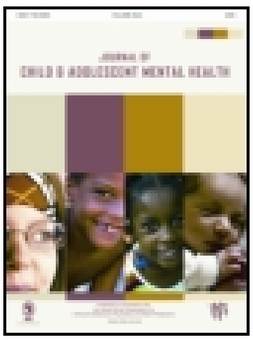

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Lucie Cluver & Frances Gardner

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Review

The mental health of children orphaned by AIDS: a review of international and southern African research

Lucie Cluver[1,2]* and Frances Gardner[1]

[1] *Department of Social Policy and Social Work, University of Oxford, 32 Wellington Square, Oxford OX1 2ER, UK*
[2] *Cape Town Child Welfare Society, PO Box 374, Gatesville 7766, Cape Town, South Africa*
* *Corresponding author, e-mail: lucie.cluver@socres.ox.ac.uk*

This paper reviews research on the mental health and psychological outcomes of children who are orphaned by AIDS. Studies are limited, scattered and often unpublished. The review focuses on research which is quantitative and based on primary research with uninfected children who are parentally bereaved by AIDS. Due to the limited available quantitative research in this area, both controlled and uncontrolled studies are included. Selected qualitative and related literature is also reviewed, with a focus on work relevant to the southern African context. This paper builds upon and updates Wild's seminal review, published in this journal in 2001 (Wild 2001). We found 24 studies worldwide, with wide variations in sample characteristics, outcome measurements and control groups. Three of these studies are ongoing. Internalising problems in orphaned children were found in 16 studies (of the 19 studies which measured them) and externalising problems were found in five studies (of 10 which measured them). There is 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.

Introduction

By 2005, 15.2 million children had been orphaned by AIDS worldwide (UNICEF/WHO 2006). In South Africa alone, an estimated 1.37 million South African children were maternal or 'double' orphans by 2005, with 830 000 of these orphaned by AIDS. Even with continued administration of the national antiretroviral programme, orphan numbers are predicted to peak at 2.3 million in 2020 (Dorrington *et al*. 2005).

Orphans frequently lack sufficient food, shelter, schooling and medical care, and are at risk of abuse and economic exploitation (ACESS 2002, Berry and Guthrie 2003, Giese *et al.* 2003). Recent research finds evidence of lower school enrolment and attendance amongst maternally-orphaned children (Case and Ardington 2005), and of higher HIV prevalence amongst orphans aged 16–24 (Operario *et al.* 2007).

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. They may have cared for, and witnessed the deaths of, a parent or parents with a debilitating illness, loss of bodily functions and possibly AIDS-related mental illness (Olley *et al.* 2003, Tedstone and Tarrier 2003). Children may experience multiple losses, for example of mother, father and perinatally-infected younger siblings. Caregivers

of orphans have been found to experience poorer psychological health than other caregivers (Ferreira, Keikelame and Mosaval 2001, Manuel 2002), and research in other populations 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 2003, Giese *et al.* 2003, Cluver and Gardner in press). Poor communication can lead to children's ignorance of causes of parental death, or fears that they will also be infected (Marcus 1999).

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

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).

Current debate in sub-Saharan Africa suggests the need for a wider definition of 'orphanhood' than parental bereavement. For example, the Children's Institute (University of Cape Town) proposes the following definition:

> … 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)

Whilst recognising that 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), 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 1996). This review uses the current definition, but some (especially earlier) studies follow the previous limit of 15 years.

This review does not focus on orphaned children who are also HIV-positive, although the mental health of this group is clearly an important area of research. There is growing evidence that an HIV-positive diagnosis and illness have adverse mental health effects, independent of orphanhood, in both adults (Olley *et al.* 2003, Tedstone and Tarrier 2003, Brandt 2004, Baingana, Thomas and Comblain 2005) and children (Gosling, Burns and Hirst 2004, Green and Smith 2004, Nozyce, Lee and Wiznia 2006). 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 neurocognitive impairment and sleep disorders. The relationship between depression and decreases in immune function in children is not yet clear (McDaniel *et al.* 2000), although UK studies suggest increased prevalence of concentration, behavioural and emotional problems (Gosling *et al.* 2004). Some HIV-infected children receive psychological support through treatment programmes, whilst others do not. Thus, 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-positive children.

Search strategy

This review draws on both published and unpublished empirical studies. Keyword searches were made of a number of electronic databases (PsycINFO, Medline, the Index to South African

Periodicals/ISAP, BMJ, TDNet, the British Library database, Zetoc, Cambridge Scientific Abstracts, Web of Science), the online publications of several organisations (UNAIDS, UNESCO, UNICEF, World Health Organisation/WHO) and government publications (South Africa, Botswana, Mozambique, Uganda, Lesotho, Tanzania, Zambia and Zimbabwe). In addition, several print publications were hand-searched (the AIDS Bulletin, ChildrenFIRST (SA) and Children's Institute publications), a number of HIV/AIDS conference websites were inspected, and dissertation/thesis searches were carried out on SABINET (1995–2005), SilverPlatter and Dissertation Abstracts International. Additional studies were located through personal recommendations, e-mailed requests to academics, web searches (Google, Google Scholar, Yahoo, Altavista, findarticles.com) and existing reviews (Siegal and Gorey 1994, Wild 2001, Stein 2003).

Results

Quantitative studies

There have been relatively few published empirical studies on the psychological well-being of children orphaned by AIDS. Thorough searching revealed 24 studies worldwide, of which five were conducted in the USA and 19 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 could not be accessed (Gelman 2003) or not accessed in full (Hirsch 2001).

Of the 23 studies with sampling information available, seven were descriptive and lacked control groups. Sixteen studies compared orphaned children with some kind of control group. All of the Africa-based studies, and all but two of the US studies, were cross-sectional. In 18 studies, children were interviewed directly, while four relied on caregiver reports. Of the three ongoing studies, one in Rwanda (Brown, Thurman and 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 into 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 which are concentrated on far fewer children than is the case in African contexts.

Controlled studies in Africa

Poulter (1996), in Zambia, interviewed carers in 22 households with orphans, 66 households with HIV-positive parents, and 75 control families. However, as controls were randomly selected from the community, this group may have included HIV-affected families. The researchers used the Rutter Scales (Rutter, Tizard and Whitmore 1970) with caregivers. Caregivers reported that orphans were significantly more likely to be unhappy or worried than children with HIV-positive 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. It also found no evidence of conduct disorders or antisocial behaviour.

Sengendo and 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 and interviews with orphans, teachers and some guardians. They found that 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 *et al.* 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), 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 for the 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), it was found that 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 was 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 = 1 160) completed a seven-item unstandardised 'worry/stress' scale developed from existing instruments. On this scale, Zambian orphans scored higher 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 socioeconomic 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 for other reasons. Children completed 60 items from the 657-item Minnesota Multiphasic Personality Inventory 2 (MMPI) (Hathaway and 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 the Impacts of Events Scale (Dyregrov and 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 (PTSD). 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 (n = 5 321). 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 1 258 orphans and vulnerable children, comparing groups by exposure to various psychosocial support programmes. An unstandardised instrument was developed from formative qualitative research, and included six items suggestive of depression and two items suggestive of poor psychosocial well-being. Orphans reported higher stress ($p < .05$) and more psychosocial distress ($p < .05$).

Wild *et al*. (2006) 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 as a result

of deaths not related to AIDS, and 43 non-orphans. AIDS-orphaned children were recruited through NGOs. The researchers used the Revised Children's Manifest Anxiety Scale (R-CMAS) (Reynolds and 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 *et al.* 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 as a result of deaths unrelated to AIDS reported more depression ($p < .05$) and anxiety ($p < .05$) than non-orphans, with AIDS orphan scores falling between the two groups and not differing significantly from either. There were no group differences in terms of externalising problems. 'Other' orphans showed lower self-esteem than both non-orphans and AIDS orphans. 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 *et al.* 2006).

In Cape Town, South Africa, Cluver, Gardner and Operario (2007) interviewed 1 061 children (455 orphaned by AIDS, matched controls of 278 non-orphaned children and 243 orphaned as a result of deaths from other causes, with 85 children orphaned as a result of deaths from unknown causes). Standardised psychological questionnaires included the Child Depression Inventory (Kovacs 1992), The Revised Children's Manifest Anxiety Scale (Reynolds and Richmond 1978), the Child Behaviour Checklist (Achenbach 1991) and the Children's PTSD Checklist (Amaya-Jackson, Newman and Lipschitz 2000), with many scales matched to those used in the South African Eastern Cape study (Wild *et al*. in press), to allow for cross-provincial comparison. The study also explored a range of potential risk and protective factors identified through qualitative data (Cluver and Gardner 2007), and suggested by a range of NGOs and South African government departments. AIDS-orphaned children reported higher levels of depression, peer problems, post-traumatic stress, conduct problems and delinquency ($p < .001$) than both non-orphaned children and children orphaned as a result of deaths from other causes. Differences remained when controlling for socio-demographic factors such as age, gender, poverty, migration and household composition. No differences were found in terms of anxiety. Multivariate and mediational analyses found strong mediational effects of risk factors — poverty, stigma and caregiver illness — and of protective factors such as receipt of social security and school attendance (all $p < .001$).

In Kenya, Elmore-Meegan *et al.* (in prep.) initially used the Achenbach Child Behaviour Checklist with orphaned and vulnerable children, but found the schedule overlong (R Conroy pers. comm.). 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 and Jones in prep.) compares levels of PTSD in AIDS-orphaned children (137) with matched control groups of orphans of non-AIDS causes (98) and non-orphans (99). No information is as yet available regarding this study, but the authors supplied the following information: children (aged 8–18) completed the Child's Reaction to Traumatic Events Scale (Jones, Fletcher and Ribbe 2002), which measures PTSD arousal, avoidance and intrusive symptoms. Teachers completed the Parent Report of Post-traumatic Symptoms (PROPS). 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 (Brody and Forehand 1986, Armistead and Forehand 1995, Forehand *et al.* 1998, Armistead *et al.* 1999, Forehand *et al.* 1999, Dutra *et al.* 2000, Shaffer *et al.* 2001, Forehand *et al.* 2002, Pelton and Forehand 2005). 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-positive and alive, and then six months after parental death. The researchers used the Child Behaviour Checklist (Achenbach and Edelbrock 1987) and the Child Depression Index (Kovacs 1992). Children of HIV-positive mothers showed more emotional and behavioural problems and lower cognitive and social competence than the control group ($p < .05$). Six 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 and Forehand 2005) compared the same group of orphaned children before and two years after maternal death from AIDS, with two comparison groups of children with living HIV-positive 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 two years after parental death. Thus, the six-month finding of non-significant improvements (described above) may not indicate long-term effects of orphanhood.

Hirsch (2001) compared 16 children (under age 12) whose mothers had died of AIDS with 18 children whose mothers had died due to other causes. Some children were HIV-positive (number not given). Attachment security was measured using the Attachment Q-Set (van Dam and van Izjendoorn 1988) and anxiety, depression and conduct were measured using scales from the Behaviour Assessment System for Children (BASC-PRS) (Reynolds and Kamphaus 1992). Results found no significant differences between groups for attachment security. Children orphaned as a result of death from causes other than AIDS showed higher levels of 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, Stein and Lin 2001, Rotheram-Borus *et al.* 2004) used longitudinal assessments with standardised instruments. The study compared adolescents orphaned by AIDS (73) with adolescents whose parents were alive and HIV-positive (138). At two years after parental death, the researchers found that bereaved children reported more emotional distress on the Brief Symptom Inventory (Derogatis and 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 two years after parental death 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) interviewed the 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 Checklist' 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) interviewed 788 adolescent orphans, randomly selected from four districts in Zambia. They used non-standardised interviews conducted 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), in the Democratic Republic of Congo, used interviews with 354 orphans, conducted by clinical psychologists. They found that 20.1% presented 'psychological troubles', and of those 34% had 'affective troubles — depression, anxiety, irritability, rivalry feeling'. Twenty-seven per cent had 'adaption troubles — school or home fugue, robbery tendency, offending and hyperkinetic 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 as a result of death from a number of causes, including 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) report that 55% of child household heads scored above the cut-off for depression and 4% reported suicide attempts in the previous two months. Females scored higher for both depression ($p < .05$) and suicide attempts. Males reported more externalising behaviours, such as delinquency and substance abuse (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 could not be accessed. Gelman (2003), a study conducted 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 and Segura 1992, Hudis 1995) used quantitative standardised instruments (scales not given) with 59 children and caregivers aged 10–19. Half the children were orphaned and half had living HIV-positive parents. There was no non-affected control group. Thirty-four per cent of caregivers reported youth externalising problems, 73% of the youths reported problems at school, and 58% reported a decline in school work, 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-positive. Participants were recruited from a mental health and primary healthcare programme for HIV-positive women. There was no control group. The researchers 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.

Qualitative studies

It is helpful to highlight 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 (Levine and Dane 1994, Siegal and Gorey 1994, Geballe, Gruendal and Andiman 1995). Other non-quantitative research includes an unpublished psychotherapeutic exploration of orphans' experiences in South Africa (Hough 2001).

Further studies do not focus on mental health, but use qualitative methods with affected and orphaned children in order to explore a range of issues. These can highlight potential factors influencing children's distress, such as stigma (Strode and Barrett Grant 2001), poverty (ACESS 2002) and community relationships (Giese, Meintjies and Proudlock 2001).

Other helpful literature includes research on non-psychological aspects of orphan well-being, which may affect mental health. These include education, immunisation, caregiving and physical health. Literature is both international (Case, Paxson and Ableidinger 2002, UNAIDS 2004, Foster, Levine and Williamson 2005) and based in southern Africa (Ankrah 1993, Marcus 1999, Giese *et al.* 2003, Ansell and Young 2004, Richter, Manegold and Pather 2004). In South Africa, survey data

also provide useful information, often with large sample sizes, on orphan well-being. This includes data from demographic surveillance areas of the Africa Centre and Agincourt (Case and Ardington 2005), surveys focused on affected families (Vermaak *et al.* 2004) and nationally-representative surveys such as the National Youth HIV and Sexual Behaviour Study (Pettifor *et al.* 2003, Operario *et al.* 2007). A further useful report recommends revision of the UNICEF psychological indicators for monitoring of orphans and other vulnerable children (Snider and Dawes 2006).

Another source of information is reports of psychosocial or psychological interventions with orphaned children, both in sub-Saharan Africa (i.e. Denis and Makiwane 2001, Jewitt 2001, Bowsky *et al.* 2002, Kaseke and Germann 2002, Southern African AIDS Training Programme 2003) and worldwide (i.e. China View 2004, Safman 2004). These often constitute anecdotal evidence in the form of case studies, but do not provide empirical evidence about effectiveness.

There is a highly relevant (although small) body of research on the mental health outcomes of non-orphaned children living with HIV-positive or AIDS-affected parents. Children's psychological well-being pre-orphanhood will clearly relate to mental health post-orphanhood. Studies include ongoing South Africa-based research on mother-infant interaction (Stein *et al.* 2005, Brandt 2007), and on children and adolescents with HIV-positive parents, both in the developed world (Forsyth and Damour 1996, Esposito *et al.* 1999, Rotheram-Borus, Lightfoot and Shen 1999, Forehand *et al.* 2002) and developing countries (Poulter 1996). Only two longitudinal studies measure child outcomes both pre- and post-bereavement (Rotheram-Borus, Stein and Lin 2001, Forehand *et al.* 2002). This is an area which clearly requires further exploration, if we are to ensure that interventions for AIDS-affected children are introduced at the appropriate point in the bereavement process.

Further relevant research includes studies on HIV-positive children, many of whom are also parentally bereaved (Esposito *et al.* 1999, Divac, Melvin and Krechevsky 2003, Gosling, Burns and Hirst 2004). However, as discussed above, HIV-positive children have unique needs beyond those of orphanhood.

Discussion

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 and 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 as a result of death from 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 caregivers who are ill with AIDS 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 are 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 and Howell 1987). Ideally, future studies would compare reports from multiple informants, but this can be exceptionally difficult with regard to 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 terms of making diagnoses and in using instruments such as the K-SADS (Kaufman *et al.* 1996). But a 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.* in press). 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 provided by established scales. There is a clear need for scales to be normed on sub-Saharan African populations (Flisher forthcoming), and it is important that such scales be appropriate for use by non-clinically trained interviewers (Dawes *et al.* 2007). Until this has been achieved, we argue that the advantages of using a single set of standardised scales, across studies of orphanhood, would outweigh methodological difficulties of cross-cultural transferability.

Despite these limitations, a pooled approach to findings does reveal some patterns. Of the 13 controlled studies measuring internalising problems, 10 found evidence of heightened difficulties (eight in Africa, two 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 (six in Africa, one in the US). Of the seven controlled studies measuring externalising behaviours such as conduct disorders, only three found evidence of increased difficulties (one in Africa, two in the US). Of the three non-controlled studies looking at externalising problems, two found evidence of difficulties (one African, one US). One study compared post-traumatic stress symptoms with control groups (Cluver *et al*. 2007). This found higher levels of symptoms and more children in the clinical range for PTSD amongst AIDS-orphaned children than amongst children orphaned as a result of non-AIDS causes and non-orphans. The remaining 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 and 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, we found only two (Wild *et al.* 2006, Cluver, Gardner and Operario in press), although some other studies include a helpful range of demographic data (i.e. Bhargava 2005). Evaluations of interventions such as Rotheram-Borus *et al*. (2004) and 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 from 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 (OVCZ). Clarification is needed about 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 on the streets.

Conclusions

There are many challenges in conducting rigorous research with children orphaned by AIDS. These include practical complications of data collection in poor and sometimes high-crime areas (Robertson *et al.* 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 which are likely to arise from child reports, and the extent of children's knowledge around causes of parental death. Furthermore, higher HIV and AIDS prevalence amongst the poorest communities means that many orphans live in contexts which are already high-risk for psychological problems such as PTSD (Ensink *et al.* 1997).

Despite such challenges, there is a growing evidence base on psychological outcomes for orphaned children. Wild's review of 2001, in this journal, found eight studies (six published and two unpublished), of which only two were based in Africa, and only one compared orphaned to non-orphaned controls (Wild 2001). In five 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 of 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, we argue that future research could usefully aim for a more synchronised 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 socioeconomic 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 as a result of death from non-AIDS causes, non-orphaned children, and children living with unwell caregivers.

The epidemiology of orphaned children is also changing. Numbers of orphans are continuing to rise, the capacity of caregiving structures is changing in response, and there have been far-reaching developments in (and differing levels of access to) antiretroviral 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. If we are to respond to the needs of orphaned children, it is vital that we know more about the prevalence of psychological problems, and about risk and protective factors which can inform interventions. In addition, it is essential that we rigorously evaluate interventions and policies for this highly vulnerable group.

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References

ACESS (2002) *Children speak out on poverty*. Report on the ACESS (Alliance for Children's Entitlement to Social Security) Child Participation Process. Soul City, The Children's Institute, University of Cape Town

Achenbach T (1991) *Manual for the Youth Self-report and 1991 Profile*. VT University of Vermont, Burlington

Achenbach T and Edelbrock C (1987) *Manual for the Youth Self-report and Profile*. Department of Psychiatry, University of Vermont, Burlington

Achenbach T, McConaughy S and Howell C (1987) Child/adolescent behavioural and emotional problems: implications of cross-informant correlations for situational specificity. *Psychological Bulletin* 101: 213–232

Amaya-Jackson L, Newman E and Lipschitz D (2000) *The Child and Adolescent PTSD Checklist in Three Clinical Research Populations.* Paper presented at the Annual Meeting of the American Academy of Child and Adolescent Psychiatry. New York

Angold A ,Weissman M, John K, Merikangas K, Prusoff B, Wickramaratne P, Gamon G and Warner V (1987) Parent and child reports on depressive symptoms in children at low and high risks of depression. *Journal of Child Psychology and Psychiatry* 28: 901–915

Ankrah E (1993) The impact of HIV/AIDS on the family and other significant relationships. *AIDS Care* 5(1): 5–22

Ansell N and Young L (2004) Children's migration as a household/family strategy: coping with AIDS in southern Africa. *Journal of Southern African Studies* 30(3): 673–690

Armistead L and Forehand R (1995) For whom the bell tolls: parenting decisions and challenges faced by mothers who are HIV-infected. *Clinical Psychology: Science and Practice* 2: 239–250

Armistead L, Summers P, Forehand R, Simon Morse P, Morse E and Clark L (1999) Understanding of HIV/AIDS among children of HIV-infected mothers: implications for prevention, disclosure and bereavement. *Children's Health Care* 28(4): 277–295

Atwine B, Cantor-Graae E and Bajunirwe F (2005) Psychological distress among AIDS orphans in rural Uganda. *Social Science and Medicine* 61(3): 555–564

Baingana F, *Thomas R and Comblain C (2005) HIV/AIDS and mental health*. Human Development Network, the World Bank

Barrett M, Berney T, Bhate S, Famuyiwa O, Fundudis T, Kolvin I and Tyrer S (1991) Diagnosing childhood depression. Who should be interviewed - parent or child? *British Journal of Psychiatry* 159 (Suppl. 11): 22–28

Barnett T and Whiteside A (2002) *AIDS in the Twenty-first Century: Disease and Globalization.* Palgrave Macmillian, Basingstoke

Beck A, Ward C, Mendelson M, Mock J and Erbaugh J (1961) An inventory for measuring depression. *Archives of General Psychiatry* 4: 561–571

Berry L and Guthrie T (2003) *Rapid Assessment: the Situation of Children in South Africa.* The Children's Institute, University of Cape Town, Cape Town

Bhargava A (2005) The AIDS epidemic and the psychological well-being and school participation of Ethiopian orphans. *Psychology, Health and Medicine* 10(3): 263–275

Bowsky S, Nnamdi-Okagbue R, Tembo S, Sangiwa G and van Praag E (2002) *Psychosocial support for orphans and other vulnerable children within the continuum of care: what's possible?* Paper presented at the XIV International AIDS Conference, Barcelona

Brandt R (2004) *Measures of Children's Exposure to Violence and its Psychological Sequelae.* Human Sciences Research Council, Cape Town

Brandt R (2007) *Does HIV matter when you are poor and how?* The impact of HIV/AIDS on the psychological adjustment of South African mothers in the era of HAART. PhD dissertation, University of Cape Town, Cape Town

Bray R (2003) *Predicting the Social Consequences of Orphanhood in South Africa.* Centre for Social Science Research, University of Cape Town, Cape Town

Bray R (2004) AIDS orphans and the future: a second look at our predictions. *Medical Research Council of South Africa AIDS Bulletin* 13(2). Available at: http://www.mrc.ac.za [Accessed December 2005]

Brody G and Forehand R (1986) Maternal perception of child maladjustment as a function of combined influence of child behaviour and maternal depression. *Journal of Consulting and Clinical Psychology* 54: 237–240

Brown L, Thurman T and Snider L (2005) *Strengthening the psychosocial well-being of youth-headed households in Rwanda: baseline findings from an intervention trial*. Horizons Research Update, Washington DC Population Council

Carter J, Lees J, Murira G, Gona J, Neville B and Newton C (2005) Issues in the development of cross-cultural assessments of speech and language for children. International Journal of Language and Communication Disorders 40(4): 385-401

Case A and Ardington C (2005) *The impact of parental death on school enrolment and achievement: longitudinal evidence from South Africa*. CSSR Working Paper No. 97, Centre for Social Science Research, University of Cape Town, Cape Town

Case A, Paxson C and Ableidinger J (2002) Orphans in Africa: parental death, poverty, and school enrolment. *Demography* 41(3): 483–508

Chatterji M, Dougherty L, Ventimiglia T, Mulenga Y, Jones A, Mukaneza A, Murray N, Buek K, Winfrey W and Amon J (2005) *The well-being of children affected by HIV/AIDS in Gitarama Province, Rwanda and Lusaka, Zambia: findings from a study*. Community REACH Working Paper No. 2. Washington DC Community REACH Program, PACT

China View (2004) *China working for the mental well-being of AIDS orphans*. Available at: www.chinaview.cn [Accessed 23 June 2004]

Cluver L and Gardner F (2006) The psychological well-being of children orphaned by AIDS in Cape Town, South Africa. *Annals of General Psychiatry* 5(8). Available at: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid= 1557503&blobtype=pdf [Accessed 19 July 2006]

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

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

Dawes A, Bray R, Kvalsvig J and Richter L (2007) *Indicators of South African Children's Psychosocial Development in the Early Childhood Period.* Human Sciences Research Council, UNICEF Cape Town

Denis P and Makiwane N (2001) *Oral history in the context of AIDS: memory boxes as a way of building up resilience in orphans and traumatised children in KwaZulu Natal*. Paper presented at the AIDS in Context conference, University of the Witswatersrand, Gauteng, South Africa

Derogatis L and Melisaratos N (1983) The Brief Symptom Inventory: an introductory report. *Psychological Medicine* 13(3): 595–605

Divac A, Melvin D and Krechevsky D (2003) Emotional and behavioural difficulties in school-age HIV-positive children. Paper presented at the International Conference of AIDS, 11–16 July 2004, Milan

Dorrington R, Johnson L, Bradshaw D and Daniel T (2005) The demographic impact of HIV/AIDS in South Africa. National and provincial indicators for 2006. Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa, Cape Town

Draimin B, Hudis J and Segura J (1992) *The Mental Health Needs of Well Adolescents in Families with AIDS.* New York Human Resources Administration, New York

DuBois D, Felner R, Brand S, Phillips R and Leas M (1996) Early adolescent self-esteem: a developmental-ecological framework and assessment strategy. *Journal of Research on Adolescence* 6: 543–579

Dutra R, Forehand R, Armistead L, Brody G, Morse E, Simon Morse P and Clark L (2000) Child resiliency in inner-city families affected by HIV: the role of family variables. *Behaviour Research and Therapy* 38: 471–486

Dyregrov A and Yule W (1995) Screening measures — the development of the UNICEF screening battery. Paper Presented at the 4th European Conference on Traumatic Stress, 7–11 May, Paris

Elmore-Meegan M, Tomkins A, Conroy R, Achenbach P, Nyambati W, Reid G, Reynolds B and Agala B (in prep.) *Identifying Vulnerable Children: Interim Results of the Adapted Achenbach Child Behavioural Scale.* Institute of Child Health, London

Ensink K, Robertson B, Zissis C and Leger P (1997) Post-traumatic stress disorder in children exposed to violence. *South African Medical Journal* 87: 1526–1530

Esposito S, Musetti L, Musetti M, Tornaghi R, Corbella S, Massironi E, Marchisio P, Guareschi A and Principi N (1999) Behavioral and psychological disorders in uninfected children aged 6 to 11 years born to human immunodeficiency virus-seropositive mothers. *Journal of Developmental and Behavioral Pediatrics* 20: 411–417

Ferreira M, Keikelame M and Mosaval Y (2001) Older women as carers to children and grandchildren affected by AIDS: a study towards supporting the carers. Institute of Ageing in Africa, University of Cape Town, Cape Town

Flisher A (2007) Indicators, measures and data sources for monitoring child and adolescent mental health, risk behaviour and substance use. In: Dawes A, Bray R and van der Merwe A (eds.), *Monitoring Child Rights and Well-being: a South African Approach*. HSRC Press, Cape Town

Forehand R, Armistead L, Mose E, Simon P and Clarl L (1998) The Family Health Project: an investigation of children whose mothers are HIV-infected. *Journal of Consulting and Clinical Psychology* 66: 513–520

Forehand R, Jones D, Kotchick B, Armistead L, Morse E, Simon Morse P and Stock M (2002) Non-infected children of HIV-infected mothers: a 4-year longitudinal study of child psychosocial adjustment and parenting. *Behavior Therapy* 33: 579–600

Forehand R, Pelton J, Chance M, Armistead L, Morse E, Morse P and Stock M (1999) Orphans of the AIDS epidemic in the United States: transition-related characteristics and psychosocial adjustment at 6 months after mother's death. *AIDS Care* 6: 715–722

Forsyth B and Damour L (1996) The psychological effects of parental human immunodeficiency virus infection. *Archives of Pediatric and Adolescent Medicine* 150: 1015–1020

Foster G, Levine C and Williamson J (eds) (2005) *A Generation at Risk: the Global Impact of HIV/AIDS on Orphans and Vulnerable Children.* Cambridge University Press, New York

Foster G, Makufa C, Drew R, Mashumba S and Kambeu S (1997) Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe. *AIDS Care* 10: 391–405

Geballe S, Gruendal J and Andiman W (1995) *Forgotten Children of the AIDS Epidemic.* Yale University Press, New Haven

Gelman S (2003) *Children Growing Up without Parents — a Study of Parental Bereavement in the Context of HIV/AIDS in Zimbabwe.* Masters Thesis, University of Tel Aviv, Tel Aviv

Germann S (2004) Psychosocial impact of HIV/AIDS on children. *AIDS Bulletin* 13(2). Available at: http://www.mrc.ac.za/aids/june2004/impact.htm [Accessed 5 December 2005]

Giese S, Meintjies H, Croke R and Chamberlain R (2003) *Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS in South Africa: research report and recommendations*. Cape Town Children's Institute, University of Cape Town, Cape Town

Giese S, Meintjies H and Proudlock P (2001) *Workshop report. National Children's Forum on HIV/AIDS (2001)*. The Children's Institute, University of Cape Town, Cape Town

Gilborn L, Apicella L, Brakarsh J, Dube L, Jemison K, Kluckow M, Smith T and Snider L (2006) *Orphans and vulnerable youth in Bulawayo, Zimbabwe: an exploratory study of psychosocial well-being and psychosocial support programs*. Bulawayo Horizons/Population Council report, in conjunction with REPSSI and CRS Strive

Goodman R (1997) The Strengths and Difficulties Questionnaire: a research note. *Journal of Child Psychology and Psychiatry* 38: 581–586

Gosling AS, Burns J and Hirst F (2004) Children with HIV in the UK: a longitudinal study of adaptive and cognitive functioning. *Clinical Child Psychology and Psychiatry* 9: 1045–1359

Green G and Smith R (2004) The psychosocial and health care needs of HIV-positive people in the United Kingdom: a review. *HIV Medicine* 5 (Suppl. 1): 5–46

Hathaway S and McKinley J (1989) *Minnesota Multiphasic Personality Inventory (MMPI-2)*. Merril/Prentice-Hall, Columbus, OH

Hirsch W (2001) A comparison between AIDS-orphaned children and other-orphaned children on measures of attachment security and disturbance. *Dissertation Abstracts International* 61 (11-B): 6137

Hough A (2001) *An Exploration of the Intrapsychic Themes in the Play of Children Affected by HIV/AIDS using the Sceno Test.* Masters in Education thesis, University of Natal, South Africa

Hudis J (1995) Adolescents living in families with AIDS. In: Geballe S, Gruendal J and Andiman W (eds.), *Forgotten Children of the AIDS Epidemic*. Yale University Press, New Haven, CT. pp 83–94

Hunter S (1990) Orphans as a window on the AIDS epidemic in sub-Saharan Africa: initial results and implications of a study in Uganda. *Social Science and Medicine* 31: 681–690

Jewitt L (2001) *Play therapy with children affected by AIDS*. Masters thesis, Department of Social Work, University of Pretoria, South Africa

Jones R, Fletcher K and Ribbe D (2002) *Child's Reaction to Traumatic Events Scale-Revised (CRTES-R): a self-report traumatic stress measure*. Virginia Polytechnic University

Kaseke S and Germann S (2002) *Facilitate Psychosocial Support for Children Affected by AIDS through Kids' Clubs.* Paper presented at the XIV International AIDS Conference, Barcelona

Kaufman J, Birmaher B, Brent D, Rao U and Ryan N (1996) Diagnostic Interview Kiddie - SADS - Present and Lifetime Version (K-SADS-PL): Version 1.0 of October 1996

Kovacs M (1992) *Children's Depression Inventory.* Multi-health Systems, Niagara Falls, New York State, USA

Lamphear V and Jones R (in prep.) *Post-traumatic Stress Disorder in Ugandan AIDS orphans.* Save Africa's Children, Los Angeles, California, USA

Levine C and Dane B (eds) (1994) *AIDS and the New Orphans, Coping with Death.* Greenwood, New York

Makame V, Ani C and McGregor S (2002) Psychological well-being of orphans in Dar El-Salaam, Tanzania. *Acta Paediatrica* 91: 459–465

Makaya J, Mboussou F, Bansimba T, Ndinga H, Latifou S, Ambendet A and Puruehnce M (2002) Assessment of psychological repercussions of AIDS, next to 354 AIDS orphans in Brazzaville. Paper presented at XIV International AIDS Conference, Barcelona

Manuel P (2002) *Assessment of Orphans and their Caregivers' Psychological Well-being in a Rural Community in Central Mozambique.* MSc Thesis, Institute of Child Health, London

Marcus T (1999) *Wo! Zaphela izingane* - it is destroying the children - living and dying with AIDS. University of Natal, KwaZulu Natal, South Africa

McDaniel J, Chung J, Brown L, Cournos F, Forstein M, Goodkin K and Lyketsos C (2000) Practice guidelines for the treatment of patients infected by HIV/AIDS. American Psychiatric Association

Nampanya-Serpell N (1998) *Children Orphaned by HIV/AIDS in Zambia: Risk Factors from Premature Parental Death and Policy Implications*. PhD Thesis, University of Maryland, Baltimore

Nozyce M, Lee S and Wiznia A (2006) A behavioural and cognitive profile of clinically stable HIV-infected children. *Pediatrics* 117: 763–770

Nyamukapa C, Gresgson S, Lopman B, Saito S, Watts H, Monasch R and Jukes M (2006) *HIV-associated orphanhood and children's psychosocial disorders: theoretical framework tested with data from Zimbabwe*. Harare Biomedical Research and Training Institute, Harare, Imperial College, London and UNICEF, Zimbabwe

Olley B, Gxamza F, Seedat S, Theron H, Taljaard J, Reid E, Reuter H and Stein DJ (2003) Psychopathology and coping in recently-diagnosed HIV/AIDS patients — the role of gender. *South African Medical Journal (SAMJ)* 93: 928–931

Operario D, Pettifor A, Cluver L, MacPhail C and Rees H (2007) Prevalence of parental death among young people in South Africa and risk for HIV infection. *Journal of Acquired Immune Deficiency Syndromes* 44: 93–98

Pelton J and Forehand R (2005) Orphans of the AIDS epidemic: an examination of clinical-level problems of children. *Journal of the American Academy of Child and Adolescent Psychiatry* 44: 585–591

Pettifor A, Rees H, Kleinschmidt I, Steffenson A, MacPhail C, Hlongwa-Madikizela L, Vermaak K and Padian N (2003) Young people's sexual health in South Africa: HIV prevalence and sexual behaviors, from a nationally-representative household survey. *AIDS* 19: 1525–1534

Pivnick A and Villegas N (2000) Resilience and risk: childhood and uncertainty in the AIDS epidemic. *Culture, Medicine and Psychiatry* 24: 101–126

Poulter C (1996) *Vulnerable Children: a Psychological Perspective.* AIDS Orphans of Africa Project, The Nordic Africa Institute, Uppsala, Sweden

Radloff L (1977) The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement* 1: 385–401

Republic of South Africa (1996) *The Constitution of the Republic of South Africa.* Government of South Africa, Pretoria, South Africa

Reynolds C and Kamphaus R (1992) *Behavior Assessment System for Children.* Circle AGS Publishing, Pines, MN

Reynolds C and Richmond B (1978) What I think and feel: a revised measure of children's anxiety. *Journal of Abnormal Child Psychology* 6: 271–280

Richter L, Manegold J and Pather R (2004) *Family and Community Interventions for Children Affected by AIDS.* Human Sciences Research Council Publishers, Cape Town

Robertson B, Ensink K, Parry C and Chalton D (1999) Performance of the Diagnostic Interview Schedule for Children Version 2.3 (DISC-2.3) in an informal settlement area in South Africa. *Journal of the American Academy of Child and Adolescent Psychiatry* 38: 1156–1164

Rotheram-Borus M-J, Lee M, Lin Y-Y and Lester P (2004) Six-year intervention outcomes for adolescent children of parents with the human immunodeficiency virus. *Archives of Pediatric and Adolescent Medicine* 158: 742–748

Rotheram-Borus M, Lightfoot M and Shen H (1999) Levels of emotional distress among parents living with AIDS and their adolescent children. *AIDS and Behaviour* 3: 367–372

Rotheram-Borus M-J, Stein JA and Lin Y-Y (2001) Impact of parent death and an intervention on the adjustment of adolescents whose parents have HIV/AIDS. *Journal of Consulting and Clinical Psychology* 69: 763–773

Rutter M, Tizard J and Whitmore K (1970) *Education, Health and Behaviour.* Longman, London

Safman R (2004) Assessing the impact of orphanhood on Thai children affected by AIDS, and their caregivers. *AIDS Care* 16: 11–19

Sengendo J and Nambi J (1997) The psychological effect of orphanhood: a study of orphans in Rakai district. *Health Transitions Review* 7: 105–124

Shaffer A, Jones D, Kotchick B, Forehand R and The Family Health Project Research Group (2001) Telling the children: disclosure of maternal HIV infection and its effects on child psychosocial adjustment. *Journal of Child and Family Studies* 10: 301–313

Siegal K and Gorey E (1994) Childhood bereavement due to parental death from Acquired Immunodefiency Syndrome. *Developmental and Behavioural Pediatrics* 15: 566–571

Snider L and Dawes A (2006) *Psychosocial vulnerability and resilience measures for national-level monitoring of orphans and other vulnerable children: recommendations for revision of the UNICEF Psychological Indicator*. UNICEF, Cape Town

Southern African AIDS Training Programme (2003) *Guidelines for Counselling Children who are Infected with HIV or Affected by HIV and AIDS.* SAT, Harare

Stein A, Krebs G, Richter L, Tomkins A, Rochat T and Bennish M (2005) Babies of a pandemic: infant development and HIV. *Archives of the Diseases of Childhood* 90: 116–118

Stein J (2003) *Sorrow makes children of us all: a literature review on the psycho-social impact of HIV/AIDS on children. CSSR* Working Paper No. 47, Centre for Social Science Research, University of Cape Town, Cape Town, South Africa

Strode A and Barrett Grant K (2001) *The role of stigma and discrimination in increasing the vulnerability of children and youth infected with and affected by HIV/AIDS*. Save the Children (UK)

Swartz L (2002) *Culture and Mental Health: a Southern African View.* Oxford University Press, South Africa

Tedstone J and Tarrier N (2003) Post-traumatic stress disorder following medical illness and treatment. *Clinical Psychology Review* 23: 409–448

UNAIDS (2004) Children on the brink, 2004: a joint report of new orphan estimates and a framework for action.

UNAIDS and UNICEF (2002) Children on the brink: a joint report on orphan estimates and program strategies

UNICEF (1989) Convention on the Rights of the Child, Geneva

UNICEF/WHO (2006) AIDS epidemic update. UNICEF, Geneva

van Dam M and van Izjendoorn M (1988) Measuring attachment security: concurrent and predictive validity of the Parental Attachment Q-set. *Journal of Genetic Psychology* 149: 447–457

Veit-Wilson J (1998) *Setting Adequacy Standards.* Polity Press, Bristol

Vermaak K, Mavimbela N, Chege J and Esu-Williams E (2004) Challenges faced by households in caring for orphans and vulnerable children. Population Council, Horizons and Frontiers, Washington DC

Volle S, Tembo S, Boswell D, Bowsky S, Chiwele D, Chiwele R, Doll-Manda K, Feinberg M and Kabore I (2002) *Psychosocial baseline survey of orphans and vulnerable children in Zambia*. Paper presented at the XIV International AIDS Conference, Barcelona

Wild L (2001) The psychosocial adjustment of children orphaned by AIDS. *Journal of Child and Adolescent Mental Health* 13(1): 3–25

Wild L, Flisher A, Laas S and Robertson B (2006) *Psychosocial adjustment of adolescents orphaned in the context of HIV/AIDS*. Poster presented at the International Society for the Study of Behavioural Development Biennial Meeting, Melbourne, Australia

Appendix 1: A brief summary of controlled studies

Country, date	Authors	Sample characteristics	Control groups	Respondents	Standardised instruments?	Brief findings
Zambia (1996)	Poulter	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 and Nambi	169 AIDS-orphans; 24 non-orphans	Non-orphans	Children; teachers; some guardians	Unstandardised	Orphans had higher levels of depression and lower levels of optimism
Tanzania (2002)	Makame *et al.*	41 AIDS-orphans with 41 non-orphans	Non-orphans	Children	Unstandardised	Orphans showed higher levels of internalising problems
Mozambique (2002)	Manuel	76 AIDS-orphans; 74 non-orphans	Non-orphans	Children	Unstandardised	Orphans showed higher depression scores and wereless likely to have trusted adult or friend
Uganda (2005)	Atwine *et al.*	123 AIDS-orphans; 110 non-orphans	Non-orphans	Children	Standardised	Orphans more anxious, depressed; more anger, hopelessness and suicidal ideation
Rwanda and Zambia (2005)	Chatterji *et al.*	1 160 AIDS-orphans, children with sick caregivers and non-affected children	(1) Children with sick caregivers (2) Non-affected children	Children	Unstandardised	Rwanda: orphans showed higher worry/stress levels than other groups Zambia: orphans and children with ill caregivers showed higher worry/stress levels than non-affected children
Ethiopia (2005)	Bhargava	479 AIDS-orphans; 574 orphans from non-AIDS causes	Children orphaned from non-AIDS causes	Children	Standardised	AIDS-orphaned children showed more social and emotional adjustment problems
South Africa (2006)	Cluver and Gardner	30 AIDS-orphans; 30 non-orphans	Non-orphans	Children	Standardised	No subscale differences. Orphans less likely to have good friends; high levels of PTSD
Zimabawe (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 levels and psychosocial distress on six items of depression, and lower psychosocial well-being on two items (single item analysis)
South Africa (2006)	Wild *et al.*	81 AIDS-orphaned children; 78 orphaned from non-AIDS causes; 43 non-orphans	(1) Non-orphans (2) Children orphaned from non-AIDS causes	Children	Standardised	Children orphaned from other causes showed more depression and anxiety than non-orphans, with AIDS-orphans not differing from either. No differences in terms of externalising problems

Appendix 1: (cont.)

Country, date	Authors	Sample characteristics	Control groups	Respondents	Standardised instruments?	Brief findings
South Africa (2007)	Cluver *et al*.	455 AIDS-orphaned children; 243 orphaned from non-AIDS causes; 278 non-orphans; 85 orphaned by unknown causes	(1) Non-orphans (2) Children orphaned from non-AIDS causes	Children	Standardised	AIDS-orphans showed more depression, peer problems, PTSD and behaviour problems than other groups. No difference in anxiety
Kenya (ongoing)	Elmore-Meegan *et al.*	Planned 400 children	Non-orphans	Children and caregivers	Unstandardised	Data collection in progress
Uganda (ongoing)	Lamphear and Jones	137 AIDS-orphans; 98 children orphaned from non-AIDS causes; 99 non-orphans	(1) Non-orphans (2) Orphans from non-AIDS causes	Children	Standardised	Data in analysis
USA – New Orleans (1999, 2005)	Forehand, Pelton *et al*. Longitudinal study	20 AIDS-orphans, 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 six months post-orphanhood, non-significant improvements. Two years post-orphanhood, orphans had more internalising and externalising problems than both control groups
USA (2001)	Hirsch	16 AIDS-orphans; 12 children orphaned from non-AIDS causes	Children orphaned from non-AIDS causes	Children	Standardised	Children orphaned from non-AIDS causes showed higher levels of depression, anxiety and conduct problems than AIDS-orphaned children.
USA – New York (2001, 2004)	Rotheram-Borus *et al.* Longitudinal study	73 AIDS-orphans; 138 children with HIV+ parents	Children with HIV+ parents	Children	Standardised	AIDS-orphaned children showed more emotional distress and more problem behaviours than children with HIV+ parents