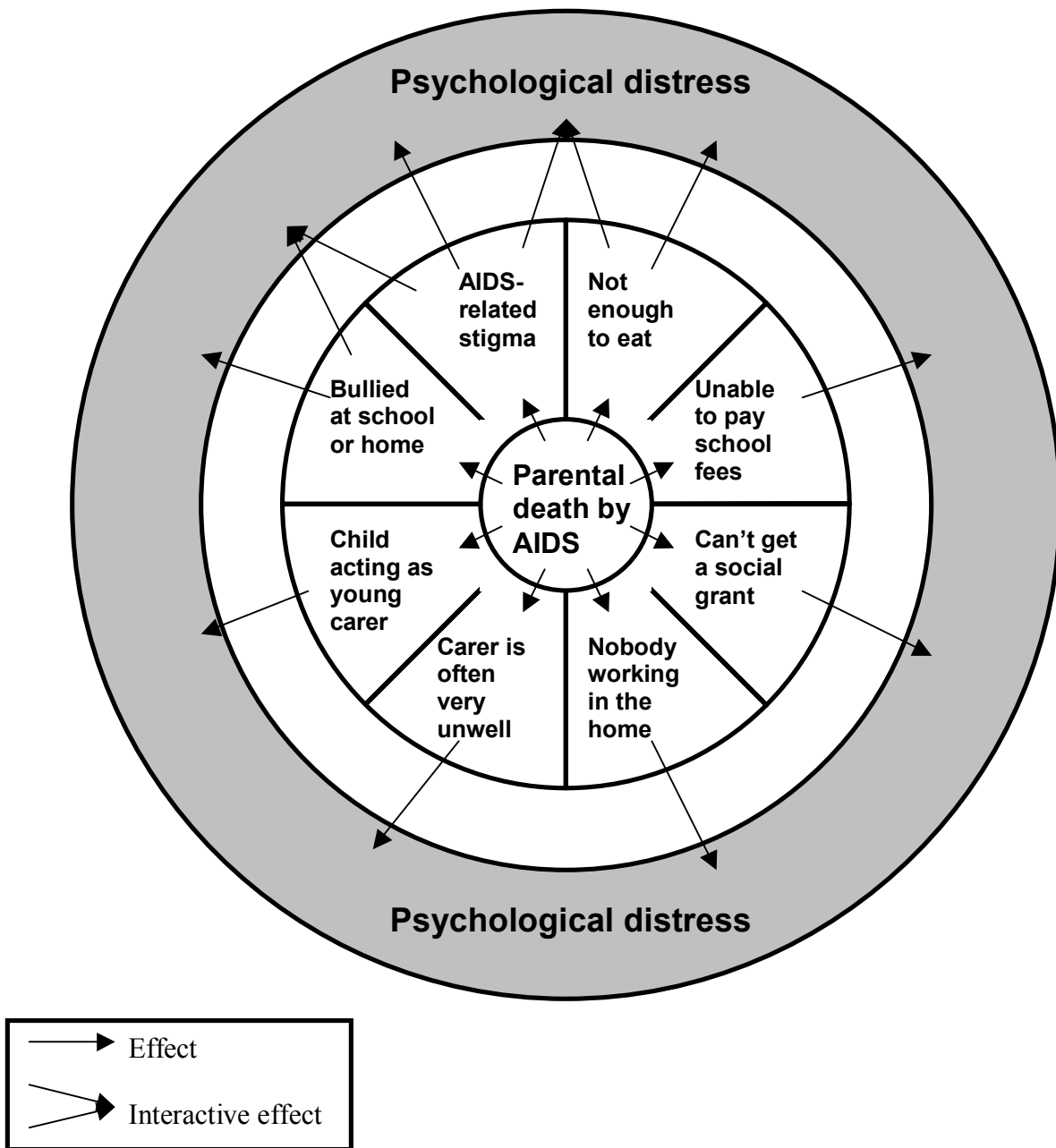
Sample group and cross-sectional design: Wider limitations included the amaXhosa sample group and the cross-sectional study design. The focus on one ethnic group was primarily for reasons of practicality: this was a single, D.Phil study on a small budget. The choice of ethnic group was the most appropriate for the Western Cape, and isiXhosa is the first spoken language of 27% of the South African population. However, it is clear that such a sample group limits the generalisability of study findings to urban, isiXhosa-speaking children. Future and improved studies should include other ethnic and population groups within South Africa, and should extend to rural areas. The use of cross-sectional rather than longitudinal design was also based on the limited fieldwork time available for a D.Phil, and extremely difficult research conditions. I argue that longitudinal designs, with large sample sizes, are essential to further our understanding of the effects of parental illness and orphanhood. However, the use of two control groups, and extensive controlling for socio-demographic co-factors, increases our confidence in the reliability of the mediating effects of risk factors identified in this study.

Summary: It is essential to acknowledge the limitations of this (and any) research study (Rutter, 2000). However, the study also shows strengths. It compares AIDS-orphaned, other-orphaned and non-orphaned children, thus allowing an isolation of the effects of AIDS-orphanhood from orphanhood more generally. It uses standardised, reliable scales. It includes extensive piloting and qualitative stages, to ensure as much cultural relevance as possible. Finally, its findings present clear indications of potential areas for further research, and areas of potential intervention to improve outcomes for AIDS-orphaned children.

7.3 Theoretical implications

The findings of the current study, as presented in Chapter 6, have implications for extending and supporting the theoretical framework described in Chapter 1. Figure 44 shows an outline representation of the relationship which this thesis has identified, between parental AIDS-death, risk factors and mental health outcomes. Exemplar mediational and interactive effects are shown. Other mediational and interactive effects may be identified in future research, or were not measured in the current study.

Figure 44: A model of AIDS-orphanhood, mental health and mediating factors



Environmental influences on child mental health: The findings of this study provide strong evidence for the influence of environmental factors on children's mental health (Rutter, 1981, 2005). Specifically, they support evidence of negative impacts of highly stressful situations during childhood (Hoge et al., 1996). Implications from this study for theories regarding children's resilience are more limited, as the study design and sample group precluded measurement of genetic or biological influences. This meant that interactions between personal characteristics and environmental factors could not be examined in depth. Future research could usefully explore the impacts of both personal resilience factors and environmental factors on the mental health of AIDS-orphaned children.

This thesis contributes to our understanding of how children respond to parental death in a context of additional stressors associated with a debilitating and highly stigmatised illness. For example, PTSD levels were comparable to those found in children experiencing war (Thabet, Abed, & Vostanis, 2004) and sexual abuse (Rowan & Foy, 1993).

The present study also adds to emerging evidence suggesting that orphanhood may adversely affect a range of child outcomes, including education (Case et al., 2002), younger sexual debut (Cakwe, 2007) and risk of contracting HIV (Operario et al., 2007). New evidence from Zimbabwe shows orphaned children to be experiencing more diarrhoeal illness, respiratory infection, and are more likely to be stunted or underweight than non-orphans, even when adjusting for extreme poverty (Watts et al., 2007). An ongoing study in Brazil shows high levels of reported stigma and discrimination towards AIDS-orphaned children, including within-family stigma (Paiva, Ayres, & Frana, 2007). Initial fears of an unsocialised 'delinquent' generation of orphans (eg. Barnett & Whiteside) have not been substantiated by these and other research findings. However, this study contributes to increasing international evidence that AIDS-orphaned children are at heightened risk of mental health problems, and may experience particularly debilitating symptoms of depression, post-traumatic stress and suicidal ideation.

Relationships between stressors and environmental factors: The findings of this thesis also add to our theoretical understanding of the relationship between poverty, major life stressors and child mental health. It adds to developed world evidence which shows increased poverty after parental death to be associated with increased levels of child post-traumatic stress (Stoppelbein, 2000). Thus poverty may act as a mediating factor when children are exposed to bereavement, or may lead to exposure to other risk factors. Studies on adolescent delinquency (Sampson & Laub, 1994) and internalising problems (C. Graham & Easterbrooks, 2000), suggest that the structural context of poverty inhibits family processes, and thus has indirect effects on child psychological outcomes. Future research with AIDS-orphaned children could usefully examine the relationships between family processes and poverty.

There is little available theory regarding the mediating relationship between stigma and AIDS-orphanhood on mental health outcomes for AIDS-orphaned children. However, this study adds to the developing body of theory regarding the interactions between stigma and mental health for HIV+ people (Holzemer & Uys, 2004; Maughan Brown, 2004). This thesis has shown that AIDS-related stigma is experienced more severely for AIDS-orphaned children than for other children, thus supporting wider theories of ‘courtesy stigma’ towards family of a stigmatised person (Goffman, 1963). It also shows that stigma may act as a mediating factor when children are exposed to bereavement. However, what the present study cannot show is the relationship between AIDS-related stigma, mental health, and having a parent who is alive but HIV+ or AIDS-unwell. Qualitative research suggests that this may be similar to, or more extreme than, the stigma experienced by AIDS-orphaned children (Richter et al., 2006; Strode & Barrett Grant, 2001). Thus, the cross-sectional nature of the present study allows only a ‘snapshot’ of distress associated with AIDS-related stigma for orphans. Theory suggests a strong likelihood that this relationship of heightened stigma is something which begins at an earlier stage in the parental illness-death cycle (Armistead et al., 2001). Future research is necessary to quantitatively determine whether this is true, and to further determine the effects of such stigma on the mental health of pre-orphaned children.

Analyses presented in Chapter 6 also add to our theoretical understanding of the impacts of caregiving on orphaned children. Maternal deprivation theory focused on attachment

to a single, primary caregiver in the early years (Bowlby, 1951). This lacked relevance to African family structures of multiple caregivers for children (Young & Ansell, 2003). Studies with institutionalised orphans have suggested that poor-quality orphanage care has negative impacts on psychological health (Kaler & Freeman, 1994). Studies with war-orphaned children have found more psychological distress amongst orphans, but ameliorated by warm, supportive residential care settings (Wolff & Fesseha, 1999). Again, institutionally-based approaches to orphanhood lacked relevance to the situation of current South Africa, where social policy has strongly discouraged residential care settings for children, and only a tiny proportion of orphans are in residential care.

The present study explores orphanhood within the sub-Saharan African tradition of extended family care (Ankrah, 1993), and finds few differences between types of family care, but higher distress amongst children living on the streets. The study also adds to developed world literature on psychological effects of children acting as young carers, which find both distress and sense of achievement (Aldridge, 2006). Increasing numbers of children are experiencing orphanhood and caring for adults suffering from AIDS. It is essential that future research expands our understanding of the processes and mediating effects of different types of orphan care in the context of AIDS.

There may be theoretical implications in understanding of mechanisms within risk factors; i.e the ways in which risk factors may impact on mental health through other risk factors. For example, caregiver illness was found in the current study to be a mediator of child psychological well-being. In developing world studies, the relationship between caregiver illness and child mental health is thought to be moderated by factors such as the illness' effect on parental functioning, family functioning and parent-child relationships. Future analyses of this dataset, or of other datasets, could usefully explore further the sub-mechanisms within mediators of AIDS-orphanhood and mental health.

An ecological model of risk and protective factors: Bronfenbrenner's (1979) ecological model conceptualizes a range of risk and protective influences which take place in different spheres, or levels, of a child's life. Bronfenbrenner's model was shown to map effectively onto the multiple life circumstances associated with experiencing parental AIDS-death. The present study was not able to examine some of the wider factors

identified by Bronfenbrenner, such as macrosystem and chronosystem levels. However, the study may identify a more complex set of connections. For example, parental bereavement by AIDS is identified as the major stressor for AIDS-orphaned children. But AIDS-orphanhood itself is more than experiencing parental death by a debilitating illness. AIDS-orphanhood seems to be a construct resulting from an accumulation of factors associated with having a parent die from AIDS. These associated factors, in a range of ecological levels, then function as risk factors for orphan psychological problems. This study suggests that the removal or mitigation of the damaging factors associated with family AIDS-death might mitigate the effects of AIDS-orphanhood on mental health (see Figure 1). The study also suggests possible positive effects of environmental factors. For example, sufficient food acted as a protective factor, as did school attendance and access to social security. Having a healthy caregiver may also be protective. Possible implications for intervention are discussed in Appendix 11.

Cumulative models of risk: This study also adds to our theoretical understanding of the impacts of interacting or cumulative effects of factors on child mental health. Rutter identifies extreme risks to child mental health as arising from multiple, cumulative adversities (Rutter, 2000). No studies were found which explore cumulative risk effects in the developing world. This study supports evidence from the developed world that risk factors interact with each other and, by interacting, have cumulative effects which are greater than those of single factors individually (Kolvin et al., 1990; Sameroff et al., 1997). This study has not been able to explore the competing theories of a linear or threshold model of cumulative risk (Appleyard et al., 2004), due to the strength of mediational effects of risk factors such as stigma. Sobel tests showed stigma to fulfil criteria for full mediation between AIDS-orphanhood and psychological scores on a number of scales. This would preclude the testing of a threshold model.

Conclusion: It is hoped that this thesis has contributed to the development of wider theory regarding orphans and vulnerable children, and of the position of AIDS-orphanhood within that group (Desmond et al., 2003; Meintjies & Giese, 2006; Richter et al., 2006). The findings of the present study can tell us about one aspect of the well-being of AIDS-orphaned children: mental health. In order to provide a reliable evidence-base, the findings of the present study must be added to longitudinal evidence of mental health of

children with HIV+ parents, and evidence from a wider set of population groups than urban, amaXhosa children. It is also essential that evidence on mental health is combined with reliable evidence on other aspects of child well-being, such as education, physical health, prevalence of abuse and child development.

7.4 Policy Implications of study findings

As stated by Professor Renfrew Christie (University of the Western Cape):

‘This study provides evidence on which to base policy by suggesting what is to be done and why it is to be done. But it does not provide evidence of when it is to be done (ie time priority of the different actions), who is to do it (ie government, NGOs, family, local or national departments), where it is to be done (ie city, rural, specific areas) or, crucially, how it is to be done...You can only give a range of options as to how, when, where, by whom and at what cost from whose budget. These are all pure speculation as far as your data are concerned and must be clearly labelled so: they cannot be answered from your research. Do give the options; but be clear that you have no evidence-base for choosing between them. All you can say from this evidence is that x must be done, and why the data demand it’. (Personal communication, March 2007).

In recognition of the fact that any policy recommendations would be beyond the findings of this study, tentative suggestions for implications have been included in Appendix 11.

7.5 Recommendations for future research

There is a clear need for further research regarding the mental health of AIDS-orphaned children, both in Sub-Saharan Africa, and in areas with emerging AIDS epidemics such as Eastern Europe and India.

- There are currently only two longitudinal research studies of AIDS-orphaned children, both of which are USA-based (Forehand et al., 2002; Rotheram-Borus et al., 2004). Longitudinal studies in the developing world are required in order to determine

mental health for children at different stages in the parental illness-death continuum. The group of children who are living with AIDS-unwell parents may be particularly important to study further (Richter et al., 2006). It is important that we understand more about this, in order to enable informed timing of interventions.

- Research is needed on a larger scale than was possible in the current study. Present findings may not be generalisable to rural areas, or to population groups other than amaXhosa.
- Large-scale, rigorous quantitative research is also needed to determine effects of AIDS-orphanhood on a wider range of child outcomes than mental health. These include early childhood development, nutritional status, growth, physical health, risk of HIV-infection and educational progress. It is important that this research is able to distinguish between AIDS-orphanhood and orphanhood by other causes. Studies exploring some of these areas have been completed (Case & Ardington, 2005) or are in planning stages (Cortina, Stein et al, Kulani Child Health and Resilience project). These studies may be especially effective in demographic surveillance areas such as the Africa Centre or Agincourt.
- In-depth studies are required to determine mechanisms by which AIDS-orphaned children are experiencing reduced access to services aimed at vulnerable children. These include social security, education and food security.
- Further studies are required to explore the influence on mental health, of factors which were not able to be examined sufficiently in this study. These include HIV+ parent-child relationships (Brandt et al., 2006; A. Stein et al., 2005), and intra-family responses to HIV/AIDS and orphanhood. Specifically, further and more rigorous studies are required to explore the impact and mechanisms of stigma towards AIDS-orphaned children, within families, schools and the community. These may require both in-depth qualitative and large-scale quantitative research, especially for highly sensitive areas such as intra-family stigma.

- This study has identified a range of mechanisms by which AIDS-orphanhood may be impacting on mental health, such as poverty, stigma and caregiver illness. Further research, or further analyses of this data, may be able to explore the possibility of these factors functioning as mechanisms of each other. For example, poverty may exacerbate caregiver illness, which may in turn impact on children's mental health.
- Ideally, future research would also allow investigation of gene-environment interactions in children's responses to risk situations in the context of HIV/AIDS. For example, children with a particular gene may be at higher risk than others, of behaviour problems following experience of abuse (Caspi et al., 2002). This is a potentially important area of investigation.
- Rigorous and controlled intervention studies are required in order to determine the effectiveness of policies and services. Ideally, these would use randomised community-based controlled trial designs, with sufficient follow-up time to determine sustainability of intervention effect. These trials would also usefully be supplemented with qualitative evidence, in order to address concerns of stigma relating to targeted interventions. A study of this kind is currently being planned in Kwa-Zulu Natal (Richter & Aber, 2007)

7.6 Background and plan for National Survey

The dissemination stage of this research included feedback to a range of NGOs, community-based organisations, and government departments (please see Chapter 5 for a detailed account of this stage). Dissemination also included meetings with the Minister of Social Development (Dr Zola Skweyiya) and the Director-General of Social Development (Mr Vusi Madonsela).

The Minister and Director-General expressed the desire to use the policy implications of this study in order to improve DSD services for AIDS-orphaned children. However, they had two key concerns regarding the use of the current study to argue for treasury funds. Firstly, that the current study is limited to the urban Western Cape. This is a comparatively highly-resourced area in a comparatively highly-resourced province of

South Africa. It is likely that circumstances and psychological problems for orphans would be more severe in poorer, more rural areas. Secondly, they were concerned that the current study is limited to mental health. There is little available evidence on risk and protective factors for other key outcomes for orphaned children, such as education, physical health and child development.

The Minister proposed that the current study be extended and expanded into a national study of outcomes amongst AIDS-orphaned children, and of policy-relevant risk and protective factors. An initial proposal was developed, and was subsequently refined and adapted in a number of meetings with senior DSD officials: the Director-General, Deputy Director-General of Integrated Development Vuyelwa Nhlapo, Chief Director of HIV/AIDS Dr Connie Kganakga and Chief Director of Children, Youth and Families Dr Maria Mabetoa.

A draft outline plan for a national survey of AIDS-orphanhood, as presented at the request of the Ministry of Social Development in March 2007, and adapted after further collaboration with the Ministry in June 2007, is included as Appendix 10. This study would aim to address the following questions:

- 1) What is the required state response to the dramatic increase in the number of child orphans per head of population?
- 2) What different response is required (if any) because the vast bulk of the child orphans in 2020 will be HIV/AIDS-caused?

The proposal uses the UN definition of orphanhood, which is followed by the South African Children's Act (2007): Children under the age of 18 with one or both parents deceased (UNAIDS & UNICEF, 2002). It will compare AIDS-orphaned, other-orphaned and non-orphaned children, matched by close location. The verbal autopsy method will be used, unless a more reliable alternative can be found. The study will expand the age-group of children, including groups of 0-5 year-olds, 6-10 year-olds and 11-17 year-olds, with age-appropriate measurement tools. The study also expands the scope of measured indicators amongst children. These would include physical health, mental health, child

development and educational outcomes. All interviews would be conducted by trained, community health workers in the child's first language.

The research aims to collect a nationally and provincially representative sample, including all 9 provinces, and a range of urban and rural, formal and informal areas. In order to capture groups which are readily missed in a community sample, there will be additional purposive sampling of streetchildren, child-headed and youth headed households. DSD were particularly concerned to include samples of children in a range of caregiving arrangements, and this may require additional sampling of children in institutions: different types of orphanages, children's homes and in prisons.

Key outcomes and indicators:

Key outcomes	Measurement
EDUCATION School enrolment and attendance Educational achievement	School registers Teacher report Achievement; grade repetition
PHYSICAL HEALTH AND HIV Child Development, Malnutrition HIV status, health status	Examination by trained community health workers. Height/weight etc Prevalence of HIV, TB, diarrhoea, lower respiratory infections and malnutrition (Bradshaw, Bourne, & Nannan, 2003).
MENTAL HEALTH Depression, PTSD Conduct problems, substance abuse	Standardised, validated psychological questionnaires: CDI, CBCL, SDQ, Child PTSD Checklist (child report).

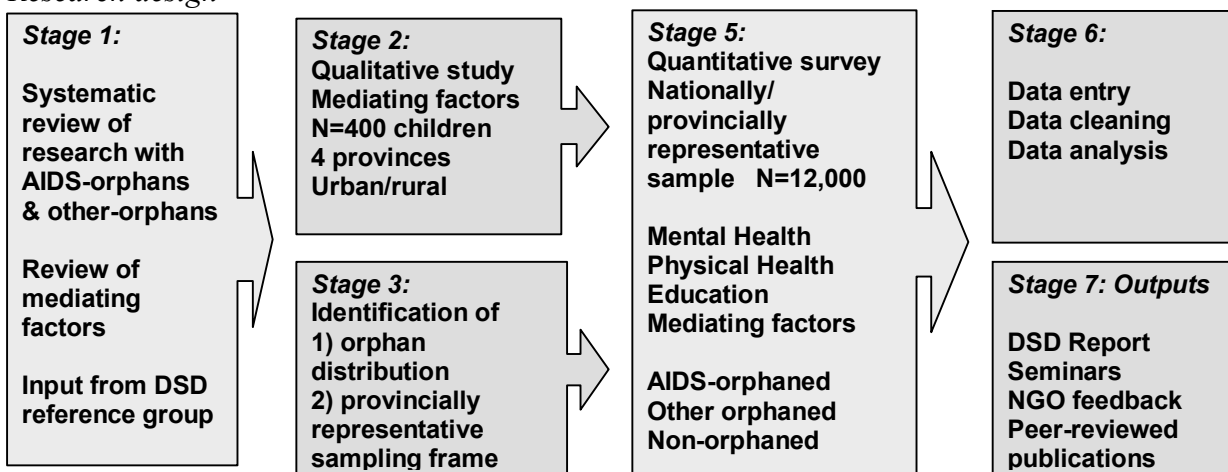
Mediating factors:

For educational and physical health outcomes, identification of mediating factors will follow the process used in the current study of mental health. Potential mediating factors will be identified by 1) Systematic review of mediating factors for physical health and education, identified by studies with AIDS-orphaned children; 2) Wider review of mediating factors for physical health and education, amongst vulnerable children and children sharing some similar life experiences to AIDS-orphaned children; 3) Identification of policy and intervention factors by Government departments and NGOs

working with AIDS-orphaned children; 4) Qualitative research with AIDS-orphaned children and their caregivers, to identify participants' perceptions of risk and protective factors which may be specific to South African orphans, or may not have emerged from the review; 5) Mediating factors will then be tested against physical health and educational outcomes in the quantitative stage, and relationships determined using multiple regression analyses and mediational tests.

Potential mediating factors would include those identified in the study which has been the subject of this thesis, such as food security, household receipt of social security, school attendance, employment within the household, AIDS-related stigma, caregiving arrangement and caregiver illness. Further potential factors identified by the Department of Social Development include African-specific cultural practices around parental death, extended family and community support.

Research design



Two main options are outlined for a sampling strategy. Only one is a representative sample, but DSD suggested that financial limitations may require a non-representative option.

1) A nationally and provincially-representative sampling strategy

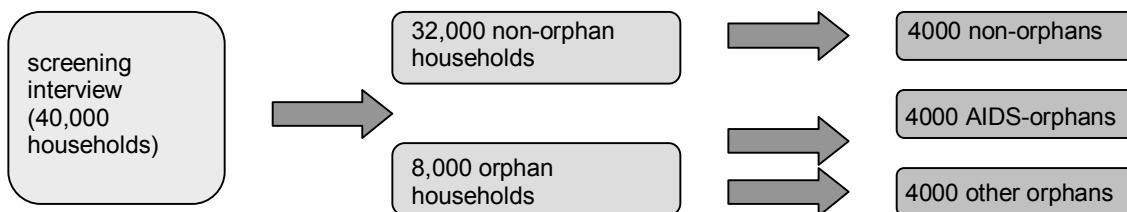
A nationally-representative or provincially-representative sample would allow for identification of priority intervention zones on a small area level. The sample would include AIDS-orphaned children, matched with other orphans and non-orphans. This

would allow identification of location density of AIDS-orphaned and all-orphaned children, and inform some area-based targeting of interventions, as well as exploring some mediating factors in orphan outcomes. This option would involve a 2-stage sampling strategy, based on estimates of proportions of orphaned and AIDS-orphaned children in South Africa. Approximately 18% of all children were orphaned in 2005 (Statistics SA, 2006a), and this is estimated to rise to 20% by 2008. Approximately 50% of these orphanhoods are attributable to HIV/AIDS (UNAIDS, 2006).

A nationally-representative study would require all 9 provinces and a larger sample size than non-representative sampling options. A provincially-representative sample would require a larger sample size than a nationally-representative sample. It would also require the identification and stratification of a national sampling frame. I would recommend an additional purposive sample of streetchildren, child-headed and youth-headed households, and children living in children's homes and in prison.

Suggested 2-stage quantitative sampling strategy for national/provincial sample:

- 1) An initial screening interview of 40,000 households to determine firstly, whether there is a child living in the household, and secondly, whether there has been a death of a parent of any child living in the household. Of non-orphan households with children, 20% would be randomly selected for inclusion as a non-orphan control group
- 2) For an estimated 8000 orphan households (from 40,000 initial, based on GHS data), a full interview would be conducted with one randomly-selected child (4000 AIDS-orphaned, 4000 orphaned by other causes)



2) A non-representative sampling strategy

A non-representative strategy would not aim to produce information regarding areas of particular need within South Africa, but would attempt to include children in a range of situations which are broadly indicative of the orphan population in South Africa. This

could include random selection of wards, with randomised school sampling within wards. Additional community sampling would capture children not attending school, streetchildren, children living in children's homes and in prison. This strategy could take place in all, or a limited number of provinces, and would allow for a range of formal/informal and urban/rural. GHS (2005) data suggests 4 provinces of Kwa-Zulu Natal, Eastern Cape, Gauteng and Limpopo. However, this method would not provide an estimation of the extent of need between provincial or within the national populations.

Current plans

The proposal outlined above is still in a process of refinement with the Ministry of Social Development and the DSD Research Reference Group. It is envisaged that the bid will go to tender, or will be externally funded and commissioned to Oxford University. Within government, the process and timescale remain unclear. However, the presence of ministerial commitment and continued collaboration of senior officials do suggest that the South African government is seriously planning a wider programme of research. Perhaps more importantly, the South African government (or departments within government) are taking seriously the problem which the current thesis has identified: the heightened mental health needs of AIDS-orphaned children.

Figure 46: Email from the Department of Social Development

From: ["Malega Kganakga" <MalegaK@socdev.gov.za>](mailto:MalegaK@socdev.gov.za)

To: "Lucie Cluver" <lucie.cluver@green.oxford.ac.uk>, ["Vuyelwa Nhlapo" <VuyelwaN@socdev.gov.za>](mailto:VuyelwaNhlapo@socdev.gov.za), ["Maria Mabetoa" <mariam@socdev.gov.za>](mailto:mariam@socdev.gov.za)

Date: Wed, 13 Jun 2007 16:26:17 +0200

Dear Lucie,

Thanks for the proposal. I will look at it today and give feedback to the team on my inputs as soon as they are back next week. Once more congratulations on the award you got at the conference for the paper that reflected scientific rigor. It was really a good paper that followed good scientific research methodology. I will be sharing the information with the team.

Connie Kganakga

Dr Connie Kganakga
Chief Director: HTV/ATDS

7.7 Conclusions

This study has largely achieved what it set out to do. It has established the existence of higher levels of psychological problems amongst AIDS-orphaned children in Cape Town, compared to other orphans and non-orphans. It has found risk and protective factors with strong mediational effects. Many of these mediating factors have direct implications for state policy and NGO interventions. The study included 1200 children in total, and is the largest in the world to examine risk and protective factors amongst AIDS-orphaned, other-orphaned and non-orphaned children. It used established methodologies and standardised questionnaires. It provides an evidence-base for the mental health effects of AIDS-orphanhood in Cape Town. It also contributes to our understanding of the effects of AIDS-orphanhood and orphanhood more generally, on children in Southern Africa.

The study has been conducted according to high standards of ethical research. Free informed consent was obtained from all participants and caregivers, and interviews were child-friendly and child-focussed. Participating schools and NGOs were consulted during the research planning stage, received capacity-building training during the fieldwork stage, and were provided with verbal and written feedback on study findings.

The study has published five papers in peer-reviewed journals, with three papers currently under review. The study findings have been presented to the 2007 South African AIDS conference and the 2007 AIDS Impact Conference. It has also been presented at seminars at the University of Cape Town, Oxford University (Department of Psychiatry), the University of the Western Cape (Department of Social Work) and to researchers and development staff at the HSRC Cape Town, Durban and Pretoria. Presentations are forthcoming at Yale University (Centre for International Research on AIDS) and Columbia University (HIV Center for Clinical and Behavioral Studies).

It is hoped that the study has contributed to our broader theoretical understanding of the impacts of major life events on child psychological health. This study measured psychological distress amongst a large sample of children who were all living in circumstances of poverty and urban violence. Within this group, children who had experienced parental death by AIDS were at particular risk for psychological problems,

and this risk was mediated by a range of environmental factors associated with AIDS-orphanhood. Thus even in situations of multiple overlapping traumatic experiences, we can determine clear mechanisms by which the presence of one environmental risk mediates the effect of another.

This study also contributes to the growing body of empirical evidence showing psychological consequences of mass parental bereavement during circumstances such as war and terrorism (i.e Barenbaum et al., 2004). It is important that empirical research, particularly in the developing world, disentangles the effects on children of concurrent traumas (Luthar et al., 2000). Poverty, stigma and caregiving may act as mediating factors when children are exposed to AIDS-related bereavement, or may lead to exposure to other risk factors which impact on mental health. Determining direct and indirect effects of mediating variables may require more complex path analysis strategies.

Beyond its academic contribution, the primary focus of the study was to provide information to NGOs and policy-makers, to inform services for vulnerable children. The study findings have been presented to 30 NGOs and schools in Cape Town, in order to directly inform their ongoing work with AIDS-orphaned children. Findings were also presented to the National Minister of Social Development and the Director General of Social Development. Proposals are underway for a scaling-up of the current study into a national survey of AIDS orphanhood.

This study has shown that amongst isiXhosa-speaking children in the urban Western Cape, AIDS-orphaned children present with more psychological problems than other-orphans, and non-orphans. Findings have also shown that specified protective factors (or the reduction of risk factors) are very likely to eliminate most, if not all, of the differences in mental health problems. Children orphaned by AIDS are made more vulnerable to psychological disorders by a range of factors such as poverty, caregiving arrangements, stigma and reduced access to education. The likelihood of AIDS-orphaned children experiencing these risk factors may be exacerbated by the circumstances surrounding parental AIDS-death and illness. These findings carry major implications, and suggest clear policy and intervention routes to improving psychological well-being of AIDS-orphaned children in South Africa.

But there is still much to be done. There is an unambiguous need for further research. This should include further studies of outcomes for AIDS-orphaned children, amongst a wider geographical range and different cultural groups. It should also include in-depth longitudinal studies of impacts of different stages of parental illness and orphanhood. Studies should explore mechanisms by which AIDS-orphaned children are experiencing reduced access to services such as social security, education and feeding initiatives. Finally, there is an urgent need for rigorously-evaluated intervention trials, to determine the effectiveness of services for AIDS-orphaned children.



Figure 47: Old Crossroads

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Risk and Protective Factors for the
Psychological Well-being of Children
Orphaned by AIDS
in Cape Town, South Africa

APPENDICES

Lucie Dale Cluver

Green College, Trinity Term 2007

*Thesis for the degree of D.Phil in Evidence-Based Social
Work in the Social Sciences Division at the University of
Oxford*

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Appendix 1: Ethical Protocol: Oxford University

DEPARTMENT OF SOCIAL POLICY AND SOCIAL WORK

DEPARTMENTAL RESEARCH ETHICS CHECKLIST

NAME *Lucie Cluver*

DEGREE *PRS/ D.Phil*

TITLE OF DISSERTATION TOPIC

Mental health, risk and protective factors amongst children orphaned by AIDS in South Africa

BRIEF DESCRIPTION (up to 150 words)

This research aims to conduct the first large-scale research study in the Western Cape of South Africa to investigate the mental health of, and risk and protective factors for, non-infected children orphaned by HIV/AIDS. This follows a pilot study in 2002 of 60 orphans and matched controls. The research questions fall into two sections.

1) Investigating the mental health of orphans compared to a control group of non-orphaned children. This aims to a) determine whether children orphaned by AIDS are suffering from more mental health difficulties than non-orphaned children, and b) find out in more detail the phenomenology of mental health problems which orphaned children may be experiencing. Within this, we hope to explore further the possibility of Post-Traumatic Stress Disorder, as was suggested in our pilot study findings.

2) Investigating risk and protective factors which may affect mental health for orphaned children. Within the orphan group, we will look at the effects of specific risk factors, such as caregiving arrangements, stigma and age at orphanhood.

Both quantitative and qualitative research methods will be used. Results from the two sections will be combined during the statistical analysis stage of the research, in order to determine the effects of specific risk and protective factors on different mental health difficulties.

It is hoped that the findings of this study will help to inform future interventions and policy for orphans. Research is needed in order to determine whether orphans are suffering from psychological difficulties, and which difficulties they are experiencing. Further information is needed in order to increase knowledge around protective factors for orphans, in order that policy interventions can be targeted most effectively.

METHODS TO BE USED IN THE STUDY – tick all that apply, and give details

Literature review	x
Interview with participants (i) structured (ii) unstructured	i) x
Questionnaire (i) postal	iv) x

(ii) telephone	
(iii) computer	
(iv) face to face	
(v) group	
Participant performs verbal/paper& pencil/computer based task/ test	x

Have you sought appropriate advice about your research methods (eg statistics)?

Yes, in both the UK and South Africa

RECRUITMENT OF PARTICIPANTS

Will the study require individual participants? YES

If so, how will participants be recruited? (how will they be identified, selected, approached?)

Orphaned children

Children will be recruited through the Cape Town Child Welfare Society (children both with allocated social workers and awaiting allocation), individual schools (already agreed with School Principals and HIV/AIDS co-ordinators) and the Planned Parenthood Association Child-Headed Household Project (already agreed).

Control (non-orphaned) children

Where orphaned children are attending school, control children will be recruited as the next child in the alphabetical register of the same age and gender, who is not known to be an orphan.

Where orphaned children are not in school, control children will be recruited by randomly selecting a non-orphaned child living in close proximity to the orphaned child's original home. This selection will be made through the community groups affiliated to the Cape Town Child Welfare Society.

(Will they be recruited as NHS patients or staff? NO

If YES, have you made an application to an NHS Ethics Committee?)

INFORMED CONSENT

What arrangements have you made to obtain informed consent from participants?

Following guidelines set out by the Medical Research Council of South Africa, and used in our 2002 pilot study, written consent will be obtained from both children and their guardians.

In the case of child-headed households and children living in street shelters, consent will be obtained from the child and the child's social worker, non-resident caregiver or shelter social worker.

In light of poor literacy levels, the study will also be explained verbally to all participants and caregivers, and verbal agreement will be obtained in addition to written consent.

Consent forms will be in easily-understandable form and will be provided in the participants' first language (whether Xhosa or English). Information sheets describing the study will also be supplied, and these will be talked through with all participants.

Does the study involve participants whose ability to give free and informed consent might be in question?

Children under five? *no*

Children/ young people <18? *yes*

People with severe learning disabilities? *no*

People with physical or mental impairment? *no*

People who are not fluent speakers of English? *yes*

If YES to any of these groups, how will you gain consent from them, and/or from parents/ carers/ guardians as appropriate?

See above. All consent forms and explanations will be in Xhosa, both verbal and written consent will be obtained. All explanations will be at a developmentally appropriate level for children (these have already been tested in the pilot study).

How will you provide information about the study to participants?

Using Xhosa information leaflets and full explanations by Xhosa-speaking interviewers

What opportunities will participants be given to refuse to participate?

Interviewers will explain to children (in their first spoken language) that they can refuse to participate in the research at any point, and that this will not have any negative effects for them. Children who refuse to participate, or who stop the interview will still receive certificates, refreshments and any tokens of thanks given to participants. Interviewers will be trained in working with vulnerable children.

In the 2002 pilot study, 1 child refused to participate in the research, 60 consented and completed the interview. None refused any individual questions.

What undertakings have you given / will you give to your participants?

(i) Anonymity x

All results will be reported anonymously. If case studies are used as examples, names and any identifying details will be changed.

Many people affected by AIDS do not disclose to their community, or may selectively disclose within their own family. Stigma associated with HIV/AIDS disclosure has as been found to negatively affect families and orphans (Armistead et al., 1999; Giese, Meintjies, & Proudlock, 2001; Van Wyk, 1998). Stigma around HIV/AIDS is such that orphans may or may not be aware

that their parent(s) have died of HIV/AIDS. It would be unethical for a research study to reveal this to children.

Following ethical guidelines for psychological research, such as The British Psychological Society's statement on Ethical Principles for Research with Human Subjects, (British Psychological Society, 1992) and the American Psychological Association's code of ethical conduct, (American Psychological Association, 2002) our primary responsibility is to do no harm to research participants. Therefore, children and families will not be identified through the research process as families affected by AIDS. HIV/AIDS will not be mentioned either in consent letters or information leaflets (following) (Makame, Ani, & McGregor, 2002; Manuel, 2002) However, where families or children identify themselves to the researcher as affected by HIV/AIDS, this aspect of the study will be discussed verbally.

(ii) confidentiality x

All data will be treated as confidential. However, we are also aware of responsibility in the case of children who may disclose information showing them to be at risk of severe harm. There are also complex issues in countries where breaking confidentiality may not lead to greater protection for the child or may put the child at further risk.

Recent research in South Africa has carefully considered these issues. Therefore, we plan to follow the guidelines set out by the ongoing HSRC/UNICEF study on children's psychosocial adjustment in South Africa (Dawes, Bray, Kvalsvig, & Richter, Ongoing) and in the South African Children's Institute/ACCESS Child Participatory Poverty Research (ACCESS, SoulCity, & The Children's Institute, 2002). This promises confidentiality except where a child is shown through the research to be at risk, in which case (with the child's consent), they will be referred to organisations which can provide assistance.

As a practicing social worker in the Cape Town Child Welfare society, I will have a realistic sense of where to refer children, and in which situations a child protection referral may be appropriate and/or is likely to result in benefit for the child.

(iii) feedback x (see below)

(iv) holding of personal data x *All data will be kept in locked cabinets, with any identifying details separate from interview papers*

(v) access by third parties to personal data x

Only the research team will have access to questionnaire data

(vi) publishing/ reporting findings based on the data collected x

All reported data will be anonymous.

HOLDING PERSONAL DATA

What arrangements have you made to hold personal data?

(i) security

All data will be kept in locked cupboards or filing cabinets, with any identifying details separate from interview records. All information will be identified by number and will not have participants' names on it. All computer data will be kept on secure files and all backup discs will be kept in locked cabinets.

- (ii) length of time held

All papers showing personal or identifying details will be destroyed when the research is complete

- (iii) access by third parties

Only the principal investigator will have access to personal data

Will these arrangements comply with the requirements of the Data Protection Act? Yes

FEEDBACK TO PARTICIPANTS

What feedback will you provide to participants?

- (i) during the study

Boyden and Ennew (Boyden & Ennew, 1997) highlight the need to give children taking part in research 'reasons for and consequences of what they are doing'. During the research process, the interviews will explain and give out information on the research process. We will also aim to give feedback on the findings of the research to all the children who take part, and will discuss the process of feedback with organisations, schools and the children themselves. This is especially important in the context of research with people who are sharing experiences of emotional difficulties: that they are able to see the results and effects of their input.

For organisations (such as schools, orphan care organisations) we plan to provide information about the mental health problems we are studying, so that they are better resourced to cope with these difficulties experienced by children. This practice follows the Stellenbosch Trauma Research Unit who are co-planning the PTSD component of the study (O'Olley et al., 2003) and who have conducted extensive studies with children in township areas (Seedat, Nyamai, Njenga, Vythilingum, & Stein, 2004). Resources will include booklets on CBT help for anxiety, depression and PTSD, and information (where available) on local clinics which children can be referred to. We will also, where possible, offer opportunities for staff training in the 'Memory Book' orphan intervention, which is supplied by the UCT AIDS and Society Research Unit. (Morgan & Stein, 2003)

All children will be given refreshments whilst participating, and will be given certificates to thank them for taking part. These proved extremely popular in our pilot study, and were valued by both children and caregivers.

- (ii) at the end of the study

All participating organisations will be sent details of the study findings, in a format which will be accessible to the participants. The principal investigator will visit organisations to explain further the findings. Where participants are not involved with an organisation, written and verbal explanations of the findings will be provided. Notably, some groups of children, such as streetchildren, may be difficult to locate after the fieldwork period, as they may have moved on from shelters. All attempts will be made to pass on findings.

In your view, does your study raise any ethical issues?

(i) Yes

The ethical issues with this study are not simple, but the research is planned with ethical responsibility towards the children and their caregivers as a foremost concern. We have followed ethical research procedures used by methodologically sound studies working with orphaned and vulnerable children in South Africa and other parts of Africa (Ensink & Robertson, 1996; Ensink, Robertson, Zissis, & Leger, 1997; Foster, 1997b; Makame et al., 2002; Manuel, 2002). We have also followed the ethical guidelines used in the pilot study 'Psychological well-being of children orphaned by AIDS in Cape Town, South Africa', which were approved by a Department of Social Policy and Social Work Departmental Ethics Committee in 2002.

(ii) no

(iii) not sure – I would like to discuss further

SIGNATURE OF STUDENT

DATE

21 Sept 2004

STUDENT'S EMAIL ADDRESS

lucie.cluver@green.ox.ac.uk

TO BE COMPLETED BY THE SUPERVISOR

I confirm that the dissertation/ thesis proposal, and the contents of this form, have been discussed with me. I confirm that the progress of the study will be monitored by me in the following ways

SIGNATURE OF SUPERVISOR

DATE

SUPERVISOR'S EMAIL ADDRESS

frances.gardner@socres.ox.ac.uk

Appendix 2: Ethics committee approval letters

2.1 Oxford University, Department of Social Policy and Social Work

2.2 University of Cape Town, Health Sciences Research Ethics Committee

2.3 Department of Education, Western Cape Provincial Government

University of Oxford

Department of Social Policy and Social Work



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TO WHOM IT MAY CONCERN

19 August 2005

Dear Sir/ Madam

Ms LUCIE CLUVER

I am writing to confirm that Ms Cluver is registered as a DPhil student in this department. Her research proposal, *Mental health, risk and protective factors amongst children orphaned by AIDS in South Africa*, has been carefully considered by the Department of Social Policy and Social Work's Research Ethics Committee, and passed all the required ethics procedures in November 2004.

Yours faithfully

Teresa Smith
Head of Department

UNIVERSITY OF CAPE TOWN



Research Ethics Committee
E52 Room 24, Old Main Building Groot
Schoor Hospital, Observatory, 7925
Queries : Lamees Emjedi
Tel : (021) 406-6338 Fax: 406-6411
E-mail : lemjedi@curie.uct.ac.za

30 August 2005

REC REF: 245/2005

Ms LD Cluver
Cape Town Child Welfare
Dept. of Social Policy and Social Work
PO Box 374
Gatesville
7766

Dear Ms Cluver

**PSYCHOLOGICAL WELL-BEING, RISK AND PROTECTIVE FACTORS FOR CHILDREN
ORPHANED BY AIDS IN CAPE TOWN**

Thank you for your letter to the Research Ethics Committee dated 05 August 2005.

*It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study on the 29 August 2005.*

Your comments to the queries raised are noted with thanks.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROF T. ZABOW
CHAIRPERSON

Navrae
Enquiries
Imibuzo

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Wes-Kaap Onderwysdepartement
Western Cape Education
Department
ISebe leMfundo leNtshona Koloni

Ms Lucie Cluver
Department of Social Policy and Social Work
University of Oxford
OXFORD
United Kingdom
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Dear Ms L. Cluver

RESEARCH PROPOSAL: PSYCHOLOGICAL WELL-BEING, RISK AND PROTECTIVE FACTORS FOR CHILDREN ORPHANED BY AIDS IN CAPE TOWN.

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **1st September 2005 to 23 June 2006.**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December 2005).
7. Should you wish to extend the period of your survey, please contact Dr R. Cornelissen at the contact numbers above quoting the reference number.
8. A photocopy of this letter is submitted to the Principal where the intended research is to be conducted.
9. Your research will be limited to the following schools: **Imbasa Primary, Kwamofundo Secondary, Yomelela Primary and Moshesh Primary.**
10. A brief summary of the content, findings and recommendations is provided to the Director: Education Research.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

**The Director: Education Research
Western Cape Education Department
Private Bag X9114
CAPE TOWN
8000**

We wish you success in your research.

Kind regards.

Signed: Ronald S. Cornelissen
for: **HEAD: EDUCATION**
DATE: 24th August 2005

Appendix 3: Consent and information forms

3.1 Child information leaflet (English)

3.2 Child consent form (English)

3.3 Caregiver consent form (English)

3.4 Child information leaflet (isiXhosa)

3.5 Child consent form (isiXhosa)

3.6 Caregiver consent form (isiXhosa)

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information sheet

WELL-BEING OF CHILDREN IN CAPE TOWN, SOUTH AFRICA

Children who have lost a parent or caregiver

You are being invited to take part in a research study. Before you decide, it is important for you to know why the research is being done and what will happen. Please take time to read this sheet carefully. Ask the interviewer if there is anything that is not clear or if you have any questions. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is this study about?

This study is aiming to look at whether children who are orphans are more likely than other children to suffer from problems such as being sad or worried.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do not want to, this will not affect any help you may be getting from anyone. If you do decide to take part you would be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to stop taking part at any time and without giving a reason. Again, this would not affect any help or support you are getting from anyone.

What would happen if I take part?

If you decided to take part, you would spend about 30-35 minutes filling in a questionnaire with an interviewer, and drawing some pictures about yourself.

What if the questions upset me?

You can stop the interview at any point, and you do not have to give a reason. You can also contact me at any point after the interview, and say that you want certain questions or the whole interview to be destroyed. This will be done- no problem. If you want to talk to someone about anything which the interview has raised, you can contact me, Lucie Cluver, at the Cape Town Child Welfare Society (021 638 3127) or email lucie.cluver@green.ox.ac.uk.

Why should I take part in the study?

This study may help us to know more about problems facing orphans, and this information may help organizations to improve support for orphans and their carers.

What if I have a complaint?

If there is anything which you are unhappy with about this research, you can complain via the Child Welfare Society (021 761 7130), or contact Dr Frances Gardner (supervisor) frances.gardner@socres.ox.ac.uk (address at the top of page 1)

Would my taking part in this study be kept confidential?

All information which you tell us about yourself will be kept strictly confidential and will not be told to anyone else. Any information about you would have your name and address removed so that you cannot be recognised from it.

During the study, it may become clear that you are suffering from serious difficulties. If so, the interviewer will explain to you some possibilities for further help. If there is a safety issue, we may contact a welfare organisation for you. All this will be talked over with you first.

What would happen to the results of the research study?

The results of this study will be published in a journal, and will be given at conferences for people working with children. Your name will not be identified anywhere. You can have a copy of the finished paper by contacting Lucie Cluver at Child Welfare Society, Cape Town, or at the Department of Social Policy and Social Work at the University of Oxford, England.

Who is organising and reviewing the research?

The research is being organised through the University of Oxford in England, at the Department of Social Policy and Social Work, and the Cape Town Child Welfare Society.

Contact for Further Information

Lucie Cluver at
Cape Town Child Welfare Society
PO Box 374
Gatesville 7766

Thank you for reading this information sheet.
You will be given a copy of this sheet to keep,
and a copy of the consent form to think about.
02/12/2004



consent form

WELL-BEING OF CHILDREN IN CAPE TOWN, SOUTH AFRICA
Children who have lost a parent or caregiver

Name of Researcher:

Please tick box

yes *no*

1. I have read and understand the information sheet for this study and have had the chance to ask questions

☐	☐

2. I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting.

☐	☐

3. I agree that any words I may say during the interview can be used, without giving my name, in the presentation of the research. I agree to take part in the study.

☐	☐

Name of Participant (child)

Signature

Date

Researcher

Signature

Date

2 copies, one for participant, one for researcher (to be kept with records)



Cape Town Child Welfare

Cape Town Child Welfare
PO Box 374
Gatesville 7766, Cape Town

University of Oxford
Department of Social Policy and Social Work



Department of Social Work
University of Oxford
32 Wellington Square
Oxford, England OX1 2ER

Dear Parents/Guardians

Your child's school/organisation has been invited to take part in a research study which is being run by the Cape Town Child Welfare Society and Oxford University. The research is looking at the well-being of children in Cape Town, and aims to provide information which will help children. Children from several grades will be asked if they would like to fill in a questionnaire about their everyday activities and feelings. Children can choose whether they would like to take part or not. If you would prefer the child who you care for **not** to take part in this research, please fill in the slip below and return it to your child's grade teacher within a week.

Thank you,

Lucie Cluver

Lucie Cluver (Researcher), Cape Town Child Welfare

Name of School
Name of child
Child's grade.....

I would not like the child whom I care for to take part in a research study for children in Cape Town.

Name of parent/guardian.....
Signature.....
Date.....

University of Oxford

Department of Social Policy and Social Work



BARNETT HOUSE
32 WELLINGTON
SQUARE
OXFORD OX1 2ER
ENGLAND

TEL 01865 270326
FAX 01865 270324
secassd@socres.ox.ac.uk

iphepha lenkcazelo

Ukonwaba kwabantwana ekapa emzantsi Afrika.

Abantwana abathe balahlekelwe ngabazali babo okanye ababa jongileyo.

Uyamenya ukube uthabathe inxaxhelab kwisifundo sophando. Phambi kokuba uthabathe isigqibo kubalulekile ukuba uqondisise ukuba kutheni oluphando lusenziwe kwaye lubandakanya ntoni. Ukuba unawo umbuzo ongacacanga okanye imibuzo uvumelekile uyibuze. Thabatha ixesha elaneleyo lokucingisisa ukuba uyafuna na ukuthabatha inxaxheba. Siyabulela ngokufunda oku.

Yintoni injongo yoluphando?

Olu phando lujongise ekujongeni ekubeni abantwana abaziinkedama bafumana iingxaki zokubalusizi.

Kufanelekile ukuba ndithabathe inxaxheba na?

Kukuwe ukugqiba ekubeni uyayithabatha inxaxheba na. Ukuba awuthandi, loo nto ayinako ukuchaphazela uncedo onako ukulufumana kulo mbutho. Ukuba ugqibe ekubeni uthabathe inxaxheba uyakunikwa eliphetshana/phepha lolwazi uligcine uze ucelwe usayine I fomu yovumo.

Ukubangaba ugqibe ekubeni uthabathe inxaxhebe usenalo ithuba. Lokuba uphinde uyeke kwakhona ngaphandle kwesizathu. Loo nto ayinako ukuchaphazela uncedo okanye inkxaso oyifumanayo nakowuphina.

Kungenzeka ntoni kum. Xa ndithabatha inxaxheba?

Ukuba ugqibe kwelokuba uthabatha inxaxheba, uyakuchitha imizuzi engema 30-35 ugcwalisa imibuzo kunye nombuzi-mibuzo. Abakhathaleli bona bophendula imibuzo emifutshane malunga nomntwana lowo. Ekhathalelwe ngabo.

Ndingenza njani xa imibuzo indikhathazile?

Ungaluyeka udliwano - ndlebe naninina, unako nolube unganiki sizathu. Unako nokuba uqhagamshelane nomphandi emva kodliwano - ndlebe kwaye utsho ukuba ufuna kubekho eminye imibuzo okanye udliwano - nxdlebe lutshatyalaliswe. Angekhe ibe yingxaki leyo into. Ukuba ufuna ukuthetha nomnye umntu malunga nodliwano-ndlebe,

qhagamshelana no Lucie Cluver kwa Cape Town Child Welfare Society (021 638 3127), lucie.cluver@green.oxford.ac.uk.

Kutheni kufuneka ndithabathe inxaxheba kwezi zifundo?

Ezi zifundo zingasanceda ukuba sazi nzulu malunga neengxaki ezifunyanwa ziinkedama, kwaye inkcukacha zinganceda.

Kwenzeka ni ukuba ndinesikhalazo?

Ukuba unesikhalazo ngesisiifundo unako ukukhala kwa Child Welfare (021 638 3127). Ungakhalaza kwa Child Welfare Society okanye udibane no Gqirha uFrances Gardner (usomaqhuzu) (idilesi emantla ephepa lokuqala).

Ukuthatha kwam inxaxheba kwezizifundo kungahlonipheka kubeyimfihlo na?

Lonke ulwazi othi usixelele Ihina ngalo ngawe luyakuhlala lukhuselekile ngawe kwaye alusayi kuxdelwa nabanina ungomnye.

Ngexesha lokufunda kwakho, siye safumanisa ukuba wena uthe wafumana ubunzima obungamandla. Xa kunjalo, umvavanyi wakho uyakuthi akucacisele neendawo onokuthi ufumane kuzo uncedo. Ukuba awukhuselekanga, thina singakudibanise noo nontlalontle bakho.

Kuya kwenzeka ntoni kwiziphumo zophando?

Iziphumo zokuku funda kuyakuthi kubhengezwe kwijournal, kwaye kunikezwe kwinkomfa ukwenzela abantu basebenze nabantwana. Igama lakho alisayi kubhengezwa nakanjani. Igama lakho nedilesi soze zichazwe nakweyiphi intatheli, ungafumana ikopi ku Lucie Cluver kwa Childwelfare, e kapa okanye. Ufowunele kule nombolo (021 638 3127)

Ngubani oququzelela oluphando ngubani oququzelelela?

OluPhando luququzelelwa yi Dyunivesiti yase Oxford, Engilane, kunye ne ChildWelfare e kapa

Ukuba ufuna incukacha ngokubanzi qhagamishelana no

Lucie Cluver
Cape Town Child Welfare Society
PO Box 374
Gatesville 7766
Tel 021 638 3127

Enkosi ngokuba ufunde eliphepha
ngaciso lophando uyakunikwa ikopi
uyigcine. 30/01/2005



i form yesivumelwano

Ukuba ngabantwana abagqibeleleyo ekapa Emzantsi Afrika.
Unengondo ngaphezu kwabanye na?

Igama lomphandi:

Fakela kwezibhokisi

yes *no*

1. ndiyavuma ukuba ndiyisfundile ndayigonda yesisifundo

☐ ☐

2. ndiyavuma ukuba inaxheba endiyithatha yeyesisa, ndinelungeto
lokurhoxa ngalo naliphina ithuba ngaphandle kokunika isizathu

☐ ☐

3. ndiyavuma ukuba amagama endiwa thethileyo xa ndeza oluphando
lesisifundo angasetyenziswa ngaphandle kokunikeza ngegama lam, kwi
ngcaciso yoluphando ndiyavuma ukuba ndakuthatha inxaxheba.

☐ ☐

Igama Iontwana (child) _____

Umtyikityo _____ Umhla _____

Umpandi _____

Umtyikityo _____ Umhla _____

Amaphepha amba bini elinye lelo mntwana elinye lelamphandi (lizakuhlala elugcinweni)



Cape Town Child Welfare

Cape Town Child Welfare
PO Box 374
Gatesville 7766, Cape Town

University of Oxford

Department of Social Policy and Social Work



Department of Social Work
University of Oxford
32 Wellington Square
Oxford, England OX1 2ER

Molo Mzali/ Umntu omele umntwana

Isikolo/Iqela lomntwana wakho limenyiwe ukuba lithabathe inxaxheba kuphando olwenziwa liCandelo leNtlalontle yaBantwana eKapa kunye neDyunivesity yase Oxford. Oluphando lujongana nentlalo-ntle yabantwana kiNtshona Koloni, kwaye liceba ukunikezela ngenkcukacha ezinokuthi zince abantwana. Abantwana abasuka kumabanga aliqela bazakubuzwa ukuba bangathanda na ukufilisha iphepha lemibuzo elimalunga nabakwenzayo nendlela abaziva ngayo mihla le. Abantwana bayakukhetha ukuba bayafuna ukuthabatha inxaxheba okanye hayi. Ukuba ungathanda umntwana wakho omkhathaleleyo ukuba angathabathi nxaxheba kolu phando, nceda ufilishe iphepha elingezantsi uze ulibuyisele kutitshala webanga/ umkhokeli weqela lomntwana kwisithuba isingange veki.

Enkosi,

Lucie Cluver

Lucie Cluver (Researcher), Child Welfare Society e kapa

Igama lesikolo/leqela

Igama lomntwana..... ibanga lomntwana

Andithandi ukuba umntwana endimkhathaleleyo athabathe inxaxheba koluphando lwabantwana eNtshona Koloni.

Igama lomzali.....

Utyikityo..... Usuku.....

Appendix 4: Certificates for child participants

- 4.1 Quantitative stage certificates (English)**
- 4.2 Quantitative stage certificates (isiXhosa)**
- 4.3 Qualitative stage certificates (English)**
- 4.4 Qualitative stage certificates (isiXhosa)**



**University
of Oxford**

Certificate

*Has participated as an
ASSISTANT RESEARCHER
in a study for children*

*With the University of Oxford, England
And The Cape Town Child Welfare Society.*

Thank you, and congratulations!

Cape Town Child Welfare





**University
of Oxford**

Isiqinisekiso

*Uthabathe inxaxheba njenge sekela mphandi
Kwizifundo zabantwana*

*Ekunye ne Dyunivesiti yase Oxford, Engilane
Kunye ne Child Welfare Society e kapa*

Enkosi, ngovuyiswano!

Cape Town Child Welfare





isiqinisekiso



**Uthabathe inxaxheba njenge sekela mphandi
Kwizifundo zabantwana
Ekunye ne Dyunivesiti yase Oxford, Engilane
Kunye ne Child Welfare Society e kapa**

Enkosi, ngovuyiswano!





certificate



Has participated as an
ASSISTANT RESEARCHER
in a study for children
With the University of Oxford, England
And The Cape Town Child Welfare Society.

Thank you, and congratulations!



Appendix 5: Questionnaires

5.1 Qualitative stage questionnaires (English)

5.2 Qualitative stage questionnaires (isiXhosa)

5.3 Quantitative stage questionnaire (English)

5.4 Quantitative stage questionnaire (isiXhosa)

Qualitative questionnaire: Buntu/Bart version (English)

CARTOON
DELETED

Buntu and
Lindiwe...



CARTOON
DELETED

What sort of things make Buntu
happy?

CARTOON
DELETED

What sort of things make Buntu
sad or angry?

CARTOON
DELETED

CARTOON
DELETED

When Buntu is unhappy, what sort
of things make him feel better?

CARTOON
DELETED

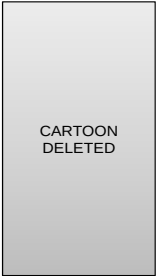




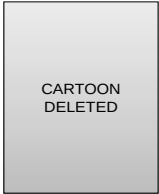
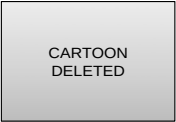
CARTOON
DELETED

Qualitative questionnaire: Lindiwe/Lisa version (English)

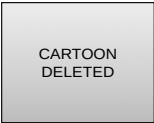
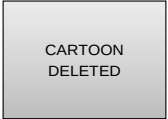
Buntu and
Lindiwe...



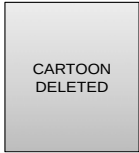
What sort of things make Lindiwe
happy?



What sort of things make Lindiwe
sad or angry?



When Lindiwe is unhappy, what
sort of things make her feel better?



thank you!

Qualitative questionnaire: DragonballZ version (English)

CARTOON
DELETED

**The mission: to
complete this sheet.**

**Write it. Draw it. We
don't mind.**

**Remember: this time,
you are the hero.**

CARTOON
DELETED

**What sort of things make you
happy?**

CARTOON
DELETED

**What sort of things make you
sad? or angry?**

CARTOON
DELETED

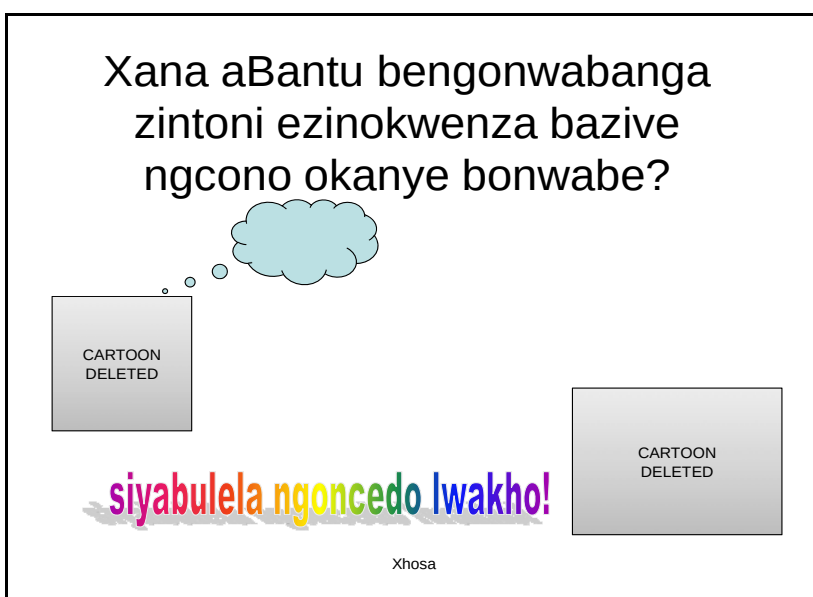
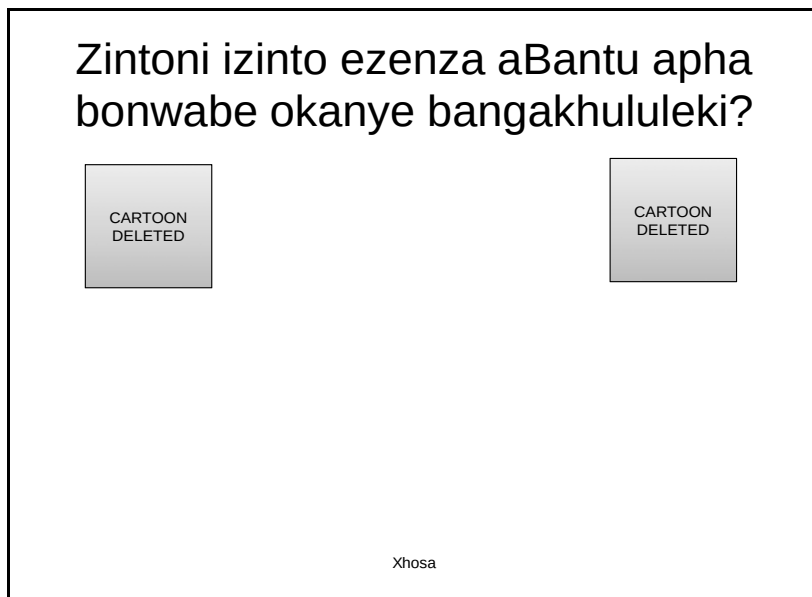
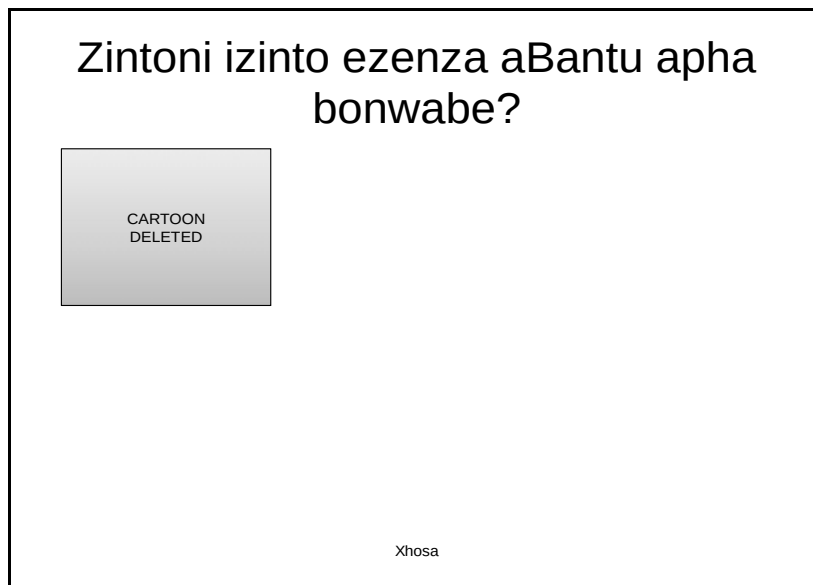
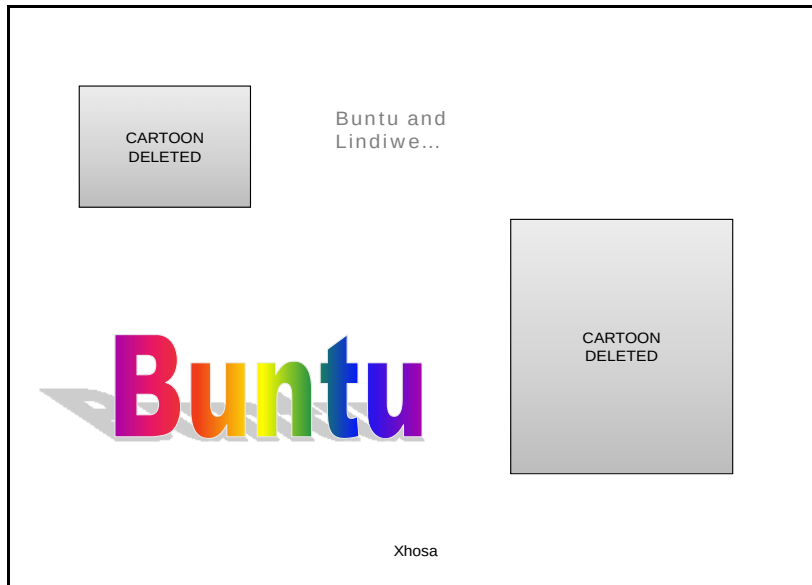
CARTOON
DELETED

**When you are sad, what sort of
things make you feel better?**

Thank you for helping us!

CARTOON
DELETED

Qualitative questionnaire: Buntu/Bart version (isiXhosa)



Qualitative questionnaire: Lindiwe/Lisa version (isiXhosa)

CARTOON DELETED

Buntu and
Lindiwe...



CARTOON DELETED

Xhosa

Ziintoni izinto ezenza uLindiwe
apha onwabe?

CARTOON DELETED

Xhosa

Zintoni izinto ezenza uLindiwe
apha angonwabi okanye
angakhululeki?

CARTOON DELETED

CARTOON DELETED

Xhosa

Xana uLindiwe engonwabanga
zintoni izinto ezinokwenza azive
engcono?



CARTOON DELETED

siyabulela ngoncedo lwakho!

CARTOON DELETED

Xhosa

Qualitative questionnaire: DragonballZ version (isiXhosa)

CARTOON
DELETED

**Eyona nto ifunekayo:
kukuba ugqibe eli phepha.**

Libhale. Lizobe. asihlupheki

**Khumbula: eli ixesha,
uliqhawe.**

CARTOON
DELETED

Xhosa

**Ziintoni izinto ezikwenza wena
ungonwabi okanye ungakhululeki?**

CARTOON
DELETED

CARTOON
DELETED

Xhosa

**Ziintoni izinto ezikwenza wena
wonwabe?**

CARTOON
DELETED

Xhosa

**Xana wena ungonwabanga,
ziintoni izinto ezikwenza wena
uzive ungcono?**

siyabulela ngoncedo lwakho!

CARTOON
DELETED

Xhosa

Questionnaire No. _____

Place of interview _____

School/org _____

Grade _____

Social Worker _____

Date _____

☐ boy

☐ girl

Interviewer _____

Tape recorder: on ☐

all about me!

the questions you answer here are confidential.
This means that we will not report your real name.

Please write your name here _____

Now, please think of a different name which we can use
when we are writing about this research. You can pick any name you want!

We would like to send you the results of the study
when it is finished. Please write your address and
telephone no so we can get back in touch

address _____

tel no _____

what is your main language spoken at home? _____

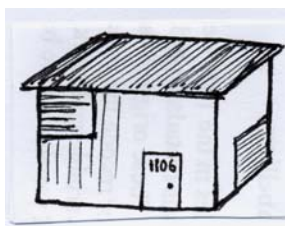
This is not a test. There are no right or wrong answers! This research aims to help children and
young people in Cape Town. Thank you for taking the time to help us

my home and...

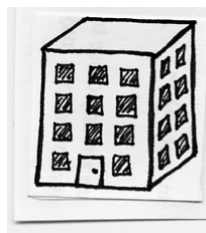
please circle the one which is most like your home



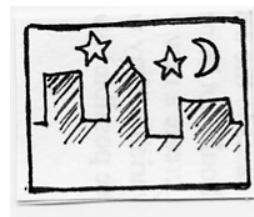
hut made of
traditional materials



shack on it's own plot



block of flats



living on the street



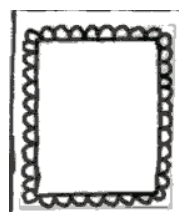
shack in a back yard



children's home or
shelter for kids



house made of brick or
concrete

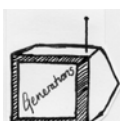


other _____

please circle the things which you have in your home (in working order)



electricity



TV



bath or shower



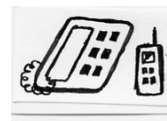
radio



fridge



water from a tap



phone/cellphone



computer

YOU AND YOUR HOME...

do you help look after younger children in your home? ☐ no ☐ yes

have you ever helped to look after unwell people in your home? ☐ no ☐ yes... who was it? _____

do you feel that you belong with the people who you live with?
☐ yes ☐ somewhat ☐ not at all

does someone at home praise you when you have done something well?
☐ often ☐ rarely ☐ never

does anyone who lives with you have a job?
☐ no ☐ yes who? _____

do you get the same food/clothes/school fees/
school equipment as other children you live with?

Do you have brothers and sisters who do not live with you?
Can you write their names and ages here?
(you can use the stickers)

people who i live with

for interviewers guiding questions...

1) how many rooms are there in your home? kitchen? Bathroom? Other rooms?

2) Who sleeps in each room? Put stickers on (with name, age, relationship to you)

(for kids living in shelters/children's homes/on the street, just draw own room/where they sleep)

A large, empty rounded rectangle with a thin black border, intended for drawing or writing. It occupies the lower two-thirds of the page.

what i think and feel...

this part of the questionnaire looks at sadness and other difficulties which many people experience at some point in their lives. This questionnaire is arranged in groups of 3 statements. Please listen to each group carefully. Then pick out ONLY ONE statement from each group which best describes the way you have been feeling during the last 2 weeks...

- I am sad once in a while
- I am sad many times
- I am sad all the time

- I feel like crying every day
- I feel like crying many days
- I feel like crying once in a while

- Nothing will ever work out for me
- I am not sure if things will work out for me
- Things will work out for me OK

- Things bother me all the time
- Things bother me many times
- Things bother me once in a while

- I do most things OK
- I do many things wrong
- I do everything wrong

- I look OK
- There are some bad things about my looks
- I look ugly

- I hate myself
- I do not like myself
- I like myself

- I do not feel alone
- I feel alone many times
- I feel alone all the time

- I do not think about killing myself**
- I think about killing myself but I would not do it
- I want to kill myself**

- I have plenty of friends
- I have some friends but wish I had more
- I don't have any friends

- Nobody really loves me
- I am not sure if anybody loves me
- I am sure that somebody loves me

slam the box!

many kids and teenagers feel nervous or anxious at times.

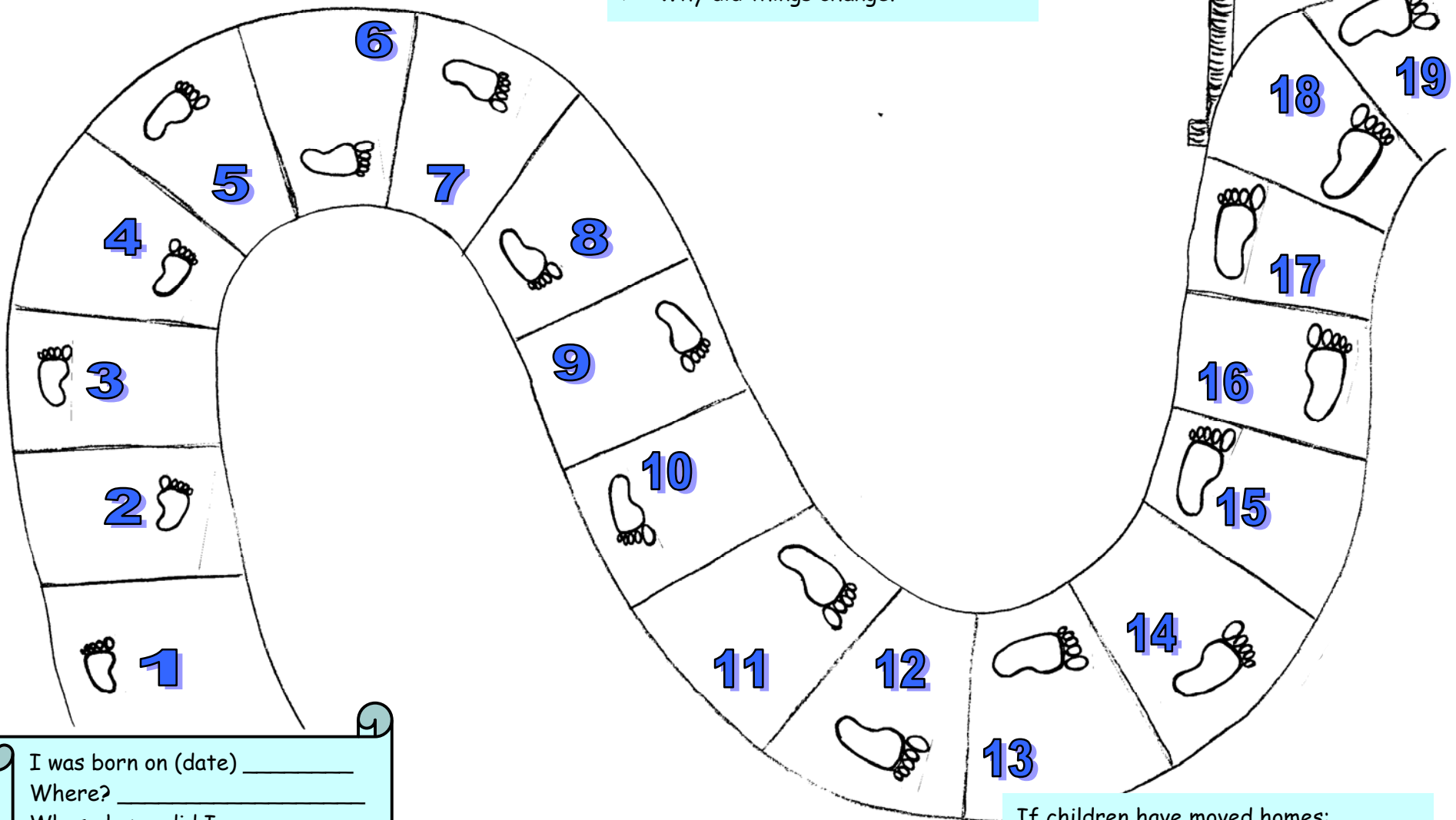
Please take a card for each question and put it into the box which best describes you. The boxes are marked 'yes' and 'no'

I have trouble making up my mind	no	yes
I get nervous when things do not go the right way for me	no	yes
Others seem to do things easier than I can	no	yes
Often I have trouble getting my breath	no	yes
I worry a lot of the time	no	yes
I am afraid of a lot of things	no	yes
I get angry easily	no	yes
I worry about what my carers will say to me	no	yes
I feel that others do not like the way I do things	no	yes
It is hard for me to get to sleep at night	no	yes
I worry about what other people think about me	no	yes
I feel alone even when there are people with me	no	yes
Often I feel sick in my stomach	no	yes
My feelings get hurt easily	no	yes
My hands feel sweaty	no	yes
I am tired a lot	no	yes
I worry about what is going to happen	no	yes
Other children are happier than I	no	yes
I have bad dreams	no	yes
My feelings get hurt easily when I am criticised	no	yes
I feel someone will tell me I do things the wrong way	no	yes
I wake up scared some of the time	no	yes
I worry when I go to bed at night	no	yes
It is hard for me to keep my mind on my schoolwork	no	yes
If 'yes', are you thinking about any particular thing which makes concentration difficult?		
I wiggle in my seat a lot	no	yes
I am nervous	no	yes
A lot of people are against me	no	yes
I often worry about something bad happening to me	no	yes

my road of life

- Whose home were you living in?
- Who was the person who looked after you most?
- Why did things change?

THE FUTURE



I was born on (date) _____
 Where? _____
 Whose home did I
 live in? _____
 Who looked after me most?

If children have moved homes:

- Were there any problems around who got the house and/or money when you moved? _____
- (if yes) who moved into your old house? _____

friends and other kids...

Other kids and teenagers can be great. They can also be really mean to each other.

For each question, please say whether you think it is ‘not true’, ‘sometimes true’ or ‘certainly true’. Think about it as how things have been for you in the last 6 months. It would help if you answered all the questions even if you are not certain or if it seems silly!

	Not true for me	Somewhat true for me	Certainly true for me
I am usually on my own. I generally play alone or keep to myself			
I have one good friend or more			
Other people my age generally like me			
Other children or young people pick on me			
I get on better with adults than with people my age			

Now we want to know about this past year. During this year other kids...

	Not at all	Once	2-3 times	4 or more times
Called me names or swore at me				
Tried to get me into trouble with my friends				
Took something without permission or stole things from me				
Made fun of me for some reason				
Made me uncomfortable by standing too close or touching me				
Punched, kicked or beat me up				
Hurt me physically in some way				
Tried to break or damaged something of mine				
Refused to talk to me or made other people not talk to me				

Did this happen mainly ☐ in school ☐ outside school ☐ both

① Do you have a parent, guardian or caregiver staying with you and taking care of you at home? ☐ yes ☐ no

↩ please draw this person or write their name here
how old are they? _____ Is this person your...

- ☐ Brother
 ☐ Uncle
☐ Stepfather
 ☐ Neighbour/family friend
☐ Grandma
 ☐ Biological father
☐ Sister
 ☐ Aunt
☐ Foster mother
 ☐ Stepmother
☐ Grandpa
 ☐ Biological mother
☐ No-one
 ☐ Social worker/careworker
☐ Foster father
 ☐ Other _____

Is this person unwell
☐ never ☐ rarely ☐ sometimes ☐ very often

how much does this person REALLY know what you do with your free time?

☐ doesn't know ☐ knows a little ☐ knows a lot

	This person is a person in my life	This person is helpful when I have a personal problem	This person is helpful when I need money and other things	I have fun with this person
	yes no	not at all sort of very	not at all sort of very	not at all sort of very
Your caregiver _____				
Your sisters or brothers				
A teacher				
The principal or assistant principal				
Your group of close friends				
Other people (tell us who) _____				

stuff that's been difficult for me...

Here are Buntu and Lindiwe, showing us some things which many kids in Cape Town have experienced. Could you tell us whether these things have happened to you also?

Buntu has been robbed and had his things stolen.

This year, how many times have you had things stolen? _____

Buntu has been unwell this year with TB. Lindiwe has had stomach upsets.

Have you been unwell this year? _____ what with? _____

There are inappropriate ways to touch Buntu and Lindiwe. Has anyone ever touched you in a way that made you feel uncomfortable? _____. Has anyone ever made you do anything with your private parts or their private parts that you did not want to do? _____

Lindiwe's carer shouts at her a lot.

How many times in an ordinary week do you get shouted at in your home? _____

Buntu was attacked and hit when he was out. Have you ever been hit or attacked outside? _____



Lindiwe's friend Andile is hit by adults at home. Have you been hit at home? _____ what with? _____

Buntu saw someone in his neighbourhood being shot. Lindiwe saw someone being stabbed one evening. Have you seen someone being shot _____? or stabbed _____?

Have you seen something else that has upset you? _____

Andile's family have lots of arguments. Sometimes adults shout at each other and sometimes there is fighting. This last week, how many days were there arguments with adults shouting in your home? _____ How many days were there arguments with adults hitting each other in your home? _____

Lindiwe and Buntu often don't have enough food in their home. How many days this week did you not have enough food? _____

Buntu and Lindiwe's mother was ill for some time before she died. Their father is unwell at the moment. Some people have been unkind to them because of this.

Have you ever been teased or treated badly because of people in your family being unwell?

Teased: ☐ not at all ☐ sometimes ☐ often *Treated badly:* ☐ not at all ☐ sometimes ☐ often

Have people gossiped behind your back about it?

☐ not at all ☐ sometimes ☐ often

Did all this upset you? ☐ not at all ☐ somewhat ☐ very much

Buntu and Lindiwe's mother died a few years ago. They had a little brother who also died.

Has anyone close to you died? Could you tell us who they were? And when? Do you know what happened? (you can write, or draw them)

Sometimes it helps to talk to someone about our feelings when a person close to us has died. Did you or do you talk to anyone about this? ☐ yes ☐ no
who? _____

Has anything happened which we have not mentioned which has upset you? _____



how do you feel about...?

Group C) Many kids go through things that are very upsetting or frightening, We would like to know about them and how you felt about it. They might have happened recently or they might have happened a long time ago, but still upset you. They might have been in the list we asked you, or something else.

Can you tell us what was the most upsetting or frightening thing that has happened to you?

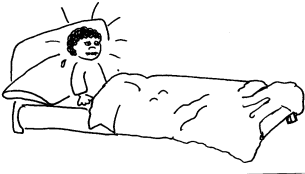
Group A & B) Many kids go through things that are very upsetting or frightening, We would like to know about them and how you felt about it. They might have happened recently or they might have happened a long time ago but still upset you. You said that your parent/s died a while ago. Would this be the right thing to ask you about, or has something else happened which has upset you even more?

Can you tell us what was the most upsetting or frightening thing that has happened to you?

Now take the tennis ball!

Please listen to each question, and stick the tennis ball on the board to show whether you have felt this way 'not at all', 'some of the time', most of the time' or 'all the time' in this past month

	not	some	most	all
 Do you get nightmares or bad dreams about what happened?	○	●●	●●●	●●●●
Do you get upset when you think about what happened? 				
When something reminds you of what happened, do you get tense or upset?				
 Do you go over and over what happened in your mind?				
Do you think about (or see pictures in your head of) what happened even when you don't want to? 				
Do you worry that it might happen again?				
Do you try not to think about what happened?				
Do you try to stay away from things that remind you of what happened?				
Do you have trouble remembering important parts of what happened?				
Do you act out things or repeat things like what happened?				
 Do you feel like its happening all over again even when it's not?				

		not	some	most	all
Do you feel it's hard to have any feelings any more, like you feel numb?					
Do you make yourself very busy and do things so you won't think about what happened?					
Do you get physically upset when something reminds you of what happened - like getting sweaty, shaking, your heart pounding, getting short of breath, or stomach aches?					
	Do you have trouble falling asleep or staying asleep?				
Is it hard for you to pay attention - like listening to your teacher, or doing your work - because you can't concentrate well?					
Do you feel you need to stay 'on guard', like something could happen and you need to be ready?					
Do you get jumpy or startle easily?					
Do you get annoyed (grouchy) or irritable (kind of angry) real easy?					
	Do you get angry or upset at people for no reason?				
Do you get so angry at people you hit or hurt someone?					
Do you ever think you won't grow up and be what you want to be?					
	Do you feel it's hard to have fun doing things?				
Do you ever feel it's hard to feel happy?					
	Do you feel alone even when other people are around?				
Do you feel bad or guilty - like what happened was your fault?					
Do you wet your pants or bed by accident?					
Do you feel like you are 'tuned out' or in a 'trance' so you can go away in your mind and not think?					

stuff i do in an ordinary week...

Please circle
the ones you
usually do



playing an
instrument



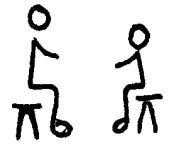
singing



playing a game
like marbles or dice



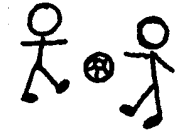
listening to
music



seeing a counselor



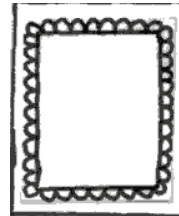
playing netball



playing soccer



swimming



doing another sport
(which one?)



dancing



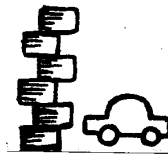
begging



socializing with
friends



using the computer



playing with toys



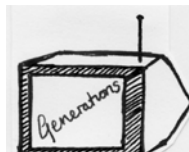
doing housework
(how many hours a day?)



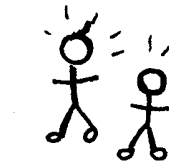
a job outside
the home (how
many hours a day?)



going out
with family



watching TV



playing games



reading

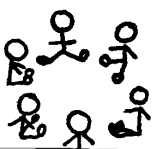
YOUTH CLUBS AND GROUPS
Do you go regularly to any youth
groups?



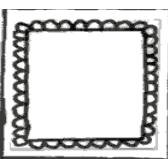
music, theatre
or dance



sports



support group



another kind of
youth group

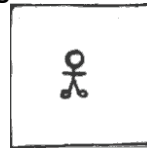
When you are feeling down or sad, do you do any
of these things to cheer yourself up?



reading



playing



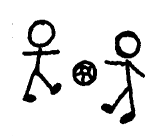
being alone



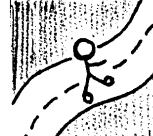
TV



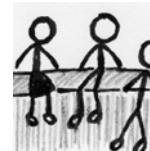
listening to music



sport



going for a walk



seeing friends



going to the library



homework



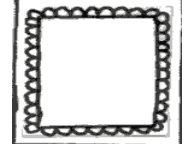
comfort
from a friend



going to bed



writing or drawing
your feelings down



other things

feeling unwell or angry

Only one more page to go! For each question, please say whether you think it is 'NOT TRUE' 'SOMEWHAT TRUE' or 'CERTAINLY OR ALWAYS TRUE'. Think about it as how things have been for you in the last 6 months.

	Not true	Somewhat true	Certainly true
I feel dizzy			
I don't feel guilty after doing something I shouldn't			
I hang around with kids who get in trouble.			
I usually do as I am told			
I would rather be with older kids than with kids my own age			
I run away from home			
I set fires			
I steal at home			

	Not true	Somewhat true	Certainly true
I steal things from places other than home.			
I swear or use dirty language.			
I use alcohol or drugs for non-medical purposes.			
I lie or cheat.			
I feel overtired			
I am unwell (without knowing why) with these problems:			
Aches or pains (not headaches)			
Headaches			

	Not true	Somewhat true	Certainly true
Nausea, feeling sick			
Problems with eyes describe.....			
Rashes or other skin problems			
Stomachaches or cramps			
Vomiting, throwing up			
I get very angry and often lose my temper			
I cut classes or skip school.			
I fight a lot. I can make other people do what I want			

the last page!

In some communities people know and talk to each other, while in other communities there is not this sense of closeness. How close do you feel to other people in this community?

☐ very close ☐ somewhat close ☐ not too close ☐ not close at all

how important is religion in your everyday life?

☐ most important ☐ somewhat important
☐ very important ☐ not important at all

Aside from weddings and funerals, how often do you attend religious services (church, temple, mosque etc)?

☐ more than once a week ☐ 1-2X a month ☐ never
☐ once a week ☐ a few times a year

For your last birthday, did you have a celebration (a cake, or a meal, or friends coming round)? ☐ no ☐ yes

How much do you like school? By that I mean how much do you enjoy learning and going to classes?

☐ do not like it at all ☐ do not like it much ☐ like it ☐ like it very much

I would like to know how you feel about your future opportunities to be successful and prosper, would you say...

Your opportunities
are limitless

you have many
opportunities

your opportunities
are very limited

you have no
opportunities at all

This is the last question! If you would like to, could you draw a picture of yourself in the future? (or write, or use the stickers) What will you be doing?

Thank you very much for giving up your time to talk to me. Before I go, is there anything you would like to ask me about the research? Is there anything that worries or concerns you about it?

If you would like to ask anything about the research at a later stage, please feel free to contact Lucie Cluver 021 638 3127. Thank you again for taking part.

thank you!

For interviewer/research team.

Attending school? ☐ yes ☐ no

If yes, attendance record

☐ very good ☐ misses some days ☐ poor

if missing school, why? _____

highest grade passed _____

Q1: Cause of Parental death

Q2: household income _____

Q3: Is the household receiving any grants? ☐ no grants ☐ foster care grant ☐ child support grant ☐ pension ☐ war veterans grant ☐ disability grant ☐ care dependency grant ☐ grant in aid ☐ social relief of distress ☐ child maintenance support (from father)

Q4: (only if child is living with 1 unwell parent) ARVs? _____

Any comments:

Questionnaire No. _____

Place of interview _____

School/org _____

Grade _____

Social Worker _____

Umhla _____

☐ yinkwenkwe

☐ yintombazona

Interviewer _____

tape recorder: on ☐

Okungam konke!

Imibuzo oyiphendulayo apha iyimfihlelo. Oku kuthetha ukuba asizukuchaza igama lakho lenyani

Nceda ubhale igama lakho apha _____

Ngoku, nceda ucinge ngelinye igama elahlukileyo esinokulisebenzisa xa sibhala ngolu phando.
Ungakhetha naliphi igama olifunayo!

Singathanda ukukuthumelela iziphumo zoluphando xa luggityiwe. Nceda bhala idilesi yakho kunye nenombolo yomnxeba ukuze sibuyele kuwe.

Idilesi _____

Inombolo mfonohayi _____

Luluphi elona lwimi luthethwayo ekhaya? _____

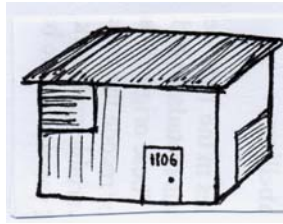
Olu ayilovavanyo. Akukho zimpendulo zilungileyo okanye ezingalunganga. Olu phando luceba ukunceda abantwana kunye nolutsha lwaseKapa. Siyabulela ngokuthatha ixesha lokusinceda

Ikhaya lam kunye....

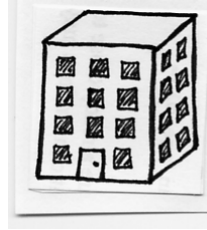
nceda wenze isangqa kuleyo ifana nekhaya lakho



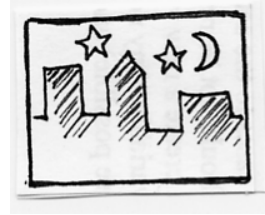
Indlu eyenziwe ngesintu



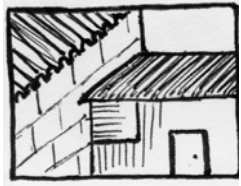
Umkhukhu okwisiza sawo



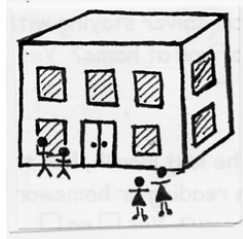
Eziflethini



Uhlala esitalatweni



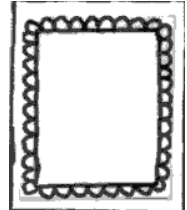
Umkhukhu osemva eyadini



Ikhaya labantwana okanye indawo yabantwana basesitratweni.



Indlu eyenziwe ngezitena okanye yesamente

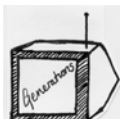


Enye... (chaza).....

Nceda wenze isangqa kwizinto ezikhoyo ekhayeni lakho (ngendlela esebenzayo)



umbane



iTV



indawo yokuhlambela okanye ishawari



unomathotholo



isikhencezisi



amanzi etephu



umnxeba/

umnxeba ophathwayo



ikhomputha

Wena kunye nekhaya lakho...

Ingaba uyancedisa ekujongeni abantwana abancinane ekhayeni lakho ☐ hayi ☐ ewe

Wakhe wanceda ekujongeni abantu abangaphilanga ekhayeni lakho? ☐ hayi ☐ ewe...
Yayingubani? _____

Ingaba uziva ngathi uyinxalenye yababantu ohlala nabo? ☐ ewe ☐ nje ☐ ha yi khona

Ingaba umntu kokwenu uyakuncoma xa uthe into kakuhle? ☐ Soloko ☐ akufane ☐ zange

Ingaba umntu ohlala naye unomsebenzi? ☐ hayi ☐ ewe Ngubani? _____

Ingaba ufumana ukutya okufanayo/impahla/imali yesikolo/izinto zesikolo njengabanye abantwana ohlala nabo? ☐ Ndifumana kakhulu ☐ Ndifumana kancinci ☐ Ndifumana ngokulinganayo

Ingaba unobhuti noosisi abangahlali nawe?
Ungabhala amagama abo kunye nobudala babo apha?
(sebenzisa izincamathelisi)

abantu endihlala nabo

for interviewers guiding questions...

3) how many rooms are there in your home? kitchen? Bathroom? Other rooms?

4) Who sleeps in each room? Put stickers on (with name, age, relationship to you)

(for kids living in shelters/children's homes/on the street, just draw own room/where they sleep)

A large, empty rounded rectangle box with a thin black border, intended for a drawing or response. The corners are smoothly rounded, and the interior is completely blank white space.

Into endiyicingayo nendiyivayo

Le mibuzo ifuna ukuva indlela ethi uzive ukhathazekile kwakunye nezinye iingxaki njengoko uninzi lwabantu lubanjalo kumaxesha athile obomi babo. Le mibuzo inikwe iinkcazelo ezithe zabekwa ngokwamaqela. Nceda mamela kwiqela ngalinye ngobunono, emva koko ukhethe inkcazelo ibenye kwiqela ngalinye eyichaza ngcohayi indlela obe uziva ngayo kwiiveki EZINE EZIDLULILEYO ukuza kutsho namhlanje. Phawula kwibhokisi emelene nenkcazelo oyikhethayo.

- Ndikhathazeka kanye kwixeshana
- Ndikhathazeka amaxesha amaninzi
- Ndikhathazeka amaxesha onke

- Ndiziva ingathi ndingalila yonke imihla
- Ndiziva ingathi ndingalila intsuku ezininzi
- Ndiziva ingathi ndingalila kanye emva kwexesha

- Akukho nto yakhe yandihambela kakuhle.
- Andiqinisekanga ukuba izinto ziza kundihambela kakuhle
- Izinto ziza kundihambela kakuhle

- Izinto ziyandikhathaza lonke ixesha
- Izinto ziyandikhathaza amaxesha amaninzi
- Izinto ziyandikhathaza kanye emva kwexesha

- Phantse zonke izinto ndizenza kakuhle
- Izinto ezininzi ndizenza kakuhle
- Yonke into ndiyenza ngokungalunganga

- Ndjongeka kakuhle
- Zikhona izinto ezimbi kwinkangeleko yam
- Ndjongeka mbi

- Ndiyazicaphukela
- Andizithandi
- Ndiyazithanda

- Andiziva ndililolo
- Ndiziva ndililolo amaxesha amaninzi
- Ndiziva ndililolo onke amaxesha

- Andicingi ngokuzibulala
- Ndiyacinga ngokuzibulala kodwa andinokuyenza
- Ndiyafuna ukuzibulala

- Ndinabahlobo abaninzi
- Ndinabo abahlobo kodwa ndinqwenela ukuba nabanye
- Andinabo abahlobo

- Akukho mntu undithanda ngenene
- Andiqinisekanga ukuba ukhona nawuphina umntu ondithandayo
- Ndiqinisekile ukuba ukhona umntu ondithandayo

bethaibhokisi!

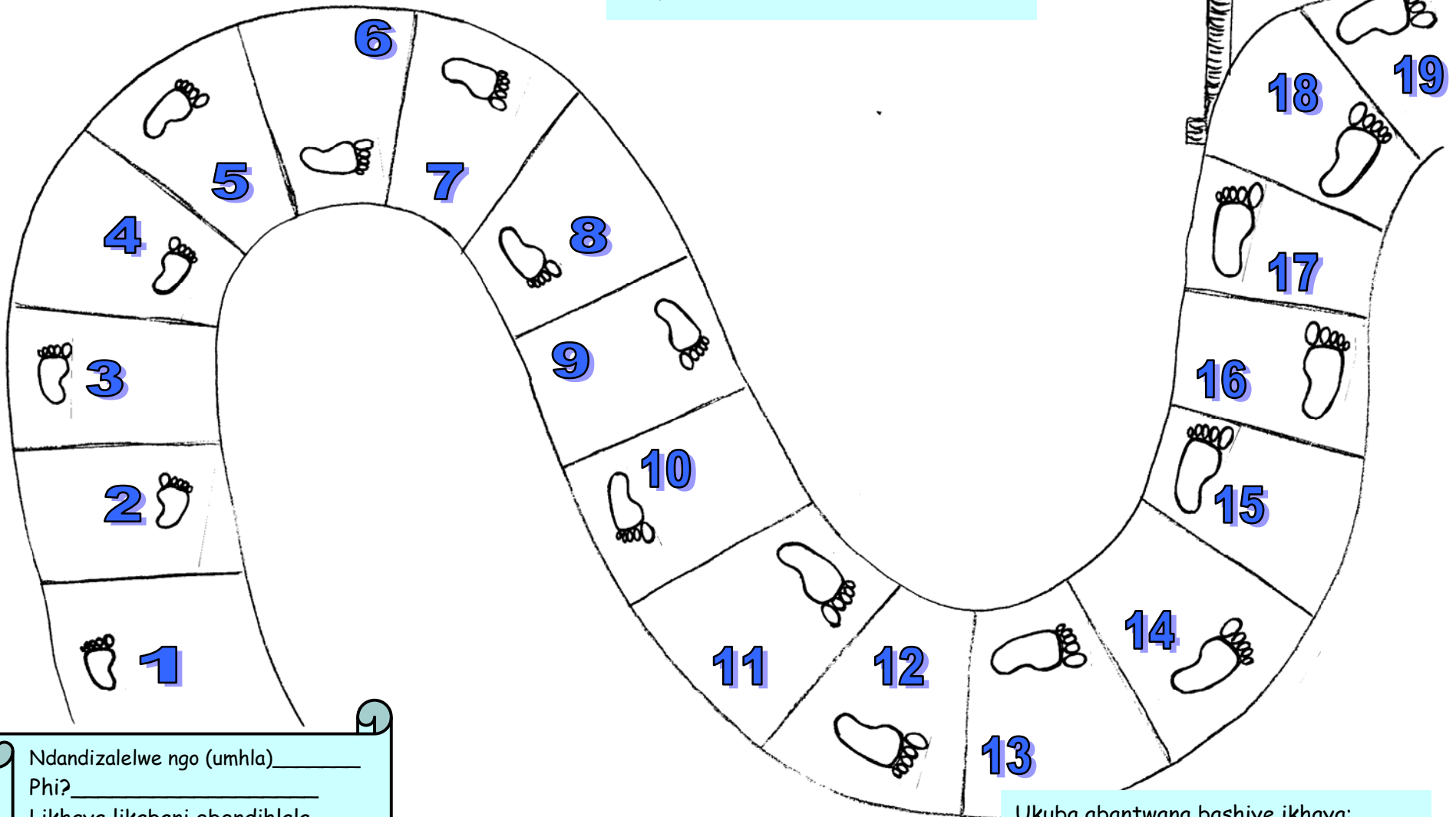
Abantwana abaninzi kunye nolutsha baziva benamanwele okanye benxunguphele ngamanye amaxesha. Nceda funda umbuzo ngamnye ngononophelo, uze ukrwele ku 'ewe' okanye 'hayi'

Ndinengxaki yokungakwazi ukuzithathela izigqibo.	hayi	ewe
Ndibanovalo xa izinto zam zingahambi ngendlela endifuna ngayo.	hayi	ewe
Abanye abantu bajongeka besenza izinto lula kunam.	hayi	ewe
Ngamanye amaxesha ndinengxaki yokuphefumla.	hayi	ewe
Ndiyakhathazeka (ndiziva) amaxesha amaninzi.	hayi	ewe
Ndiyazoyika izinto ezininzi (izinto ezindoyikisa).	hayi	ewe
Ndibanomsindo lula.	hayi	ewe
Ndicinga ukuba abanye abantu abayithandi indlela endenza ngayo izinto.	hayi	ewe
Ndicinga ukuba abanye abantu abayithandi indlela endenza ngayo izinto.	hayi	ewe
Kunzima ukuba ndilale ebusuku.	hayi	ewe
Ndiyaxhalaba ngezinto abanye abantu abazicingayo ngam.	hayi	ewe
Ndiziva ndindedwa noxa ndikunye nabanye abantu.	hayi	ewe
Ngamanye amaxesha ndiziva ndinesisu umzekelo xa ndikhathazekile.	hayi	ewe
Ndikhathazeka ngokukhawuleza.	hayi	ewe
Izandla zam ziyafuma/ Izandla zifumile kukubila.	hayi	ewe
Ndidiwa kakhulu.	hayi	ewe
Ndibanexhala ngento ezakwenzeka.	hayi	ewe
Abanye abantwana bonwabile kunam.	hayi	ewe
Ndiphupha kakubi.	hayi	ewe
Ndikhathazeka ngokukhawuleza xa ndigxekwa.	hayi	ewe
Ndicinga ukuba umntu uzakundixelesa xa ndingenzi izinto ngendlela.	hayi	ewe
Ndivuka ndisoyika ngamanye amaxesha.	hayi	ewe
Ndiyoyika xa ndisiya kulala ebusuku.	hayi	ewe
Kunzima ukugcina umsebenzi wesikolo.	hayi	ewe
Ukuba ewe, Ingaba kukho nto ithile onokucinga ngayo ekwenza ukuba kubenzima uku?		
Ndiyangcangcazela kakhulu xa ndihleli.	hayi	ewe
Ndinovalo (<i>I am nervous</i>).	hayi	ewe
Abantu abaninzi abekho ngakwicala lam.	hayi	ewe
Ndiyaxhalaba xa kusenzeka into embi kum.	hayi	ewe

Indlela yam yobomi

- Likhaya likabani obuhlala kulo?
- Ngubani umntu ebekujongana nawe kakhulu?
- Kwakutheni izinto zitshintshe?

IKAMVA



Ndandizalelwe ngo (umhla) _____
 Phi? _____
 Likhaya likabani ebendihlala kulo? _____
 Ngubani obendijonge kakhulu? _____

Ukuba abantwana bashiye ikhaya:

- Ingaba bekukhona ingxaki zokuba ngubani ofumene indlu/ okanye imali xa ubuhamba? _____
- (ukuba ewe) ngubani ongene endlini yakho endala? _____

Abahlobo kunye nabantwana...

Abanye abantwana kunye nolutsha balungile. Bangaphinda bakhohlakale kwabanye.

Kumbuzo ngamnye, nceda utsho ukuba ucinga yinyani okanye asiyonyani okanye zombini impendulo. Iyakunceda into yokuphendula yonke le mibuzonokuba uyathandabuza okanye ibonakala njengesigezo! Cinga ngendlela into ebezigiyo kwinyanga ezintandathuezi ellulileyo.

	ayiyonyani	awuqinisekanga	yinyani
Ndisoloko ndindodwa. Ndibandedwa ukuze ndigcine loo nto kum			
Ndinomhlobo wenene omnye okanye ngaphezulu			
Abanye abantu abalingana nam bayandithanda			
Abanye abantwana okanye abancinci bayandichukela okanye bandinyhukule			
Ndiqhuba kakuhle nabantu abakhulu kunabo balingana nam			

Ngoku sifuna ukwazi ngonyaka ophelileyo. **Kulonyaka abanye abantwana ...**

	Nakanye	kanye	kanye-kathathu	kane okanye ngaphezulu
Bandibiza ngamagama okanye bandithuka				
Bazama ukundifaka enkathazweni netshomi zam				
Bathatha into ngaphandle kwemvume okanye baba izinto kum				
Bahlekisa ngam ngenxa yezizathu wezithile				
Bandenza ndizive ndingakhululekanga ngokuthi basondele okanye bandibambe				
Bandibetha ngenqindi, bandikhaba okanye bandibethe				
Bandibetha ngenqindi, bandikhaba okanye bandibethe				
Ndazama ukophula okanye ukumosha into yam				
Wala ukuthetha nam okanye wenza abanye abantu bangathethi nam				

kwenziwa ☐ esikolweni ☐ ngaphandle kwesikolo ☐ zombini

① Ukhona umntu ohlala nawe okujongayo? ☐ ewe ☐ hayi

⇨ nceda uzobe lo mntu okanye ubhale amagama abo apha.
Badala kangakanani?_____Ingaba lomntu uyi.....

☐ Umnakwethu	Umalume
☐ Utata omncinci	ummelwane/ umhlobo wosapho
☐ Umakhulu	Utata okuzalayo
☐ Udadewethu	Umakazi
☐ Umama ondigcinayo	Umama otshate notata
☐ Utatomkhulu	Umama okuzalayo
☐ akukho mntu	Unontlalontle/umntu okukhathaleleyo
☐ Utato ondigcinayo	Olunye _____

Ingaba lomntu akaphilanga ☐ zange ☐ akafane ☐
ngamanye ☐ ngamanye amaxesha ☐ amaxesha onke

Ngezantsi luluhlu lwabantu. Sithanda ukwazi ukuba loluphi uncedo kunye nokunakekelo abakunika wena..

	Lomntu ngumntu osebomini bam	Lomntu uyandinceba xa ndinengxaki zam	Lomntu uyandinceba xa ndifuna imali kunye nezinye izinto	Ndiyowaba nalomntu
	ewe hayi	not at all sort of very	not at all sort of very	not at all sort of very
Umntu okukhathaleleyo				
usisi wakho okanye ubhuti				
utishala				
inqununu okanye isekela nqununu				
iqela labahlobo benene				
abanye abantu (sixelele ngobani)				

Izinto ebezinzima kum...

Nanku uBuntu no Lindiwe, basibonisa izinto apho abantwana abaninzi eKapa abathe behlangabezana nazo. Ungasixelela ukuba ezizinto zakhe zakwehlela nawe?

Ubuntu ukhuthuziwe kwaye kwabiwa izinto zakhe.
Kulonyaka, kukangaphi apho uthe wanezinto ezibiweyo? _____

UBuntu ebegula kulonyaka sisifo sephepha(TB). Ulindiwe ebekhe akaziva kakuhle esuswini. Ubukhe wagula kulonyaka?_____ yintoni?_____

Kukhona iindlela ezingalunganga zokubamba uBuntu noLindiwe. Ingaba kukhona umntu owakhe wakubamba ngendlela apho uzive ungonwabanga?_____. Ingaba kukhona umntu owathi wakwenza nantoni na kumalungu akho esini okanye kumalungu abo esini obungafuni ukuyenza?_____

Umnakekeli ka Lindiwe uyamngxolisa kakhulu.
Kukangaphi evekini eqhelekileyo apho uthi ungxoliswe kokwenu?_____

Ubuntu wahlaselwa kwaye wabethwa xa wayephumile. Wakhe wabethwa okanye wahlaselwa ngaphandle?_____



Umhlobo ka Lindiwe ongu Andile ubethwa ngabantu abadala kowabo. Wakhe wabethwa kokwenu?____ngantoni?

Ubuntu wabona umntu ebumelwaneni edutyulwa. Ulindiwe wabona umntu ohlatywayo ngobunye ubusuku. Wakhe wabona umntu odutyulwayo_____okanye ohlatywayo?_____

Wakhe wabona into engenye ekucaphukisayo? _____

Usapho luka Andile lunengxabano ezininzi. Ngamanye amaxesha abantu abadala bayangxolisana ngamanye amaxesha kuyaliwa.

Kuleveki iphelileyo, zingaphi iintsuku ebekukho iingxabano nabantu abadala bengxolisana ekhayeni lakho?_____
Zingaphi iintsuku apho bekukhe kwakhona iingxabano nabantu abadala bebethana ekhayeni lakho?

ULindiwe no Buntu basoloko bengenakutya kwaneleyo emakwabo.
Zingaphi iintsuku kuleveki apho ubungenakutya kwaneleyo?_____

Umama kaBuntu no Lindiwe babegula ixesha elide phambi kokuba asweleke. Utata wabo akaphilanga ngalomzuzu. Abanye abantu bebengenabubele kubo ngenxa yoku.

Wakhe wahlekwa okanye waphathwa kakubi kuba abantu kusapho lwakho lungaphilanga?

Teased ☐ Azange ☐ Ngamanye amaxesha ☐ Rhoqo

treated badly ☐ Azange ☐ Ngamanye amaxesha ☐ Rhoqo

Ingaba abantu bakha bakuhleba ngalonto ungazi?

☐ Azange ☐ Ngamanye amaxesha ☐ Rhoqo

Ingaba yakukhathaza? ☐ Azange ☐ kancinci ☐ kakhulu

Umama kaBuntu no Lindiwe wasweleka kwiminyaka embalwa edlulileyo.

Babenomfo wabo omncinci owaswelekayo.

Ingaba unomntu okufutshane nawe owaswelekayo? Ungasixelela ukuba yayingobani? When? Do you know what happened? (ungabhala, okanye ubazobe okanye usebenzise izincamathelisi)

Ngamanye amaxesha kuyanceda ukuthetha nomntu malunga nendlela oziva ngayo xa umntu osondeleleneyo naye eswelekile. Ingaba wakhe okanye wathetha naye nabani ngalento? ☐ ewe ☐ no
Ngubani? _____

Ingaba kukhona enye into ekhe yehla esingakhange siyichaze ethe yakoyikisa? _____



Uziva njani nge...?

Iqela C) Abantwana abaninzi bahamba kwizinto ezibuhlungu okanye ezoyikisayo, Singathanda ukwazi ngazo nokuba waziva njani ngazo. Ingathi kanti zisanda kwehla okanye zehla kwixesha elidlulileyo, kodwa zisakukhathaza. Zingaba kuluhlu esikubuze kulo, okanye enye into.

Ungasixelela ukuba yeyiphi into eyakukhathazayo kakhulu okanye yakoyikisa eyakhe yehla kuwe?-

Iqela A&B) Abantwana abaninzi bahamba kwizinto ezikhathazayo okanye ezoyikisayo,. Singathanda ukwazi ngazo nokuba uzive njani ngazo. Zingabe zisandula ukwenzeka okanye zenzeke kwixesha lakudala kodwa zisakukhathaza. Uthe abazali bakho basweleka kwixesha elide elidlulileyo. Ingaba yinto elungileyo le ukuba sikubuze ngayo, okanye enye into yenzeka eyakukhathaza nangaphezulu?

Ungasixelela ukuba yeyiphi into eyakukhathaza kakhulu okanye yakoyikisa eyakhe yakwehlela.

Ngoku thatha le bhola yentenetya.

Nceda uphulaphule umbuzo ngamnye, uze uncamathisele ibhola yentenetya ebhodini ukubonakalisa ukuba uzive ngoluhlobo'azange' ngamanye amaxesha,' amaxesha amaninzi,' onke amaxesha' kulenyanga iphelileyo.

		Hayi nakanye	nagmaxesha athile	ngamaxesha amaninzi	ngamaxesha onke
	Ingaba unamaphupha amabi nawoyikisayo ngento eyenzekayo?	○	●●	●●●	●●●●
Uyakhathazeka xa ucinga ngokwenzekayo?					
Uyakhathazeka uxhalabe xa kukho into ekukhumbuzayo ngokwenzekayo?					
	Uyaphinda - phinda ukucinga ngokwenzekayo?				
Uneengcinga okanye umfanekiso - ngqondweni ekufikelayo ngento eyenzekayo, noxa ungafuni?					
Unexhala lokuba lo nto ingenzeka kwakhona?					
Uyazama ukungacingi ngokwenzekayo?					
Uyaziphepha okanye awuzibandakanyi nezinto ezithi zikukhumbuze ngento eyenzekayo?					
Unengxaki yokukhumbula izinto ezithile ezibalulekileyo ngento eyenzekayo?					
Wenza izinto ngokulinganisa ngendlela esenzeka ngayo isiganeko eso?					
	Uva ngathi lo nto iyenzeka kwakhona noxa ingenzeki?				
		Hayi nakanye	nagmaxesha athile	ngamaxesha amaninzi	ngamaxesha onke

Uva ngathi kunzima ukuba uvakalelwe, va udangele emphefumleni?				
Uzigcina uxakekile usenza izinto ukuze ungacingi ngento eyenzekayo?				
Uva iintshukumo zomzimba xa kukho into ekukhumbuza ngokwenzekayo (umzekelo: usuke ubile ungancazele, intliziyo ibethe nagamandla, uphelelwe ngumphefumlo, isisu sibebuhlungo? 				
 Uba nengxaki yokulala okanye uyaphuthelwa?				
 Uba nengxaki yokumamela ngenyameko - umzekelo: ukumamela izifundo, kuba ungakwazi ukuzikisa ukucinga?				
Uva ngathi kufuneka usuloko uphaphamile /ugadile ukuba kunokwenzeka?				
Uba phaku-phaku okanye wothuka msinya?				
Uba nomsindo okanye ucaphuka lula?				
 Uba nomsindo okanye ucaphukiswe ngabantu ebantwini ngaphandle kwesizathu?				
Uba nomsindo kakhulu ebantwini kangangoba ungambetha okanye umenzakalise umntu? 				
Ingaba kukho nto ithile onokucinga ngayo ekwenza ukuba kubenzima uku?				
 Ingaba uziva kunzima ukonwabela ukwenza izinto?				
Ingaba ukhe uzive kunzima ukonwaba?				
 Ingaba uziva uwedwa nokuba uhleli nabanye abantu?				
Uziva kakubi okanye unesazela - ukuba okwenzekileyo bekuyi mpazamo yakho?				
Ingaba uyazichamela okanye imondlalo ngempazamo?				
Uziva ingathi owiqiqi okanye ingathi awubhadlanga kangangokuba umke ezingqondweni zakho kwaye ungacingi?				

Izinto endizenza evekini...

Nceda wenze
isangqa kwezo
udla
ngokuzenza



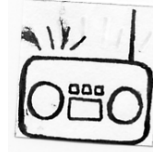
Ukudlala isixhobo



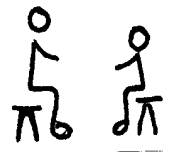
ukucula



ukudlala umdlalo
njengamapetyu okanye idayisi



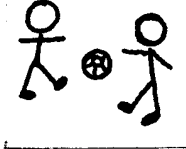
ukumamela umculo



Ukubonana
nekhansila



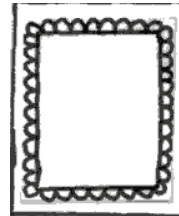
ukudlala umdlalo
webhola yamantombazana



ukudlala ibhola ekhatywayo



ukudada



ndenze omnye umdlalo
owuphi?



Ukudanisa



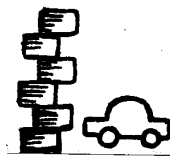
Ukucela



ukuhlala nabahlobo



ukusebenzisa ikhomputha



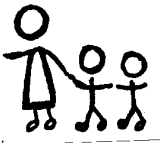
ukudlala ngethoyi



Ukwenza umsebenzi
wasendlini (zingaphi iyure ngemini)



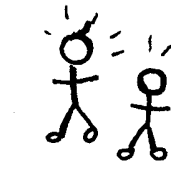
umsebenzi ongaphandle
kwekhaya(zingaphi
iyure ngemini)



ukuphuma nosapho



Ukubukela I TV



ukudlala imidlalo



ukufunda

AMAQEMBU OLUTSHA KUNYE NAMAQELA

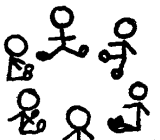
Ingaba uya rhoqo kumaqela olutsha?



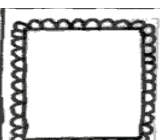
Umculo, iqonga
okanye umdaniso weqela



iqela lemidlalo



iqela loncedo



Olunye uhlobo
lweqela lolutsha

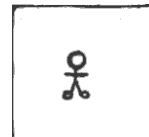
Xa uziwa uphantsi okanye udakumbile, ingaba wenza enye yezizinto
ukuzonwabisa?



Ukufunda
umculo



ukudlala imidlalo



Ukuba wedwa



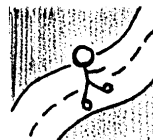
iTV



ukumamela



sport



ukuhamba-hamba



ukuhlala nabahlobo



ukuya kwithala leencwadi



Umsebenzi
wesikolo



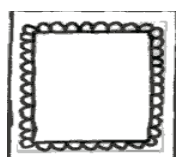
Ukucengwa
yitshomi



ukuya kulala



ukubhala okanye
ukuzoba indlela



enye...chaza

Ukuziva ungaphilanga okanye unomsindo...

Kumbuzo ngamnye, nceda utsho ukuba ucinga yinyani okanye asiyonyani okanye zombini impendulo. Cinga ngendlela into ebezigiyo kwinyanga ezintandathuezi ellulileyo.

Nceda thatha ikhasi lombuzo ngamnye uze ulifake ebhokisini eyona ichaza wena. Ezi bhokisi zibhalwe AYIYONYANI' 'AWUQINISEKANGA' and 'YINYANI'

	ayiyonyani	Awuqinis-ekanga	yinyani
Ndiyeba ekhaya			
Andizifumanisi ndinetyala emva kokuba ndenze into ebekungafanelekanga ukuba ndiyayenza			
Ndihamba nabantwana abasoloko bengena ezinkathazweni			
Ndisoloko ndisenza oko ndikuyalelweyo			
Kungcono ndibe nabantwana abadala kunabalingana nam			
Ndibalekile ekhaya			
Ndenza umlilo			
Ndiyeba ekhaya			

	ayiyonyani	Awuqinis-ekanga	yinyani
Ndiyeba kwezinye iindawo ngaphandle kwasekhaya			
Ndiyathuka okanye ndithethe izinto ezimdaka			
Ndisebenzisa utywala neziyobisi (andizisebenziseli kugula)			
Ndiyaxoka okanye ndiqhathe			
Ndiziva ndidinwe kakhulu			
Iingxaki zomzimba ngaphandle konobangela wokugula			
Amahlaba okanye iintlungu(ingabi yintloko ebuhlungu)			
Intloko ebuhlungu			

	ayiyonyani	Awuqinis-ekanga	yinyani
Ukuziva ngathi uzakukhupha, ukuziva ugula			
Iingxaki zamehlo....chaza			
Irhashalala okanye ezinye ingxaki zolusu			
Isisu esibuhlungu okanye iinkantsi			
Ukugabha, ukukhupha			
Ndiyacaphuka ndibenomsindo ogqithileyo			
Andiyi eklasini ngamanye amaxesha, ngamanye nditsiba iintsuku zokuya esikolweni.			
Ndilwa rhogo. Ndingenza abantu benze into ethandwa ndim			

Iphepha lokugqibela!

Kwezinye iindawo abantu ekuhlaleni bayazana kwaye bayancokola, kanti kwenzinye abantu abaqhelenanga ngoluhlobo. Niqhelene kangakanani apha ekuhlaleni?

☐ siqhelene kakhulu ☐ siqhelene olohlotyana ☐ Asiqhelenanga kangako ☐ Asiqhelenanga konke-konke

Kubaluleke kangakanani ukukholwa empilweni yakho?

☐ most important

☐ somewhat important

☐ very important

☐ not important at all

Ngaphandle kwemitshato nemingcwabo uzihamba kangakanani iindibano zenkolo (icawa, temple, mosque etc)?

☐ more than once a week

☐ 1-2X a month

☐ never

☐ once a week

☐ a few times a year

Ngomhla wakho wokuzalwa, wawunomnyhadala(ikhekhe, okanye isidlo, okanye watyelelwa ngabahlobo)? ☐ hayi ☐ ewe

Ukuthanda kangakanani ukubasesikolweni? Okokuthetha ukuthi uyakonwabelana ukufunda nokuya eklasini?

☐ do not like it at all ☐ do not like it much ☐ like it ☐ like it very much

Ungathi ikamva lakho kunye namathuba akho okuphumelela anjani...?

Akhonto ithintela
amathuba akho

Unamathuba
amaninzi

Amathuba akho
ambalwa

Awunamathuba,
konke-konke

Lo ngumbuzo wokugqibela . Ukuba ungathanda ungazoba umfanekiso wakho kwixesha elizayo? okanye ubhale okanye usebenzise izincamathelisi) Uyakuba usenza ntoni?

Ndiyabulela kakhulu ngexesha ondinike lona ukuba ndithethe nawe. Phambi kokuba ndihambe, akukhonto ofuna ukuyibuza ngoluphando? Ayikho into ekuxhalabisayo okanye ekuhluphayo ofuna ukuyibuza? Ucinge ntoni ngalemibuzo uyibuziweyo? Ukuba ufuna ukubuza nayiphi into ngoluphando kwixesha elizayo, wamkelekile ukunxibelelana Lucie Cluver – Cape Town Child Welfare. Siyabulela kakhulu ngokuthi uthabathe inxaxheba.

siyabulela ngoncedo lwakho!

For interviewer/research team.

Attending school? ☐ yes ☐ no

If yes, attendance record

☐ very good ☐ misses some days ☐ poor

if missing school, why? _____

highest grade passed _____

Q1: Cause of Parental death

Q2: household income _____

Q3: Is the household receiving any grants? ☐ no grants ☐ foster care grant ☐ child support grant
☐ pension ☐ war veterans grant ☐ disability grant ☐ care dependency grant ☐ grant in aid ☐
social relief of distress ☐ child maintenance support (from father)

Q4: (only if child is living with 1 unwell parent) ARVs? _____

Any comments:

Appendix 6: Letters of thanks

6.1 Example letter to participating school

6.2 Letters to children

University of Oxford

Department of Social Policy and Social Work



BARNETT HOUSE
32 WELLINGTON
SQUARE
OXFORD OX1 2ER
ENGLAND
TEL 01865 270326
FAX 01865 270324

Cape Town Child Welfare

Ms Mandisa Ngqongqo
Yomelela Public Primary School
PO Box 172
Khayelitsha 7784

Dear Mandisa,

I wanted to write to thank you again for all your help with our research project for children in Cape Town. We appreciate your time and effort. The students at Yomelela were really fantastic participants, and they gave us very useful ideas.

I'm sending you a summary sheet of all the research findings so far, so that you can see how the whole project is going.

I've included letters to all the students who filled in worksheets, thanking them for their participation, and giving them a summary of what children all over Cape Town said in their worksheets. I'm including a copy of this for you so that you can see what we've sent them. Many of the children who took part in the whole project identified bullying as a worry for them, and I have also included a leaflet on bullying which might be helpful for schools.

We will be back in touch in September, and I hope that we can continue to work together with this project.

Kind Regards,

Lucie Cluver
Cape Town Child Welfare

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University of Oxford

Department of Social Policy and Social Work



Cape Town Child Welfare

Dear

In April or May this year, you filled in a worksheet for us, as part of some research which we are doing with children in Cape Town. (You might remember choosing Bart or Lisa Simpson, or DragonBall-Z) We are writing to say a huge THANK YOU for your time and effort. You are the experts and we couldn't do this without you.

We have taken some of the things which children have said, and put them together in a 'summary sheet'. we thought it might be interesting for you to see what other children have said, and you might even recognize some of the things you wrote or drew!

We hope that you enjoyed doing the research, and we may be getting back in touch with you in a few months to see if you would like to join in again.

Thanks so much. we really really appreciate your help

Lucie Cluver

Lucie Cluver
Cape Town Child Welfare

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Research with Children in Cape Town, 2005

Things that make children in Cape Town happy...

Having enough of... food, clothes, having a room with curtains, having enough money, having everything you need

school stuff... going to school, passing exams, getting an education, praise for doing well

family stuff... being loved, being told if you have done something wrong, spending time with people you love, brothers and sisters

doing stuff... reading, family outings, playing with toys, listening to music, watching TV, outings with other kids, playing on the computer, swimming, playing marbles, playing drums, relaxing, singing, dancing, playing pool, going to the beach, playing games, jumping on the bed, discussing what is happening in your community and in the world, listening to the radio, debates at school, playing sport, football and netball, having the opportunity to be a child, birthday celebrations

other stuff... being listened to, respect, attention and love, being with people who are positive, being treated like other children.

Things that make children in Cape Town sad or angry...

Not having stuff... not having enough food, school equipment, not having enough money or a place to live, not being able to wash or wash clothes

School stuff... not going to school, problems with school uniform and school fees, not being able to afford outings

being unwell...being in an unsafe area... having things stolen from you...being mugged...being accused of things you haven't done...people telling your secrets...being ignored

teasing... people swearing or teasing them about their parents, other children shouting, gossiping or being rude to them, fighting with friends, being bullied, friends not wanting to play with them

family stuff.. not being taken care of, when other children in the home are treated better, fighting with brothers & sisters, missing family, when someone you love dies, people fighting at home

other stuff...feeling alone, when a child is being abused, thinking too much, being shouted at

Things that make children in Cape Town happy when they are sad...

stuff you can do yourself...knowing yourself and who you are, praying, going to bed, writing in a life story book, writing in a diary, drawing your feelings, singing songs, going to be alone for a while, going for a walk to calm down, consoling yourself

family and friends... being with family, talking to friends, making jokes, talking through your problems, talking to someone you trust, getting advice from teachers or neighbours

going to school, playing, doing homework, watching football, watching TV, playing pool, playing netball or football or other sports

Resources which might come in useful one day...

We always include a sheet of resource numbers to all children who participate in our research. You may never need to use them, but sometimes it's useful to have numbers handy.

Elukhanyisweni

(counselling for children)

613 Silumko Street, Khayelitsha

021 361 3468

Empilweni

Victim support and life skills training

A 500, Makhabeni Road, Khayelitsha

021 361 7063

Legal Aid

Free legal advice For legal help, call 08610 LEGAL(53425) or email: talk@legal-aid.co.za

National AIDS helpline Free, 24 hrs a day 0800 012 322

Xhosa Language AIDS Information & Counselling Helpline

Wola Nani, Khayelitsha Office hours (Monday-Friday) Tel: (021) 361 6480.

Emergency Contraception Hotline

24-hour toll-free hotline for information and referrals on emergency contraception.

Toll-free Helpline: 0800 246 432

Rape Crisis Cape Town

Observatory: (021) 447 9762 Khayelitsha: (021) 361 9085

Counselling enquiries can be sent to:

kath@rapecrisis.org.za (English) ntombomzi@rapecrisis.org.za (Xhosa)

Our counselling service offers free and confidential support to women and men, over the age of 16, who have been raped or sexually assaulted: 24 hours a day

Childline (free line, 24 hrs a day. You can call with any concerns about abuse)

08000 55555 <http://www.childline.org.za/>

Childline Khayelitsha 021 361 5382

Al-Anon

For families and friends of problem drinkers, with a special section (Alateen) for children of alcoholics, as well as for adult children of alcoholics. Main office: (021) 591 6847 E-mail:

alanongso@iafrica.com

Red Cross Children's Hospital, Klipfontein Rd, Ronderbosch 021 658 5111

Appendix 7: Forms for participating organisations

7.1 Training forms for participating organisations

7.2 Consent forms for participating organisations

7.3 Forms for child identification

University of Oxford
Department of Social Policy and Social Work



BARNETT HOUSE
32 WELLINGTON
SQUARE
OXFORD OX1 2ER
ENGLAND

TEL 01865 270326
FAX 01865 270324



Cape Town Child Welfare

For: Participating organisations and schools

On behalf of Cape Town Child Welfare, the University of Oxford, and the Medical Research Council (SA), we would like to say how much we appreciate your time and effort in participating in this research.

As a small thank-you, the research team can offer your organisation/school 2-3 hours of training sessions for staff. Below is a list of the training which we can offer, although if there is something which you would find especially useful, and which is not on the list, please do discuss this with the research team. The training sessions are usually 1 hour long (although they may be up to 1 $\frac{1}{2}$ hours), and we can arrange to do them at a convenient time. Please choose 2 courses.

TRAINING OPTIONS (1 hour each)

- 1. Child abuse:** identifying signs of abuse, talking to children about abuse, and referring to social services
- 2. Child mental health A:** types of mental health problems for children, identifying the signs, and some basic techniques (Anxiety, depression, post-traumatic stress)
- 3. Child mental health B:** types of mental health problems for children, identifying the signs, and some basic techniques (Behaviour problems, drug use, schizophrenia)
- 4: Talking to children:** basic counselling skills and communication with children
- 5: Interviewing parents and home visits:** skills for talking to parents and guardians about children's well-being, and recording home visits.
- 6: Research and Evaluation:** guidelines for setting up a new project or evaluating a current one. Very useful when applying for funding!

The research team are happy to discuss more details of these sessions if you are unsure of which to choose. The training will be in English. Please say if you would need us to bring a translator for staff who do not speak English.

If you have any questions, please contact Lucie Cluver at Cape Town Child Welfare (contact details below)

Many thanks again for your participation

Lucie Cluver

Dept of Social Policy & Social Work
University of Oxford
Oxford
England
Tel (+44) 7980 856 651

Cape Town Child Welfare Society
Head Office
PO Box 374, Gatesville 7766
South Africa
Tel (0027) 21 638 3127

e-mail lucie.cluver@green.ox.ac.uk

Name of participating school/organisation

Address of school/organisation Tel no

Name of contact person

Training sessions chosen:

1) 2)

Number of staff who will be attending

University of Oxford
Department of Social Policy and Social Work



BARNETT HOUSE
32 WELLINGTON
SQUARE
OXFORD OX1 2ER
ENGLAND
TEL 01865 270326
FAX 01865 270324



Cape Town
Child Welfare Society

Date:

Re: Research with children experiencing bereavement in Cape Town

Dear Cape Town Child Welfare,

We confirm that we are happy to participate in the research project 'Risk and Protective Factors in the psychological well-being of orphaned children in Cape Town' (Data collection Sept 05-Mar 06). We will discuss what feedback and help (ie training for teachers) can be provided in thanks for our participation. The research team will provide feedback for the school on general findings.

Name of School _____

Principal/HIV/AIDS Co-ordinator _____

Signature _____

School Stamp.

We would like to express our thanks for your participation. This research hopes to provide information which will teach us how to best help vulnerable children in Cape Town.

Yours truly,

Lucie Cluver

Lucie Cluver

Email: lucie.cluver@green.ox.ac.uk

UK

Department of Social Policy and Social Work
University of Oxford
32 Wellington Square
Oxford OX1 2ER
Tel: (+44) 1865 270 325
Fax: (+44) 1865 270 324

South Africa:

Cape Town Child Welfare
Lower Klipfonten Rd
Gatesville, Athlone
Cape Town 7764
Tel: (+27) 21 638 3127
Fax: (+27) 21 638 4193

Thank you. This is page 2

School Name: **Grade:** **Class:** **Teacher Name:**



For each child who has experienced a parent dying, we also need to interview a child whose parents have not died. Please record the details of the children in your class whose parents have not died.

[illegible]

Appendix 8: Examples of referral letters

12.1 Examples of referrals to social services

12.2 School fees exemption requests

12.3 Examples of letters to children



Cape Town Child Welfare

To: Cape Town Child Welfare
Khayelitsha Office

Re: **Anda XXXXXX**
Date of Birth: **14.12.XXXX**
Address: **XXXX XXXXX Road, Site C, Khayelitsha**
School: **Vuzamanzi Primary School**

Cape Town Child Welfare is currently undertaking mental health research with vulnerable young people in Cape Town. Where we feel that a young person is at risk of significant harm, we make referrals to relevant organisations.

Anda is living with her mother, after her father's death. She identified in the research that her uncle attempted to rape her, but that she managed to escape. We consider that this child is at risk of future abuse, and are concerned that this be allocated to a social worker for further investigation.

Please do not hesitate to contact me if you require any further details, or wish to discuss this in more detail.

Yours truly,

Lucie Cluver

Lucie Cluver
Social Worker
Cape Town Child Welfare
Head Office
Lower Klipfontein Rd
Gatesville 7764
021 638 3127 (extension 213)

OFFICES

Head Office
Lower Klipfontein
Road
GATESVILLE 7764
Athlone

Tel: 021 638 3127
Fax: 021 638 4193

Manenberg
c/o Shawco
Building
Kasouga Road

Tel: 021 638 5131
Fax: 021 633 9132

Khayelitsha
Bancedeni Centre
D Section Site C

Tel: 021 387 0163
Fax: 021 387 5877

Guguletu
New Siseko Ctr
NY43

Tel: 021 638 1674
Fax: 021 637 2140

POSTAL ADDRESSES

S
P.O. Box 18008
WYNBERG 7824
South Africa

NPO No. 003 214
Tax Exemption #



Cape Town Child Welfare

To: Social Worker
PAWC Social Services Nyanga
Fax: 021 386 4030

Re: **Thulani XXXX (d.o.b 1997)**
Nomfusi XXXX (d.o.b 11.12.1989)
Miseka XXXX (b.o.b 20.02.1991)
Address: **XX XX XXXXXXXXXXXX Street, Veza Crossroads 7755**
Tel: **XX XXX XXX X**

Cape Town Child Welfare is currently undertaking mental health research with vulnerable young people in Cape Town. Where we feel that a young person is at risk of significant harm, we make referrals to relevant organisations.

This set of children's parents are both deceased, and they live in a Child-Headed Household, headed by Thulani. Nomfusi and Miseka are both attending school, but Thulani has dropped out of school due to inability to pay fees. The family are in dire financial circumstances, and are not receiving any grants or income. We request that this family be allocated to a social worker (if Social Services are not already aware of this case) for further investigation and support.

Please do not hesitate to contact me if you require any further details, or wish to discuss this in more detail.

Yours truly,

Lucie Cluver

Lucie Cluver

Social Worker
Cape Town Child Welfare
Head Office
Lower Klipfontein Rd
Gatesville 7764
021 638 3127 (extension 213)

OFFICES

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Lower Klipfontein
Road
GATESVILLE 7764
Athlone

Tel: 021 638 3127
Fax: 021 638 4193

Manenberg
c/o Shawco
Building
Kasouga Road

Tel: 021 638 5131
Fax: 021 633 9132

Khayelitsha
Bancedeni Centre
D Section Site C

Tel: 021 387 0163
Fax: 021 387 5877

Guguletu
New Siseko Ctre
NY43

Tel: 021 638 1674
Fax: 021 637 2140

POSTAL ADDRESSES

S
P.O. Box 18008
WYNBERG 7824
South Africa

NPO No. 003 214
Tax Exemption #
1811/12/2014



Cape Town Child Welfare

To: The Principal and Governing Body
Thandokhulu High School

Re: Learner: **Nosikelo XXXX**,
Date of Birth: **15.March XXXX**
Address: **XX XXX Macassar**

Dear Principal and Governing Body

Nosikelo XXXX has come to the attention of Cape Town Child Welfare as part of our work with orphaned children.

Nosikelo has been doubly orphaned – his mother was killed in community violence, and his father passed away from Natural Causes. Nosikelo completed Grade 10, and was forced to leave school due to lack of money to pay school fees.

We request that the school and Governing Body consider re-admitting Nosikelo XXXX, with allowance for the family's lack of ability to pay school fees in full.

With many thanks for your consideration of this matter.

Yours truly,

Lucie Cluver

Lucie Cluver

Social Worker
Cape Town Child Welfare
Head Office
Lower Klipfontein Rd
Gatesville 7764
Office: 021 638 3127 (extension 213)
Cell: 082 650 5815

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New Siseko Ctre
NY43

Tel: 021 638 1674
Fax: 021 637 2140

POSTAL ADDRESSES

S
P.O. Box 18008
WYNBERG 7824
South Africa

NPO No. 003 214
Tax Exemption #
1011112054



Cape Town Child Welfare

To: Mr A Clausen
Director: Examinations, Western Cape Education Department
Fax: 021 461 5637

Re: Learner: **Singathwa XXXXXX**
School: **Harry Gwala Secondary School, Khayelitsha**

Dear Mr Clausen

Thank you for taking the time to consider this request, which we would not be asking if this was not an exceptional circumstance.

Singathwa XXXXXX (d.o.b 26.12.XX) took her Matric in October 2005 at Harry Gwala Secondary School, Khayelitsha, and was reported to be a hardworking and dedicated learner. Her father is deceased, and she was the sole carer for her young brother and mother, who was in the final stages of dying of AIDS, and who passed away in December 2005.

Due to the caregiving burden, Singathwa failed two of her subjects. She is now sole carer for her young brother, and is determined to return to school to repeat her Matric. Harry Gwala Secondary school has expressed willingness for her to return this year, given her special circumstances and her strong previous record. The Principal has also offered to write a letter of support for the possibility of re-opening Matric Registration to allow Singathwa to complete her education. As her social worker, I also consider return to school to be crucial in restoring some normality and continuity in Singathwa's life.

We are aware that Matric registration has closed for this year. However, we can only ask you to consider the possibility of allowing Singathwa to return to school and re-take her Matric, and to give her the opportunity of overcoming the tragic experiences of the past year.

I appreciate that you are extremely busy, and thank you for reading this. I am available on my cellphone (082 650 5815) and will also attempt to contact you after your meeting today.

Yours truly,

Lucie Cluver

Lucie Cluver
Social Worker
Cape Town Child Welfare
Head Office, Lower Klipfontein Rd, Gatesville 7764
Office: 021 638 3127 (extension 213)
Cell: 082 650 5815

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Fax: 021 387 5877

Guguletu
New Siseko Ctre
NY43

Tel: 021 638 1674
Fax: 021 637 2140

**POSTAL
ADDRESS**
P.O. Box 18008
WYNBERG 7824
South Africa

NPO No. 003 214
Tax Exemption #
18/11/13/3954

General Email:
helpkids@mweb.co.za

www.helpkids.org.za



Cape Town Child Welfare

Nosiviwe XXXXXX
XX-XXX Makhaza XXXXX St
Makhaza
Khayelitsha

Dear Nosiviwe

Thank you again for taking part in the Child Welfare research this year. When you were doing the worksheet, you said that sometimes you felt very alone and thought about hurting yourself. We wanted you to know that there are people who you could talk to when you feel very sad. Even if you do not have money to make a phone call, Childline is a free call. There is also a clinic in Macassar and one in Site B where you can go and talk to them about seeing someone.

LifeLine Cape Town
(021)461 1111
(Lifeline also do Counselling in their Khaylelitsha office)

Childline
08000 55555

Macassar Community Psychology Project
Zandvliet Secondary School
Zandvliet Road
Macassar 7130
Tel / Fax: 857-1566

Empilweni Community Mental Health Project
Spine Road, Site B
021 361 7063

Wishing you all the best for the future

Lucie Cluver

Lucie Cluver

Social Worker
Cape Town Child Welfare



Cape Town Child Welfare

Yandiswa XXXX
XXX New Rest
Guguletu 7750
XXXXXXXXXX Primary School

Dear Yandiswa

Thank you again for taking part in the Child Welfare research this year. When you were doing the worksheet, you said that a while ago, you had been raped. We wanted to say that you are a very brave girl and that you must remember that it was not your fault. If you ever want to talk to someone about this, these are telephone numbers which might be able to help.

Rape Crisis Khayelitsha
- +27 (0)21 361 9228
Counselling line - +27 (0)21 361 9085

LifeLine Cape Town
(021)461 1111

Childline
08000 55555

AIDS Helpline
0800 012322

Wishing you all the best for the future

Lucie Cluver

Lucie Cluver

Social Worker
Cape Town Child Welfare
Head Office

Appendix 9: Summary briefs for NGOs, schools and government

Appendix 10: Current plan for a national survey



National Survey: AIDS-orphanhood in South Africa

Lucie Cluver

Revised Proposal June 2007

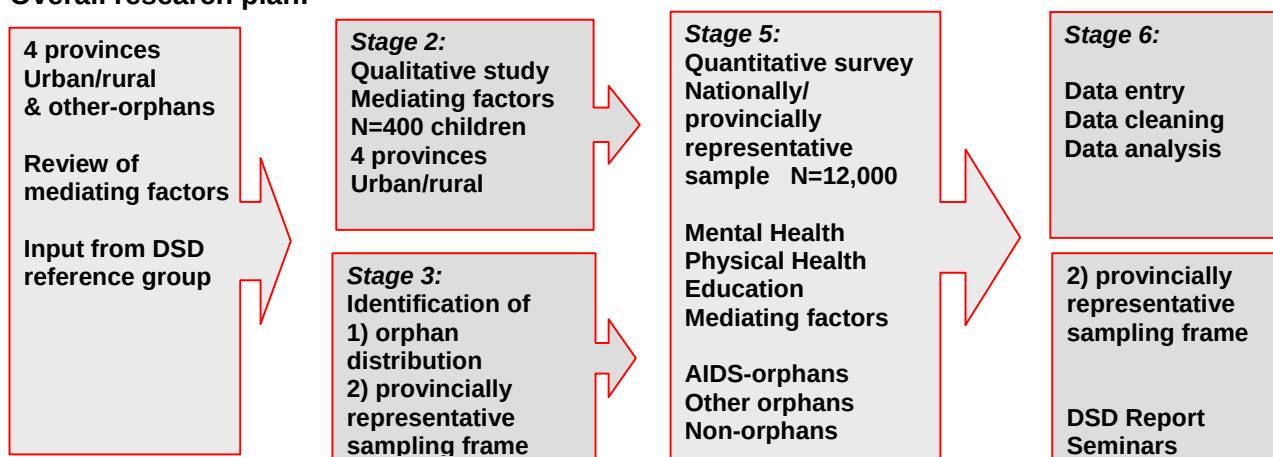
Background:

The number and proportion of orphans in South Africa will rise dramatically in the next decade. 19% of all children were orphaned in 2005 (GHS, 2005). HIV/AIDS alone will cause 2.3 million orphans by 2015: 86% of all orphans will be due to HIV/AIDS (Dorrington et al, 2005). What is the required state response to this increase, and will this response need to differ for AIDS-orphans and other orphans?

Reliable scientific evidence is required for proactive policy responses: a qualitative and quantitative national survey of orphanhood, conducted in all 9 provinces and balanced between rural and urban areas. An effective pilot for this national study has been conducted in the Western Cape (Cluver, Gardner et al, 2006, 2007).

This revised draft proposal has been developed with the input of Minister Zola Skweyiya, Director-General Vusi Madonsela, Deputy Director-General Vuyelwa Nhlapo, Chief Director HIV/AIDS Dr Connie Kganakga and Chief Director Children, Youth and Families Dr Maria Mabetoa.

Overall research plan:



Child outcomes to test:

Broad outcomes, with example indicators. Additional outcomes to be added by the DSD Reference Group.

Key outcomes

Measurement

EDUCATION School enrolment and attendance Educational achievement	School registers Teacher report Achievement; grade repetition
PHYSICAL HEALTH AND HIV Child Development, Malnutrition HIV status, health status	Examination by trained community health workers. Height/weight etc Prevalence of HIV, TB, diarrhoea, lower respiratory infections and malnutrition (Bradshaw, Bourne, & Nannan, 2003)
MENTAL HEALTH Depression, PTSD Conduct problems, substance abuse	Standardised, validated psychological questionnaires: CDI, CBCL, SDQ, Child PTSD Checklist (child report)

Mediating factors:

Multiple methods will be used to identify implementable, policy-relevant factors to improve orphan well-being:

- Systematic review of mediating factors identified by studies of AIDS-orphans
- General review of mediating factors amongst vulnerable children
- Identification of further policy-relevant factors by DSD Reference Group (ie specific caregiving arrangements)
- Qualitative study with AIDS-orphans to identify factors not emerging from review
- Combined factors piloted and tested in large-scale quantitative study

Stages a-d already completed for mental health outcome (Cluver et al 2007)

Mediating factors already identified from pilot study:

- Food security
- Household receipt of social security
- School enrolment and attendance
- Employment within household
- AIDS-related stigma
- Caregiver illness
- Type of caregiving arrangement

Further factors identified by DSD:

- African-specific cultural practices around parental death
- Extended family support and stigma
- Community support
- Children in non-family foster care
- Reasons for non-access of social grants

Collaborative capacity-building:

Each Research specialist (Mental health, Physical Health, Education) will engage and collaborate with a research partner from a formerly disadvantaged university. The Department of Social Policy and Social Work has a strong working relationship with Fort Hare University.

Sample:

- One or both parents deceased (UN definition of orphanhood)
- 9 provinces, urban/rural, formal/informal spread: 12,000 children.
- Additional samples of streetchildren, child-headed and youth-headed households.
- Stratified age groups: 0-5, 6-10, 11-17 (using age-appropriate measurement tools)
- Comparing AIDS-orphans, other orphans, non-orphans (matched by location)
- Due to ethical implications, HIV+ children will not be interviewed as a separate sample, but will be included within the community sample.
- Children in range of caregiving arrangements: additional sampling to ensure inclusion of children in institutions, orphanages, children's homes and prisons.
- Parental death classified by verbal autopsy method (Hosegood et al, 2004)

- DSD have suggested interviewing of caregivers as well as children: this would be highly valuable evidence but would raise research costs considerably

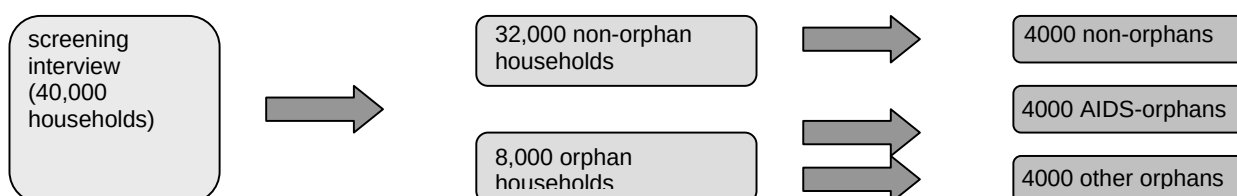
Sampling strategy (quantitative stage):

Two main options are outlined for sampling strategy.

1) *A nationally and provincially-representative sample* would allow for identification of priority intervention zones on a small area level. However, this would require all 9 provinces and a larger sample size than non-representative sampling options. A provincially-representative sample would require a larger sample size than a nationally-representative sample. It would also require the identification and stratification of a national sampling frame. I would recommend an additional purposive sample of streetchildren, child-headed and youth-headed households, and children living in children's homes and in prison.

Suggested 2-stage quantitative sampling strategy for national/provincial sample:

- 1) Screening interview of 40,000 households to determine a) presence of child, b) death of parent. Of non-orphan households with children, 20% randomly selected for inclusion as control group
- 2) For estimated 8000 orphan households (from 40,000 initial, based on GHS data), full interview conducted with one randomly-selected child (4000 AIDS-orphaned, 4000 orphaned by other causes)



2) *Non-representative options* include random selection of wards, with randomised school sampling within wards. Additional community sampling would capture children not attending school, streetchildren, children living in children's homes and in prison. This strategy could take place in all, or a limited number of provinces, and would allow for a range of formal/informal and urban/rural. GHS (2005) data suggests 4 provinces of Kwa-Zulu Natal, Eastern Cape, Gauteng and Limpopo. However, this method would not provide an estimation of the extent of need between provincial or within the national populations.

Proposed timetable:

Start date: April 2008 End date: October 2009.

It is essential that this research is undertaken by a methodologically strong and independent research institution. It is also essential that rigorously scientific methods are used, and that peer-reviewed publications are produced in order to validate findings. The Department of Social Policy and Social Work at Oxford University have extensive capacity in research design, data collection, analysis of national-level datasets and publication. The department has a strong working relationship with the University of Fort Hare, and an already-established history of working with the Department of Social Development. Lucie Cluver has conducted the world's largest study of mental health amongst AIDS-orphaned children, which will serve as the pilot study for this project.

Contact: Lucie Cluver
(MA Cantab, MSc/DipSW Oxon, MSc Oxon)
Cape Town Child Welfare/Oxford University

lucie.cluver@socres.ox.ac.uk
SA cell +27 82 650 5815
UK cell +44 7980 856 651

References:

- Bradshaw, D., Bourne, D., & Nannan, N. (2003). *What are the leading causes of death amongst South African children?* Cape Town: MRC Policy Brief no.3.
- Cluver, L, Gardner, F & Operario, D (2007) *Psychological distress amongst AIDS-orphaned children in urban South Africa*. Journal of Child Psychiatry and Psychology 48(8)
- Cluver, L & Gardner, F (in press) *The Mental Health of Children orphaned by AIDS: A review of International and South African Research*. Journal of Child and Adolescent Mental Health. July 2007
- Cluver , L. & Gardner, F. (2007) *Risk and protective factors for well-being of children orphaned by AIDS in Cape Town, South Africa: a qualitative study of children's views*. AIDS Care 19(3) 318-325
- Cluver , L. & Gardner, F. (2006) *Psychological well-being of children orphaned by AIDS in Cape Town, South Africa*. Annals of General Psychiatry. 5, 8. BioMed Press.
- Dorrington, R., Johnson, L., Bradshaw, D., & Daniel, T. (2005). *The demographic impact of HIV/AIDS in South Africa: National and Provincial indicators for 2006* Cape Town: South African Medical Research Council and Actuarial Society of South Africa.
- Hosegood, V, Vanneste, A, & Timaeus, I. (2004). *Levels and causes of adult mortality in rural South Africa: the impact of AIDS*. AIDS, 5(18), 663-671.
- Statistics SA. (2006). *General Household Survey 2005*. Pretoria.

Appendix 11: Policy Implications of study findings

The findings of this study suggest a number of potential policy implications, applicable to both government and NGO responses to AIDS-orphanhood. The following discussion is a result of consultation and refining of arguments with key academics and policy-makers in Cape Town, Pretoria and Durban. Particular thanks are due to Professor Renfrew Christie (Dean of Research, University of the Western Cape), Chris Desmond (Joint Learning Initiative on Children Affected by AIDS), Kate Orkin (University of Cape Town) and Dr Rachel Bray (Human Sciences Research Council).

The policy implications suggested here are also a result of discussion with members of government directly responsible for orphaned and vulnerable children: Dr Zola Skweyiya (Minister of Social Development, South Africa), Vusi Madonsela (Director-General of Social Development, South Africa), Vuyelwa Nhlapo (Deputy Director-General of Integrated Development), Dr Connie Kganakga (Chief Director of HIV/AIDS) and Dr Maria Mabetoa (Chief Director of Children, Youth and Families).

Increased vulnerability of AIDS-orphaned and orphaned children

The findings of this current study show that AIDS-orphaned children are at higher risk of psychological distress than other children. These findings add to emerging evidence of increased vulnerability in other areas. A large study in Kwa-Zulu Natal suggests strongly that AIDS-orphaned children have lower school enrolment and attendance (Case & Ardington, 2005). Disaggregation of national survey data found that orphaned children (no distinction was made within orphanhood) are less likely to complete primary education (Operario et al., in press) and are at higher risk of contracting HIV (Operario et al., 2007).

Targeted services and targeting access to services

Study findings establish the following for the isiXhosa-speaking urban Western Cape:

- 1) AIDS-orphaned children have more psychological problems than other children;

- 2) AIDS-orphaned children are living in poorer households;
- 3) AIDS-orphaned children are less likely to be accessing poverty-alleviation services;
- 4) Poverty and lack of access to services mediates the effect of AIDS-orphanhood on mental health;
- 5) AIDS-orphaned children are also more vulnerable because of a range of other factors, such as stigma, caregiver illness and young carer responsibilities.
- 6) Risk factors are interacting to produce strong cumulative effects, which further heighten children's risk of mental health problems.

This study suggests that several important mediating factors in the relationship between AIDS-orphanhood and mental health take place at a family or household level within Bronfenbrenner's ecological framework (Bronfenbrenner, 1979). These include poverty-related factors such as school access, and care factors such as caregiver illness and housework. Such findings suggest the potential utility of supporting the 'informal safety-nets' (Richter et al., 2006, p. 44) of family and households in order to provide care for orphaned children.

It seems as if some of the heightened vulnerability experienced by AIDS-orphaned children has the potential to be diminished by existing poverty alleviation services and policies. AIDS-orphaned children were found to be poorer, and are less likely to be accessing services such as grants. Qualitative research suggests that lack of access to grants is due to a range of reasons, including inadequate service delivery (Meintjies et al., 2003), lack of documentation such as death certificates (Young & Ansell, 2003b), and limited knowledge of systems of accessing services (Essop, 2004).

Do these research findings suggest a need for targeting of services to AIDS-orphaned children? As discussed below, currently both policy and academia seem caught between the two poles of targeting and non-targeting (Desmond, personal communication, March 2007). I argue that this ideologically-loaded debate is obscuring our responsibility towards AIDS-orphaned children. It is essential to identify whether AIDS-orphaned children, or all orphans, do have particular needs. If they do, it is essential to respond to

these needs. What is required is an evidence-based approach to the question of service provision for AIDS-orphaned children.

Using evidence from this current study, and other studies, I argue that AIDS-orphaned children in South Africa are (largely) not in need of new or specific services regarding poverty alleviation. But they *are* in need of additional support to ensure that they access those services for which they are eligible. Such support may include services such as increased provision of social workers to assist in grant applications, or anti-stigma training amongst service providers. In addition, AIDS-orphaned children are in need of services to target other areas of risk and protective factors. These services should be targeted, as relevant, to particular groups or areas.



Figure 45: 'What do you want to be when you grow up?' Girl, 13, Khayelitsha.

The targeting debate

AIDS-orphanhood is a relatively new policy concern. In the past decade, South African approaches to vulnerability and service provision to AIDS-orphaned children have 'swung' between targeting and non-targeting. Throughout this 'swing', very little evidence has been available to inform arguments.

In the mid-late 1990s, the emerging phenomenon of large numbers of AIDS-orphaned children prompted great concern within the international community. Targeted services were aimed specifically and exclusively at AIDS-orphaned or AIDS-affected children. These were often provided through NGOs, and included services such as food parcels and 'psychosocial support'. However, arguments emerged which challenged the targeting of services. Qualitative evidence suggested that targeting of services and resources caused

stigmatisation of 'AIDS-orphans' (Giese et al., 2003). It was argued that targeting was missing the point: AIDS-orphaned children were in many aspects no more vulnerable than other poor children. It was also argued that by targeting AIDS-orphaned children, many other highly vulnerable children were being excluded from services (Meintjies & Giese, 2006; Richter et al., 2006).

The debate on targeting of services to AIDS-orphaned children takes place within the context of a much wider and bitter debate within South Africa regarding provision of social security. Arguments for targeted grants (the current system of Child Support Grant, Foster Care Grant etc) contrast with a strong political movement for a universal Basic Income Grant. These debates are, in turn, contextualised by the problems of corruption and variability of service provision (particularly of social security) in South Africa (Goldblatt et al., 2006). In response to demands for improved social security, the February 2007 budget proposes a mandatory earnings-related social security scheme, financed by a social security tax. This aims to provide improved unemployment insurance, disability and death benefits, but will not be implemented until 2010. This wider ideological debate around grant provision continues to influence and frame the debate on AIDS-orphanhood and AIDS-related services.

Targeting of any service (even targeted interventions to improve access to services) to AIDS-orphaned children may be difficult to achieve in practice. For example, in a context of stigma and secrecy around HIV/AIDS, provision of services to AIDS-affected families risks increased stigma (which itself was shown to be a key risk factor in psychological distress) (Richter et al., 2006). It further risks the paradoxical exclusion of AIDS-affected people who do not wish to be identified as such, and thus cannot access services aimed specifically at them.

Possible approaches include 'area targeting': the provision of increased levels of services to areas most affected by HIV/AIDS (Desmond, 2007), or 'orphanhood targeting', such as the government's encouragement of registration on the 'orphan register' of all orphaned children in South Africa.

The question of targeting of any intervention or policy to a particularly vulnerable group presents difficulties. By focusing on a particular vulnerable group, other children in need of services are excluded. However, by relying on universal provision or public health approaches, the particularly vulnerable group are rendered even more vulnerable as they do not access services at the same rate as other children. The in-between response of area-targeting (such as Surestart areas in the United Kingdom - www.surestart.gov.uk) presents problems of exclusion of AIDS-orphaned children who do not live in target areas. Area-based targeting also risks potential exclusion of AIDS-orphaned children within target areas, as they may continue to be more vulnerable within their communities. For example, evaluations of SureStart showed that the most vulnerable groups showed low take-up of services, compared to higher take-up amongst less vulnerable groups within targeted areas (Belsky et al., 2006).

Richter et al (Richter, Manegold, & Pather, 2004) recommend the use of local-level orphan registration programmes. These can facilitate monitoring; provide basic information on the needs of vulnerable children, some assessment of main causes of children's vulnerability, and records of assistance given. Local-level programmes with child participation are considered preferable to national-level programmes, which are costly, difficult to maintain, and raise expectations for assistance which is not always available or sustainable. However, local-level orphan registration programmes may not be suitable for high-density urban areas with high levels of migration.

Relevant responses to a range of risk factors

Responses to AIDS-orphanhood depend, to an extent, on how we view AIDS-orphaned children's vulnerability. This current study provides evidence to challenge the argument (at least in mental health) that AIDS-orphaned children are no more vulnerable than other orphaned or other poor children. However, there seem to be a wide range of interlocking factors which are contributing to their poorer psychological health. These include poverty and lack of social security, but also include stigma, bullying, caregiver illness, housework, access to school and quality of care. They may also include factors not yet measured in this or any research.

The wide range of factors contributing to increased vulnerability suggests that we should not view AIDS-orphaned children simply as a group of poor children who are especially vulnerable. We should instead recognise that a package of policies and interventions is necessary, based on the most rigorous available evidence of risk and protective factors.

Different types of risk factor will require different responses, and may be aimed at different sectors of society. For example, programmes to reduce stigma against AIDS-orphaned children should not be focused only (or at all) on the affected group, but also on the wider community. Using the findings of this study, I argue that a package of interventions which aim to improve psychological health of AIDS-orphaned children must include:

- 1) *Services which are aimed specifically at AIDS-affected families*, such as provision of anti-retrovirals to HIV+ caregivers of AIDS-orphaned children.
- 2) *Services aimed at improving AIDS-orphaned children's access to existing services*, such as increased support for accessing grants. In order to prevent stigmatisation, this kind of increased support may not in practice be openly targeted at AIDS-affected families. It may also be necessary to have services which encourage and support AIDS-affected families in accessing area-level services such as education, perhaps through existing support groups and faith-based organisations. Service providers such as schools need to be alerted to the particular needs of AIDS-orphaned children.
- 3) *Area-targeted services and poverty-targeted services* may have potential to improve outcomes for AIDS-orphaned children, such as no-fees schools, school feeding schemes and anti-stigma programmes.
- 4) *Universal or public health services* also have the potential to increase likelihood of AIDS-orphaned children accessing services, such as increasing numbers of social workers (through schemes such as education bursaries), and provision of social security.

Furthermore, any suggested interventions require rigorous testing of acceptability, piloting, efficacy and effectiveness. Why, then, is it necessary or desirable to provide such policy recommendations at all? From a purist scientific perspective, such recommendations are a leap into the unknown. However, during the dissemination stage of this project, it was apparent that the findings of this current study presented an important and immediate problem. It was further apparent that government and NGOs were desperate for guidelines to respond to the needs of AIDS-orphaned children. The set of possible responses listed in Tables 22 and 23 are to be approached only as tentative speculation. Areas requiring further research, and suggestions for such research, are presented later in this chapter.

Table 22: Summary of suggested policy goals to reduce psychological problems for AIDS-orphaned children in South Africa

<i>Policy Goal</i>	<i>Potential mental health benefits</i>
Improve levels of food security for AIDS-orphaned children	Reduce depression, conduct problems and delinquency, reduce likelihood of child having a clinical disorder
Improve grant access for families caring for AIDS-orphaned children	Reduce depression, conduct problems and delinquency.
Increase access to education for AIDS-orphaned children	Reduce depression, conduct problems and delinquency
Reduce numbers of AIDS-orphaned children living with very sick caregivers	Reduce depression, anxiety, delinquency and conduct problems
Reduce numbers of children having 3 or more changes of caregiver	Reduce likelihood of child having a clinical disorder
Reduce caregiving burden on AIDS-orphaned children	Reduce depression, anxiety, delinquency and conduct problems
Reduce AIDS-related stigma	Reduce depression, PTSD, peer problems, delinquency and conduct problems, reduce likelihood of child having a clinical disorder
Reduce bullying of AIDS-orphaned children	Reduce likelihood of clinical disorder

Table 23: Possible policy responses

Improved levels of food security for AIDS-orphaned children				
<i>Possible services</i>		<i>Targeted at (if targeted service)</i>	<i>Potential service provider/s</i>	<i>Indicator and source</i>
Reliable and regular food parcel schemes, combined with food gardening schemes (see below) Food gardening schemes School feeding schemes		Families identified by social services	Provincial Departments of Social Development /NGO partnership	Indicator: Proportion of orphaned children receiving at least 10 monthly food parcels per annum
		Families with children on the orphan register		Source: NGO and state records, specific research studies. Stratified urban/rural
		Child-headed and youth-headed households		Indicator: Proportion of orphaned children with a household member actively involved in a food garden
				Source: NGO and state records, specific research studies. Stratified urban/rural
		Poor areas	Provincial Education Departments/ School partnerships	Indicator: Proportion of schools in low-income areas with feeding schemes
		Schools with high numbers of non fee-paying learners		Source: Provincial Indices of Multiple Deprivation for Children (Noble et al, 2007), Education department administrative records
		No-fee schools		

Improve grant access for families caring for AIDS-orphaned children				
<i>Possible services</i>		<i>Targeted at</i>	<i>Potential service provider/s</i>	<i>Indicator and source</i>
Specific research project to investigate barriers to grant access for AIDS-affected families.				
Information for caregivers in poor areas on complex grant applications, ie missing documentation		Caregivers of all orphans (through support groups)	NGOs	Number of attendees at training sessions on grant application
		Applicants at grants offices	Government information	NGO records
		Caregivers in schools		Specific research on length of time from application to grant receipt for caregivers of orphans
Support for particularly vulnerable caregivers in negotiating grant application process		HIV+ caregivers identified through clinics	Trained NGO staff	Indicator: Child Support Grant and Foster Care Grant uptake, stratified by age and high HIV-prevalence areas
		Elderly caregivers identified at grants offices	Auxiliary social workers	

		Child-headed and youth-headed households		Source: SOCPEN dataset, ante-natal clinic HIV sero-prevalence data (Department of Health)
	Reduce backlogs of applications for Foster Care Grants: increase numbers of social workers to assess grants, or allow parts of Foster Care assessment to be done by auxiliary or community workers	Children applying for Foster Care Grants	Social Services NGOs providing social work services	Indicator: Proportion of initial applications for foster care proceedings per annum, which are fully assessed within 1 year of application Source: provincial social services and NGO records. Stratified urban/rural
	Support for child-headed households and youth-headed households in process of grant application	Child-headed and youth-headed households, identified through NGOs, schools and churches	Social Services NGOs providing social work services	Indicator: Number of children in child-headed and youth-headed households receiving grants, as proportion of number of child-headed and youth-headed households Source: SOCPEN data, GHS/Census data

Increase access to education for AIDS-orphaned children				
	<i>Possible services</i>	<i>Targeted at</i>	<i>Potential service provider/s</i>	<i>Indicator and source</i>
	No-fees schools in areas of high HIV prevalence	High HIV-prevalence areas	National Department of Education	Indicator: Proportion of neighbourhoods which have HIV prevalence of 20% or higher, with a no-fees school Source: Ante-natal clinic HIV sero-prevalence data (Department of Health), Department of Education data
	For fee-paying schools, support for poor families in applying for fee reduction/exemptions	Poor areas	NGOs, schools	Indicator: number of schools with identified staff member to assist families with applying for reductions/exemptions Source: school data

Reduce numbers of AIDS-orphaned children living with very sick caregivers Reduce numbers of children having 3 or more changes of caregiver				
	<i>Possible services</i>	<i>Targeted at</i>	<i>Potential service</i>	<i>Indicator and source</i>

			<i>provider/s</i>	
	Improve access to anti-retroviral medication for HIV+ caregivers	ARV rollout targeted at all HIV+ people with relevant CD4 count	National and Provincial Departments of Health	Public sector, NGO and private-sector data on ARV rollout. Actuarial Society of South Africa (ASSA) models
	Improve healthcare access for elderly caregivers of orphaned children	Home-based care support for elderly caregivers Medical support (ie lower prescription and treatment costs) for elderly poor	Department of Health	Indicator: Proportion of elderly caregivers receiving home-based care services. Prescription and treatment costs for pension-eligible people.
Reduce caregiving burden on AIDS-orphaned children				
	Practical support to children acting as home-based carers for AIDS-unwell caregivers	Children in AIDS-affected families, identified via HIV+ clinic attendees Children living with elderly grandparents, identified through NGOs and schools	Provincial departments of Health NGOs	Indicator: Number of children receiving at least fortnightly visits from Home-Based Care professionals or Home Visitors. Source: Local government and NGO Home-based care supplier data. Stratified urban/rural

Reduce AIDS-related stigma				
	Possible services	Targeted at	Potential service provider/s	Indicator and source
	Very little available evidence on effective reduction of stigma in the developing world. No available evidence could be found on effective reduction of stigma towards non-infected, AIDS-orphaned children. Establishment of research into potential interventions in the developing world, and rigorous evaluation of any interventions, preferably using area-based randomised controlled trials.			
	Effective government and NGO campaigns to reduce stigma (both within the family and more generally) seem strongly desirable, based on the findings of the present study.			
Reduce bullying of AIDS-orphaned children				
	Anti-bullying programmes in schools	all schools	Department of Education	Indicator: Proportion of schools with active anti-bullying programmes
				Source: Department of Education data

Appendix 12: Consultations

Academic consultations: Dr Lauren Wild (University of Cape Town, Department of Psychology) and Dr Soraya Seedat (Medical Research Council, Unit for Anxiety and Stress Disorders) contributed extensively to the choice of standardised questionnaires. This collaboration with UCT and the MRC is described in Chapter 1.

Professor Andrew Dawes (Human Sciences Research Council, Director of Child, Youth and Family Research Programme) advised on sampling design and use of picture-based items. Professor Leslie Swartz (Chair, University of Stellenbosch Department of Psychology) advised on cultural transferability of standardised instruments. Dr Harriet Deacon (Human Sciences Research Council, Social Aspects of HIV and Health Research Programme) and Brendan Maughan-Brown (University of Cape Town, AIDS and Society Research Unit) advised on stigma items. Professor Sally Grantham-McGregor (Institute of Child Health) advised on poverty and hunger items.

Professor Brian Robertson (Groote Schuur Hospital, Department of Psychiatry) advised on depression and PTSD scales. Dr Deborah Kaminer (University of Cape Town, Department of Psychology) advised on translation of the Child Depression Inventory and Child PTSD Checklist. Dr René Brandt (University of Cape Town, AIDS and Society Research Unit) advised on questionnaire structure. Professor Alan Stein and Tamsen RoCHAT (Oxford University, Department of Psychiatry) advised on use of standardised questionnaires. Professor Lorraine Sherr (University College London, Department of Primary Care and Population Sciences) advised on items discussing bereavement with children.

Professor Lynne Murray (Reading University, Department of Psychology) and Dr Mark Tomlinson (Child Guidance Clinic, Department of Psychology, University of Cape Town) advised on interviewing techniques, as did Lorraine Townsend (University of Cape Town, Department of Psychiatry). Dr Julie Carter (Institute of Child Health, Centre for International Health and Development) advised on adaptation of standardised questionnaires to developing world contexts. Dr Cathy Ward and Amelia Van der Merwe (Human Sciences Research Council, Child, Youth and Family Research Programme) advised on the use of the Social and Health Assessment items. Desiree Michaels (School of Public Health, University of Cape Town) and Dr Jonathan Morgan (Regional PsychoSocial Support Initiative) advised on interviewing AIDS-affected families.

Governmental and Non-Governmental Organisations: Professor Sandra Burman (South African Law Commission) contributed items for the questionnaire on property-grabbing amongst orphans. Dr Jennie Gamlin (International Labour Organisation) contributed items on child labour and child work. Patrice Engle (Senior Advisor, UNICEF) contributed items on child bereavement. Veronica Cloete (Provincial Administration of the Western Cape, HIV and AIDS Directorate) contributed items on religious institutions. Sharon Kleintjies (Department of Health Western Cape) and Professor Melvyn Freeman (World Health Organisation and Human Sciences Research Council) advised on questionnaire design and items regarding HIV+ parents. Clarissa Arendse (Planned Parenthood Association of the Western Cape, child-headed household scheme) advised on items relating to child-headed and youth-headed households.

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