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**MATERNAL WELL-BEING,
CHILDCARE AND CHILD
ADJUSTMENT IN THE
CONTEXT OF HIV/AIDS:**

**WHAT DOES THE PSYCHOLOGICAL
LITERATURE SAY?**

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CSSR Working Paper No. 135



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Maternal Well-Being, Childcare and Child Adjustment in the Context of HIV/AIDS: What does the Psychological Literature say?¹

Abstract

This paper outlines the findings of the psychosocial and psychological literature on the impact of mothers and primary caregivers' HIV infection on maternal well-being, childcare and child adjustment. Drawing on an ecological approach, the paper outlines a model that both demonstrates the link between parental HIV/AIDS and child outcome, and examines the pathways that account for this relationship. These include personal, familial and environmental factors. Some of the key findings that emerge from the literature are that children of HIV positive mothers are at greater risk for emotional and psychological problems than children of uninfected mothers, especially internalising problems such as depression. However, children in poor, affected communities also experience detrimental developmental effects, indicating that HIV/AIDS typically serves as an added stressor in already at-risk communities. Further, disruptions to parental monitoring and the quality of the parent-child relationship are a key pathway whereby these impacts are felt, and are more likely where maternal HIV infection has progressed to AIDS. It is recommended that policy responses take cognisance of children's contexts and the pathways to child outcomes when attempting to respond to the HIV/AIDS epidemic.

Introduction

This paper attempts to come to terms with the literature that considers the question of the impact of maternal HIV/AIDS on uninfected children. The review aims to assist in conceptualising an area of increased importance in the field of HIV/AIDS due to the marked increase in numbers of HIV-infected women and mothers, particularly in the developing world (Aberg, 2005;

¹ I would like to thank Lauren Wild and Nicoli Nattrass for their useful comments on this paper.

UNAIDS, 2004b; 2004c), and with this the impact of the disease on children and families (Campbell, 1999). With the decrease in perinatally transmitted HIV, an even narrower, but large, group of affected/uninfected children has emerged as important in addressing the crisis, both at the present moment and in terms of later sequelae (Lewis, 2001). While fewer children may be infected (by their mothers), large numbers of children are affected by virtue of the prevalence of HIV/AIDS in the homes and communities in which they live. Further, a major risk to the child's socio-emotional and cognitive development is posed by the HIV positive mother or caregiver whose capacity to provide emotionally responsive care to the child may be reduced by his/her illness.

The paper provides an up to date review that extends work produced in recent years. Most notable amongst these are: Foster and Williamson's (2000) review of the impact of HIV/AIDS on children in sub-Saharan Africa, including coping mechanisms and the impact of HIV on children; and Wild's (2001) review of empirical research and clinical evidence regarding the impact of parental AIDS and orphanhood on child adjustment. Also relevant, but more tangential, are Hunter and Williamson's (2002) demographic portrait of children affected by HIV/AIDS in 23 countries, and Richter, Manegold and Pather's (2004) review of family and community interventions for children affected by AIDS, as well as several other policy documents that have addressed some of the same issues, although in broader terms. In contrast with the aforementioned articles, this paper focuses specifically on children still living with infected parents (whether asymptomatic or with full-blown AIDS). It is not intended to focus on children already orphaned. Further, the paper will provide a critical review of the psychological and psychosocial literature in order to develop a model of the relationships between HIV positive mothers' well-being, childcare and children's psychosocial adjustment. The model aims to move beyond the simple linking of parental illness and child adjustment to examine family process and other relevant variables (Wild, 2001). The paper will therefore delineate the critical conceptual issues and evaluate and discuss the empirical evidence. It is hoped that such a framing of the literature will be useful for considering the relevance of research findings for the conceptualisation, planning and implementation of programmes for infected mothers and their children, as well as their households and broader networks.

Methodology used to source literature

The review draws on both published and unpublished material from 1990 to 2005 which was largely identified using keyword searches of electronic databases. Keywords used included HIV/AIDS, mother or caregiver, child or infant, caring or caregiving, psychosocial or mental health, depression or

anxiety, stigma or disclosure, and social support or coping. A range of online databases were sourced² and a limited number of additional papers were identified by scanning the reference lists obtained through the above-mentioned sources.

It should also be noted that the majority of papers sourced draw on samples of North-American mothers and children. Further, many of the studies cited form part of Forehand *et al.*'s Family Health Project (1998b), a six-year longitudinal investigation of 249 inner-city African-American women and their 6- to 11-year-old children. Thus, rather than referring to the context of each study, context will be specified only where it differs from Forehand *et al.*'s inner-city, American setting and is relevant to a critical comparison of findings across different studies. Further, with regard to the stage of illness, asymptomatic mothers (and caregivers) comprise approximately 50 percent of the total sample in the majority of studies, followed by symptomatic mothers and mothers who meet the criteria for AIDS (see, for example, Hough *et al.*, 2003; Forehand *et al.*, 1998b; Forsyth *et al.*, 1996; and Tostes, Chalub & Botega, 2004). Where the differential impact of stage of illness has been explored (or the sampling differs significantly from this profile), this will be noted. However, in many cases, such analyses were not undertaken.

Approach of review

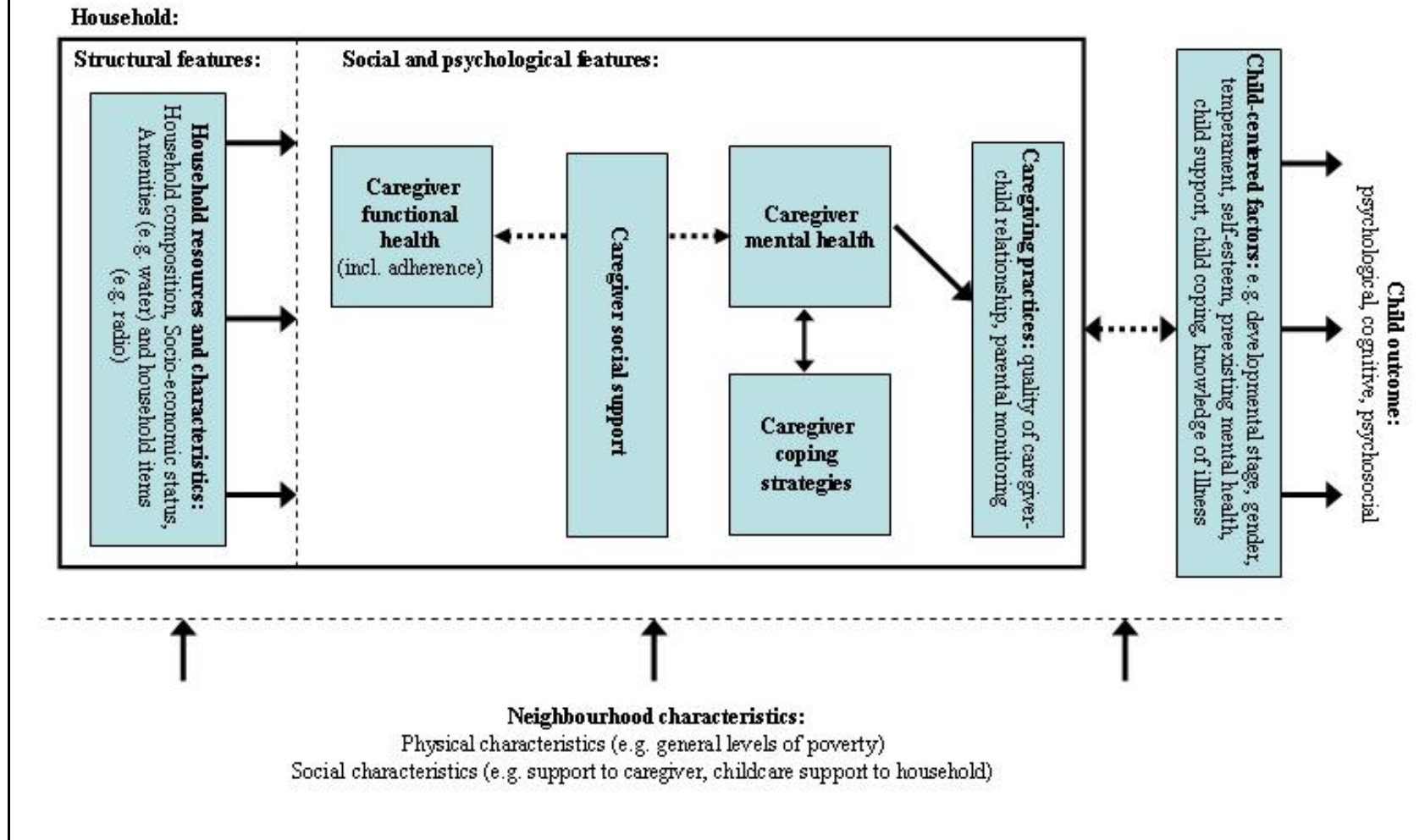
The model presented below (see Figure 1)³ draws on an ecological approach in the tradition of Bronfenbrenner (1986; 1997) that situates development and the individual within a context. The context comprises a series of subsystems within which children grow and develop (e.g. the home, school and neighbourhood). These subsystems influence each other and jointly determine outcomes for individuals, in this case, child adjustment. The model will be used to structure the discussion of the literature that follows.

Since the review covers mainly the psychological literature, the focus of the paper will be on the social and psychological features of the caregiver situated within the household (see Figure 1), and its implications for the care of children and, ultimately, their cognitive, psychosocial and psychological outcomes.

² The following databases were sourced: PsycINFO and PsycARTICLES; Academic Search Premier; Medline; Family and Society Studies Worldwide; Child Abuse, Child Welfare and Adoption; Sociological Abstracts; Ebsco Electronic Journals Services; Index to South African Periodicals (ISAP); South African ePublications; and PubMed, ISI Web of Science and ProQuest.

³ For other examples of models of the impact of parental HIV/AIDS on child adjustment, see Hough (2003) and Forehand *et al.* (1998).

Figure 1. Conceptual model of the impact of caregiver HIV infection on maternal mental health, childcare and child well-being



As will be evident, caregiver's functional health, in particular their HIV status, has direct (and indirect) implications for the levels and types of social support which they receive, which in turn affects their mental health and coping strategies. Further, these factors combine to influence the quality of caregiving that mothers and women caregivers are able to provide to their children. This component of the model represented in Figure 1 is the focus of most of the papers reviewed that reflect a traditional psychological approach, as opposed to one which draws on the contributions of disciplines such as sociology and anthropology. While less attention is paid in the literature to structural features of the household or characteristics of the neighbourhood and surrounding environment (e.g. general levels of poverty, childcare support to household), their role in their model will be discussed and the available evidence examined. These aspects of the model are considered important for extending research into the field of applied social science and programme design, particularly in developing world contexts. Finally, child-centred factors that mediate or moderate the impact of these collective factors on child adjustment will be mentioned, including the child's developmental stage, temperament, history of mental illness and support available to the child. While as the literature will show, multiple relationships between these variables exist, the model reflects only the primary pathways of effect and association for the sake of illustration.

Impacts on child development

Psychological effects

While the evidence is oftentimes muddled by a lack of methodological rigour or comparability of findings, there does appear to be sufficient evidence that children of HIV positive women have a moderately increased risk for psychosocial adjustment problems when compared with children of noninfected women (Forehand *et al.*, 1998a; Forehand *et al.*, 2002; Forsyth, Damour, Nagler & Adnopo, 1996; for review see Wild, 2001). This is consistent with the findings from a review of children of parents with other physical illnesses, including arthritis, diabetes and cancer (Armistead, Klein & Forehand, 1995), although, as Forehand *et al.* (2002) have stated more recently, this literature, too, remains in its infancy.

One of the more robust of these findings is that children have an increased likelihood of experiencing the internalisation of problems, most notably depression (Esposito *et al.*, 1999; Forsyth *et al.*, 1996; Forehand *et al.*, 1998a;

Forehand *et al.*, 2002; Hough *et al.*, 2003; Kotchick *et al.*, 1997b). This finding has been supported by three cross-sectional analyses (Esposito *et al.*, 1999; Forsyth *et al.*, 1996; Forehand *et al.*, 1998b) and four-year longitudinal data (Forehand *et al.*, 2002), all of which drew on studies with matched comparison groups of noninfected mothers from the same community. The latter study included 175 mothers and children at all four assessment points, and found no change in children's adjustment over time, a finding that might be explained by the fact that the health status of the mothers (measured by CD4 cell count and the percentage of women on antiretroviral therapies) remained remarkably stable over time⁴. There is additional evidence for other internalising problems such as being withdrawn (Forsyth *et al.*, 1996) and anxious (Esposito *et al.*, 1999; Forehand *et al.*, 1998a). Further, Hough *et al.* (2003) noted that the children in their sample experienced difficulties with adjustment equivalent to those of children referred to an outpatient clinic, indicating relatively high levels of risk.

The results regarding externalising behaviour are more mixed. Several studies have reported elevated levels of externalising symptoms such as aggression and behaviour problems amongst the children of infected mothers (Elkin *et al.*, 1995; Esposito *et al.*, 1999; Forsyth *et al.*, 1996; Gerstadt, 2003; Hough, 2003; Kotchick *et al.*, 1997b; Wild, 2001). However, the differences are less marked than with internalising symptoms, and Forehand *et al.*'s (2002) longitudinal study found no differences at all across the four-year assessment period, based on either children or mother's reports. This is consistent with Reyland, McMahon, Higgins-Delessandro and Luthar's (2002b) finding with a slightly older sample of 11 to 16 year old children in which there was no difference with respect to either internalising or externalising behaviour.

While findings with respect to internalising problems were fairly robust, differences based on self versus maternal report were also noted. Both longitudinal data from the United States (Forehand *et al.*, 1998a; 2002) and cross-sectional data from Italy found that, in contrast with children's reports, mothers' reports failed to show elevated levels of internalising symptoms amongst children compared with controls (Forehand *et al.*, 1998a; Forehand *et al.*, 2002). Dorsey *et al.* (1999b) also found discrepancies in mother and child reports, with the direction of the prediction depending on the mother's

⁴ In this respect, Forehand *et al.*'s (2002) sample and finding reflect the profile of children and families in developed countries where antiretroviral therapy is widely available and many study participants may have been receiving treatment for several years already (see also Ciambrone, 2003). However, in developing world contexts where drugs have only become available more recently and roll-out is not widespread, the situation is likely to be different.

health status. While children reported increasing problems with the increasing severity of mothers' symptoms, mothers reported an increase through the infected symptomatic stage and a decrease in the AIDS stage. However, another (cross-sectional) study produced congruent maternal and child reports of internalising problems, but differed with regard to externalising problems (Forsyth *et al.*, 1996), while a study employing the self-reports of adolescents found no evidence of higher levels of emotional distress among the children of infected mothers compared with same-age norms (Rotheram-Borus, Lightfoot & Shen, 1999). Comparing child self-report with the findings of a structured clinical interview, Gerstadt (2003) found that the latter predicted higher levels of problems with children that were otherwise undetected.

One argument regarding differences in reports is that children may under-report their symptoms and problems because they are not permitted by their mothers to discuss these topics openly (*ibid.*). The nature of HIV/AIDS itself, particularly its fluctuating course and associated stigma, has also been found to contribute to children's feelings of uncertainty, stigma, secrecy and isolation (Antle *et al.*, 2001; Geballe, Gruendel & Andiman, 1995; Wild, 2001). Consequently, parents' experience of HIV/AIDS may become "unnamed, unspoken, and often unspeakable to children" (Nagler, Adnopoz & Forsyth, 1995: 75), thereby increasing the likelihood of adjustment difficulties and the underreporting of problems. Nonetheless, these findings have at least two important implications. Firstly, the adjustment problems of children affected by parental HIV/AIDS may frequently be masked from the attention of significant adults in the children's environments (due to its typically internalising nature) (Forehand *et al.*, 2002; Forsyth *et al.*, 1996; Gerstadt, 2003; Kotchick *et al.*, 1997b); and secondly, researchers should give careful thought to their chosen methods, in particular their choice of informants on child adjustment.

Some other findings regarding children's psychological functioning must also be mentioned. Children have been reported to experience biopsychosocial symptoms such as malaise, loss of appetite and sleep disturbance, increased attachment behaviours, regression, frightening fantasies, and the reactivation of pre-existing psychiatric symptoms (Lewis, 1995). At least some of these symptoms, in particular regression and the reactivation of previous symptoms, are likely to be the consequence of children's feelings of hopelessness, loneliness, anger and confusion that can arise in the context of HIV and AIDS (Wild, 2001).

Studies focusing on older children, in one case, children between 11 and 16 years of age, have shown that living with an HIV positive mother resulted in a shift in the children's core assumptions about life, fear of death, and a sense

of stigma and isolation (Reyland, Higgins-D'Alessandro & McMahon, 2002a). While the stage of illness of these mothers is not stated, it should be noted that the mothers were all receiving home-based health-care and were likely to be at the symptomatic stage. Further, most were single parents. The results suggest that both factors are associated with increased levels of risk to their children. In other qualitative studies with children 10 to 19 years old, 34% of children have been reported to show significant acting out behaviour (Hudis, 1995). Other children with mothers with AIDS have also spoken of behaviour problems, as well as risky sexual behaviour with multiple partners and difficulties in their relationships with their mothers (Duggan, 2000).

Cognitive effects

While most of the research on the impact of HIV on child development addresses the effect of the virus on the central nervous system of infected children (Dedomenico, 1999; Lowenthal, 1997; Knight, Mellins, Levenson, Arpadi & Kairam, 2000; Mellins, Levenson, Zawadzki, Kairam & Weston, 1994), there is also some research indicating that the uninfected children of HIV positive mothers may experience detrimental effects on their development as well. A study of the developmental status of infants of infected mothers found that children showed poorer development (compared with same age norms) across a range of developmental outcomes, and that their development declined over the course of their second year (Holditch-Davis *et al.*, 2001).

Other studies, all with older children, have found more attention problems (Eposito *et al.*, 1999; Forsyth *et al.*, 1996) and language disorders (Elkin *et al.*, 1995) compared with norms for children with uninfected mothers. Forehand *et al.* (1998a) has also shown that children of HIV positive mothers (including those who are asymptomatic) are at greater risk for lower levels of social competence and cognitive competence, measured by a reading achievement test. This study did not analyse the potentially differential effects on children with asymptomatic mothers versus those with symptomatic or AIDS-sick mothers. However, another study similarly found that the negative effect on children's attention problems held for both the children of symptomatic and asymptomatic mothers (Forsyth *et al.*, 1996).

Psychosocial effects

Particularly with regard to psychosocial impacts, it is important to note that HIV/AIDS has a disproportionate impact on children in impoverished

communities, both during the course of a caregiver's illness and following their death to AIDS (Case & Ardington, 2004; Foster & Williamson, 2000; Hunter & Williamson, 2002; Richter, Manegold & Pather, 2004). Children are likely to be faced with the cumulative presence of "a set of material and psychosocial stressors", including economic deprivation and disrupted schooling (Wild, 2001: 8). Girls in particular may take on the role of care providers, experiencing a shift in parent-child relationship, and assume increasing household responsibility in order to ward off problems regarding shelter, material needs and access to adequate health services (Fair *et al.*, 1995; Foster & Williamson, 2000; Wild, 2001). Consequently children become more vulnerable to abuse and exploitation (Foster & Williamson, 2000; UNICEF, 2004), and may experience a loss of educational opportunities and health status, and even increased exposure to HIV infection (Hunter & Williamson, 2002). Adolescents report frequent changes of residence (Duggan, 2000), family role reassignments (Reyland *et al.*, 2002a) and a lack of social supports and other resources (Hudis, 1995; Reyland *et al.*, 2002a). Some adolescents have also reported that families experience difficulties identifying and maintaining custody placements in the event of their parent or caregivers' death (Hudis, 1995). In addition to the multiple losses that children in AIDS-infected households are likely to experience, including the loss of caregivers (Hudis, 1995; Reyland *et al.*, 2002a; Woodring, 2000), many continue to suffer added psychosocial insults, such as those mentioned above. Longitudinal demographic surveillance data from an area in South Africa with high HIV prevalence provides convincing, methodologically rigorous evidence that children whose mothers have died are significantly more disadvantaged than children from either the same community or non-orphans with whom they live (Case & Ardington, 2004). This analysis demonstrated that these children were less likely to be enrolled in school, had completed fewer years of schooling, and had less money spent on their school-related expenses.

Moderating and mediating factors affecting child outcome

While many of the findings regarding child outcome are of interest in exploring children's experiences, it is more useful to understand the mediating and moderating factors that account for these outcomes. While mediating factors explain the pathways that account for the impact of stressors such as parental HIV/AIDS on children (for example, parenting), moderating factors influence outcomes by either increasing or decreasing the

impact of stressors on children (for example, sex and age)⁵. As research in the context of HIV/AIDS has begun to address, the link between parental HIV status and child adjustment is unlikely to be a simple one (see, for example, Forehand *et al.*, 1998a; Hough, 2003). As with other stressors that can impact on child adjustment (for example, divorce), it is important to note that differential impacts are likely depending on a range of personal, familial and environmental factors (Wild, 2001). These factors serve as potential risk and protective factors for children (and potentially their HIV-infected caregivers, too), moderating the impact of HIV/AIDS (Garmezy, 1993; Luthar & Zigler, 1991; Luthar, Cicchetti & Becker, 2000; Masten, 1994).

Most immediate in the model outlined (Figure 1) are child-specific factors such as developmental stage, gender, temperament or personality, pre-existing mental health problems, level of intelligence and coping strategies. An additional factor, located in the child's environment, is the availability of social and emotional support. While some of these factors have not been empirically tested in the context of HIV/AIDS, with the link having been drawn between HIV and other psychosocial stressors, there is convincing evidence from related fields to support the role played by these factors (see Dutra *et al.* (2000) and Hough *et al.* (2003) for notable exceptions). These general principles regarding child development can be generalised to the experiences of children (and caregivers) made vulnerable by HIV/AIDS (Richter *et al.*, 2004). Moreover, they can be drawn upon in order to examine some of the potentially context-specific issues, such as AIDS-related stigma.

Before addressing specific findings in the literature in more detail, it is important to note that the relationship between children's adjustment and these risk and protective factors is not unidirectional. Temperament, for one, is a particularly good example of a personal protective factor that reflects the extent to which children and their own perceptions and experiences of their environment (such as living with an HIV positive caregiver) can facilitate their better handling of a potentially stressful situation. While the stressor still acts on the child, the child similarly exerts an influence on the stressor, thereby moderating its impact on his or her levels of psychosocial adjustment.

Some of the implications of child-specific moderating factors have already been noted. For example, disruptions in schooling, often due to increased caretaking responsibilities, are more likely in boys than girls (Foster & Williamson, 2000; UNAIDS, 2004a). However, this conclusion, based on clinical observations and anecdotal evidence has not been unequivocally

⁵ See Baron and Kenny (1986) for a more detailed discussion of the difference between mediating and moderating factors.

supported by the empirical data. For example, two empirical studies with children of infected mothers and one with the children of infected fathers did not find an association between gender and children's levels of adjustment (Bauman *et al.*, 2002; Forehand *et al.*, 1998b; Steele, Forehand & Armistead, 1997). In contrast, a study of developmental outcomes of infants exposed to HIV (i.e. born to an infected mother)⁶ found that males had poorer psychomotor development and scored lower on a scale of adaptive behaviour that comprises language, self-help, socialisation and motor development, than females (Holditch-Davis *et al.*, 2001). It is probable that some effects are more likely to be gender-specific or differentiated according to gender than others, for example, care work into which girls rather than boys are usually socialised. Alternately, gender-based differences may be more pronounced, and reach statistical significance, at an age older than that included in the study samples, namely, in adolescence.

The effects of parental HIV/AIDS at any given point in time are also dependant on the particular developmental challenges that a child is facing. Lewis (1995) states that preschool children of HIV-infected (but not necessarily AIDS-sick) parents are likely to become withdrawn, show symptoms such as food refusal and temper tantrums, and become excessively dependent on caregivers, resulting in impaired peer relationships; school-age children may suffer from depression, school difficulties and oppositional or disruptive behaviours; and adolescents may experience ambivalent feelings toward parents, resulting in failure to separate properly from parents and serious psychological disturbance. Adolescents may also engage in risk-taking such as risky sexual behaviour in order to compensate for their fear regarding the outcome of the illness for themselves and their parent or caregiver (Duggan, 2000; Lewis, 1995). In terms of psychosocial effects, preteens are most vulnerable to sexual exploitation (Richter *et al.*, 2004). However, once again, empirical evidence has not provided unequivocal support for the role of age. One large-scale study of mothers at various stages of the disease which included a control group found no effect for age (Forehand *et al.*, 1998b). Another study with mothers with late-stage AIDS found a weak (but significant) relationship between the child's age and poor psychological adjustment (with older children displaying more problems). However, further analyses showed that the association between poor outcomes and age is moderated by the child's level of independence (Bauman *et al.*, 2002).

Other factors that have been shown to be protective for children include good pre-existing mental health, an internal locus of control, high self-esteem, a

⁶ 8.6% of the sample tested HIV positive at 8 to 10 months of age.

sociable personality or easy-going temperament, and intelligence (for a review of risk and protective factors in children, see Luthar & Zigler, 1991). A study with 5- to 12-year-old children of HIV-infected mothers evaluated the role of both temperament and intelligence on school performance. The findings showed that children who had been kept behind a grade at school had more adjustment problems, while those with temperaments that predisposed them to persist with and complete tasks on their own (i.e. be productive and independent) were likely to have fewer problems than average (Bauman *et al.*, 2002).

Finally, research has addressed children's coping strategies as well as the role of support available to them in promoting positive psychosocial adjustment. Research has also shown that the availability of social support to HIV affected children from peers, family and teachers protected them from adverse psychological outcomes – directly, as well as indirectly through promoting more adaptive coping strategies in children (Hough, 2003). Other research has further differentiated categories and sources of support that moderate child outcome, showing that support from parents is more protective of children's well-being than support from less significant or less proximal others. This is reflected in Kotchick *et al.*'s (1997b) finding that while extra familial support served as a buffer against internalising problems, parental support served as a buffer against both internalising problems (as reported by parents) and child-reported depression. Further, children's perceptions of parental support were more strongly associated with psychosocial adjustment than perceptions of extrafamilial support. Klein *et al.* (2000) also found that more socio-emotional support from the mother was associated with less depressive mood and disruptive behavior among children. Given the findings that children of infected mothers receive lower levels of socioemotional support than children of noninfected mothers (Klein *et al.*, 2000) as well as less support in their relationships with parents, teachers and friends (Reyland *et al.*, 2002b), the importance of effective coping and support to children becomes especially critical.

Apart from child-specific factors, there are several variables which research shows tend to mediate or moderate the relationship between primary caregiver HIV infection and child outcome.

Caregiver-child relationship, parental monitoring and other parenting practices

Key among these mediators (and moderators) is caregiving or parenting practices. In the broader child development literature, as well as in the context of HIV/AIDS, caregiving practices have been shown to constitute a significant pathway whereby environmental and individual factors impact on child development, serving either as a risk or protective factor (see Figure 1).

In the HIV/AIDS literature, two of the few available studies with the infants of infected mothers showed that mothers' HIV status does not independently influence the quality of mother-child interaction (Black *et al.*, 1994; Johnson & Lobo, 2001). The quality of parenting, however, has been shown in another study with infants to exert some influence on the child, as suggested by the path model already outlined (see Figure 1). Holditch-Davis *et al.*'s (2001) study of the infants of HIV-infected mothers found that both high parenting quality and consistency of the primary caregiver was associated with better developmental outcomes. More specifically, parenting quality, in particular positive attention, was associated with higher mental development, motor skills, language abilities and adaptive behaviours in HIV-exposed infants, while changes in caregiving arrangement predicted poorer adaptive behaviour and psychomotor development. Negative control also had an effect on all domains except language, however, only where positive attention or warmth was present as well. Holditch-Davis *et al.* also found that parenting was a significant mediator of child outcome even in children infected with HIV, and that it predicted significantly more variance in children's cognitive development than their HIV status (Holditch-Davis *et al.*, 2001; Jacquess, 1994 in Holditch-Davis *et al.*, 2001).

In studies with older (6- to 15-year old) uninfected children, support for the role of parenting practices has also been found. Several different studies with HIV-infected mothers all found that a good mother-child relationship predicted better child adjustment (Bauman *et al.*, 2002; Dutra *et al.*, 2000; Forehand *et al.*, 2002; Kotchick *et al.*, 1997a). Moreover, research has shown that a family's adaptability (Bauman *et al.*, 2002) and effective parental monitoring (Kotchick *et al.*, 1997a) are additional protective factors, while family cohesion was associated with risk (Bauman *et al.*, 2002). The negative impact of family cohesion may be attributable to the fact that such families were typically enmeshed, causing children to be more vulnerable to feelings of sadness if their mother is ill.

Kotchick *et al.* (1997a) found that HIV-infected mothers reported poorer mother-child relationship quality and less monitoring of their children's activities than noninfected mothers, while Reyland *et al.* (2002b) reported that children (11 to 16 years old) perceived greater hostility and indifference in their parental relationships. In contrast, Forehand *et al.* (2002) found no differences in mothers' report across the two groups with respect to either monitoring or relationship quality. Further, Forehand *et al.* (2002) reported that a positive mother-child relationship consistently predicted fewer adjustment difficulties in children only where either mother or child reported on both. Thus the clearest conclusion that can be drawn (from Forehand *et al.*'s study) is that children of HIV-infected mothers who view (and therefore report) their relationship with their mothers as less warm and supportive than children of uninfected mothers, are more likely than other children to experience adjustment problems.

Research has also investigated the more precise components of parenting that are beneficial to children, and the mechanisms whereby the mediating effect of parenting and the mother-child relationship may be disrupted in HIV-infected households. With respect to the components of parenting, Dutra *et al.* (2000) showed that of three parenting variables investigated (parent-child relationship, parental monitoring outside the home, and parental structure within the home), parent-child relationship was the only significant individual predictor. However, structure and monitoring, and monitoring and parent-child relationship together appeared to potentiate each other, suggesting that monitoring is a key variable, perhaps functioning as a moderator for both parental structure and parent-child relationship. Consequently, a positive parent-child relationship and structure may promote resiliency only in the context of high levels of monitoring outside the home.

With respect to the mechanisms of the mediating effect, one explanation supported by empirical research is that the stresses accompanying HIV infection cause a negative shift in mother's parenting (Forehand *et al.*, 2002), while another is that HIV positive caregivers engage in lower levels of effective parenting behaviours (Armistead, Klein & Forehand, 1995; Fair *et al.*, 1995; Forehand *et al.*, 2001; Kotchick *et al.*, 1997a). These behaviours include: reduced parental support for the child, fewer efforts at discipline and supervision more generally, neglect of the child due to reorganisation of the family around illness, changes in family routines, and parental absence. The lack of adequate care and control may be the result of caregivers wrestling with their own feelings of guilt and anxiety (Fair *et al.*, 1995; Foster & Williamson, 2000), together with the fact that the dynamic nature of

symptoms in HIV disease can be distressing and frustrating to caregivers (Hudson, Lee & Portillo, 2003).

Functional health and antiretroviral treatment

Clearly, living with HIV/AIDS has multiple implications for caregivers' functional health, with the extent of symptoms and consequent impairment differing with the stage of illness. In a study conducted in rural Uganda, Mast *et al.* (2004) found that HIV positive women reported poorer health and physical functioning, more pain, and poorer role functioning and overall quality of life than non-HIV positives in the same community, with impairment most substantial in women reporting four or more symptoms.

For infected caregivers with access to antiretroviral therapy (ART), it is also important to note that, in addition to the effects of the illness on functional health (and other related factors – see Figure 1), the treatment itself can have side-effects, particularly in the early phases of treatment. These include: numbness or pain in the feet, diarrhoea, headaches, skin rash, dizziness, sleep disturbances and hepatitis (Department of Health, 2004). Further, partly due to the side-effects, ART can be a leading cause of psychological problems. Contrary to some assumptions, there is not equivocal evidence, either from the developed or developing world, to indicate that patients on ART experience significantly improved mental health (Bogart *et al.*, 2000; Siegel, Karus & Dean, 2004). Rather, some researchers have argued that treatment is likely to change the nature of depression (and other mental health problems) rather than preventing them altogether, or significantly decreasing their prevalence (Freeman, 2004). While research findings are mixed, there is also some indication that depressive symptoms can contribute to the progression of HIV disease (Rompa, 2002). However, Jones *et al.* (2001a) only found an association between levels of depression and subjective, as opposed to objective, measures of disease status. It may be that the association is only present where depression is at least of moderate severity, and that many studies only include relatively healthy women with mild symptoms of depression that are less likely to impact on their physical well-being, in particular markers such as CD4 cell counts.

Research has also begun to establish important links between functional health and quality of life, demonstrating that quality of life and HIV symptomatology, treatment effects and side-effects interact with each other. Treatment may result in improved functional health and quality of life, with research in a resource-poor setting in South Africa indicating progressive

improvement up to one-year after starting treatment (Jelsma, Maclean, Hughes, Tinise & Darder, 2005). However, quality of life (mental health, coping and levels of social support) is also necessary to achieve the levels of treatment adherence required for sufficient viral load suppression (Baer & Roberts, 2002; Gordillo, del Amo, Soriano & Gonzalez-Lahoz, 1999; Judd *et al.*, 2000). This is in addition to treatment-related factors such as fewer numbers of drugs, fewer side-effects, more advanced disease, and greater expectations regarding treatment, that are also associated with improved adherence and functional health. With reference to the context of the infected mother and her child, Mellins, Kang, Leu, Havens and Chesney (2003) found that mother's non-adherence to ART and missing medical appointments at an 18-month follow-up visit was associated with the presence of a psychiatric disorder, negative stressful life events, more household members, and parenting stress. Substance abuse at baseline and lack of disclosure to family members, including children, was also associated with non-adherence and missed appointments at follow-up respectively. An additional finding in an earlier cross-sectional study was that single parenting status was also predictive of missed appointments (Mellins *et al.*, 2002).

An important qualifier with respect to functional health, both for mothers and caregivers with or without access to ART, is that health status *per se* may have relatively little direct impact on child adjustment. Instead, the impact is indirect or mediated, and may often be a function of the degree of symptoms experienced by the mother. One exception to this principle is Forsyth *et al.*'s (1996) study that found a difference between levels of depression in HIV-infected and noninfected mothers, but no difference between symptomatic and asymptomatic mothers. This would suggest that a positive diagnosis in itself, negatively impacted on the emotional well-being of these women. However, several other studies have found degree of symptoms and functional impairment to be a mediating factor. Bauman *et al.* (2002), for example, found that the presence (versus) absence of activity limitations in HIV positive mothers was associated with scores on a standardised child adjustment scale, although number of hospitalisations or opportunistic infections were not. One possible explanation for this finding is that children had already been accustomed to their mother's health difficulties since they had been diagnosed, on average, 4.1 years previously (Bauman *et al.*, 2002). However, Forehand *et al.* (1998b) did not find an association between child adjustment and length of time since mother's diagnosis either. Further, some research has indicated that objective rather than subjective measures of the impact of the illness on a parent might be related to child adjustment problems (Kotchick *et al.*, 1997b).

With respect to the caregiver-child relationship, research has also tended to show that disruptions are most evident in parents with advanced stage disease, and thus with more symptoms and functional impairment. At least four different studies with infants of infected mothers found that the stage of the caregiver's illness was associated with the quality of the caregiver-child relationship and children's security of attachment, rather than their HIV status per se (Black, Nair & Harrington, 1994; Hale *et al.*, 1999; Johnson & Lobo, 2001; Peterson *et al.*, 2001). The role of functional health may be due to the fact that, in comparison with symptomatic mothers who are less able to interact positively with their infants and children (Peterson *et al.* 2001), asymptomatic mothers experience less stigma and rejection by society (Srisurapanont, Sombatmai & Jarusuraisin, 2002), become more tolerant and involved than previously (Black *et al.*, 1994), and attempt to compensate for their eventual absence (Johnson & Lobo, 2001). Evidence to support this finding comes both from the United States, and from a study conducted in Uganda (Peterson *et al.*, 2001). Even in the face of HIV/AIDS, the well being of children is still (often) the primary concern of mothers (DeMatteo *et al.*, 2002), and many women maintain their parental status, even at the cost of their own physical and emotional well-being (Ciambrone, 2003; Freeman, 2004). Alternatively, it has been argued that mothers may be in denial regarding the eventual outcome associated with their condition while still physically healthy, thereby decreasing the likelihood of potential impacts on the parenting relationship (Black *et al.*, 1994). One study also found that infants themselves may attempt to compensate where HIV positive mothers exhibit difficulties in engaging in the mother-infant relationship (Byrne, 1998).

Caregiver's psychological well-being

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

Mental health

Several studies have shown that HIV positive women and mothers are at high risk for depressive symptoms and general psychological distress (Jones, Beach, Forehand & The Family Health Research Group, 2001b; Miles *et al.*,

1997; Miles, Gillespie & Holditch-Davis, 2001; Moneyham *et al.*, 2000; Morrison *et al.*, 2002; Olley *et al.*, 2004a; Silver *et al.*, 2003; Tostes *et al.*, 2004). In comparison, there is less support for elevated levels of anxiety amongst this population (Morrison *et al.*, 2002; Orlando *et al.*, 2005; Tostes *et al.*, 2004).

Of the studies reviewed, a minority include control groups (Johnson & Lobo, 2001; Jones *et al.*, 2001b; Morrison *et al.*, 2002), although others do compare mean scores for positive women and mothers with those from normative populations (Moneyham *et al.*, 2000; Murphy *et al.*, 2002). Jones *et al.* (2001b) reported a high degree of emotional distress amongst HIV positive and negative mothers in their sample, with both sets of scores consistent with psychiatric inpatient samples. However, Murphy *et al.* (2002) found levels of depression amongst infected women were well below the cut-off for clinical depression, while Morrison *et al.* (2002) and Johnson and Lobo (2001) failed to find significant risk for depression amongst noninfected women in their respective samples. A further discrepancy is that while Tostes *et al.* (2004) found that as many as half of the women interviewed in their study presented with a mental disturbance (depression, anxiety or some other minor, non-psychotic psychiatric problem) despite the fact that half were asymptomatic, Murphy *et al.* (2002) found low levels of depression amongst their mostly healthy sample. The latter finding is more consistent with the results of Silver *et al.*'s (2003) investigation which showed that as many as three-quarters of mothers with late-stage AIDS experienced extreme psychological distress. These two studies suggest that levels of depressive symptoms are likely to increase with the progression of the disease.

Some of these findings are explained by the association between levels of depression in this population and range of other factors, most notably health-related factors and markers of HIV disease progression. For example, risk for depression has been associated with an accumulation of factors that reflect mothers' poor health-related quality of life and an inability to perform usual activities. These comprise high levels of physical symptoms, including non-HIV-related medical conditions (Miles *et al.*, 1997; Moneyham *et al.*, 2000; Orlando, Tucker, Sherbourne & Burnam, 2005); non-significant changes in viral load (Kalichman, Difonzo, Austin, Luke & Rompa, 2002); poor perceptions of health (Miles *et al.*, 1997); having more activity restrictions, including difficulty caring for one's child due to ill health (Murphy *et al.*, 2002a; Olley *et al.*, 2004b; Silver *et al.*, 2003); children having increased responsibility for household tasks (Murphy *et al.*, 2002a); and lower levels of reported quality of life (Moneyham *et al.*, 2000; Tostes *et al.*, 2004). A large-

scale⁷ seven-year longitudinal analysis of HIV-related epidemiological data in the United States also reported that despite several potential confounders, their data showed that depressive symptoms contributed uniquely to mortality (Ickovics *et al.*, 2001). They found that women with chronic depressive symptoms were two times more likely to die than women with limited or no depressive symptoms (after controlling for clinical evidence of declining health over time and eliminating somatic symptoms of depression that could potentially overlap with health indicators). Among women with AIDS-defining illnesses, HIV-related mortality rates were 54, 48 and 21% for those with chronic depression, intermittent depressive symptoms, and limited or no depressive symptoms, respectively. Chronic depressive symptoms were also associated with significantly greater decline in CD4 cell counts. Of interest, another smaller-scale study found that symptomatic participants, as opposed to those who were either asymptomatic or had AIDS-defining illnesses, displayed the poorest quality of life as well as poorest mental health (Tostes, Chalub & Botega, 2004). The authors suggest that this may be accounted for by these persons recent entry into the symptomatic stage.

Non-illness-related predictors of depression include lower education, experiencing more negative life events, failure to mobilise adequate social support (Silver *et al.*, 2003), lower levels of self-esteem (Moneyham *et al.*, 2000) and poorer family cohesion (Moneyham *et al.*, 2000; Murphy *et al.*, 2002a). In some instances, risks to emotional well-being have also been associated with women's need to maintain their parental status, even at the expense of their own physical well-being (Ciambrone, 2003; Freeman, 2004).

Some research has also investigated methods of report and the potential overlap between disease symptoms and somatic symptoms of depression. Jones *et al.* (2001b), in a one-year follow-up study, found that HIV-infected women reported higher levels of depressive symptoms than noninfected women at both time points, regardless of method of assessment (self-report and clinician-rated). Similarly, Morrison *et al.* (2002) found elevated levels of depression based on both self-report and clinical assessment; however, self-reports of anxiety were not supported upon clinical assessment. With respect to the relationship between disease and depressive symptoms, both Jones *et al.* (2001b) and Ickovics *et al.* (2001) found that the magnitude of difference was unaffected by the inclusion of somatic (as opposed to cognitive and affective) symptoms, while Kalichman, Rompa and Cage (2000) found that 29% of persons identified as depressed by one of their two self-report measures were no longer depressed when somatic items were removed.

⁷ With a sample size of 765 HIV positive women aged 16 to 55 years, this is the largest study known to the author of the relationship between depression and HIV/AIDS.

Kalichman *et al.* (2000) argue that overlapping somatic symptoms of depression and HIV disease inflate depression scores in this population and subsets of somatic symptoms should be removed when assessing this group in order to improve the clinical utility of the measures.

With reference to the link to child outcome, research amongst both infected (Bauman *et al.*, 2002) and uninfected women (Jones *et al.*, 2002) has shown that maternal depression predicts poor monitoring of children, as well as other more general adverse impacts on children's emotional and intellectual development. In studies with infants, however, the association between maternal depression and child outcome in the context of HIV/AIDS is equivocal. One study found that while HIV positive mothers exhibited more depression than HIV negative mothers, depression was not associated with a noticeable reduction in the quality of interaction with their infants (Johnson & Lobo, 2001). Moreover, another study found no relationship between maternal depressive symptoms and infant's development (including, language, adaptive behaviour, and mental and motor development) (Holditch-Davis *et al.*, 2001). Holditch-Davis *et al.* concluded that in populations already at-risk for depression, quality of caregiving rather than depression *per se* affects children's developmental outcomes. This is consistent with findings from other research which shows that the relationship between depression and child adjustment is largely mediated by quality of parenting (Murray *et al.*, 1996). Similarly, in a study with older children, Dutra *et al.* (2000) found that in contrast to parenting variables - including parent-child relationship - maternal distress was not associated with child adjustment. A further possible explanation is that more direct links between depression and parenting or child outcome are only evident where levels of depression are particularly high or even chronic. Consequently, relatively low levels of risk in certain studies (for example, Johnson & Lobo, 2001), may account for the absence of an association with depression.

Social support

Several studies have found evidence for the positive effects of social support for people living with HIV/AIDS (PLWHA), including the benefits to health-related quality of life for those with and without access to antiretroviral treatments (Burgoyne & Renwick, 2004; Kirksey, Hamilton & Holt-Ashley, 2002). Together with clinical factors such as immune status and physical functioning, perceived social support appeared to contribute at some level to improved perceptions of health-related quality of life (Burgoyne & Renwick, 2004).

Research has investigated the sources of support received by mothers, women and men living with HIV as well as the relationship this support has to the well-being of both the infected person and their child. With respect to familial support, several studies point to difficulties receiving support from family, particularly where women are concerned. Siehnhold (1999) reported that HIV-infected women receive their highest support from medical personnel and the least from families, while Weiner and Lorber (1998) found that less than half of family members who were aware of women's HIV status were supportive. Similarly, Sambamoorti, Crystal and Dermatis (1995) reported that women were less likely than men to receive support from a parent (as opposed to other kin or formal sources) and were 50% more likely to have unmet needs for social support. A study of HIV-infected women living in India also described them experiencing significantly less familial as well as socio-economic and spiritual support after contracting the disease (Majumdar, 2004). Similarly, a study conducted in Senegal reported a decline in traditional networks of support in the community (Mbaye & Mbaye, 1998). This finding was not confirmed by a study in the United States amongst African-American women in which the African family was shown to be a source of strength in dealing with a positive diagnosis (Owens, 2003). Owens found that women had an active extended family network and that, although women experienced difficulties talking about their failing health with family, familial bonds were sometimes strengthened through the women's sharing of her experience. The difference between these two findings might be attributable to the considerably higher rates of infection in African countries, resulting in greater and more continuous strain of family systems. However, a particular women's history with her family should also be borne in mind, such as in Weiner and Lorber's (1998) study where women with a history of drug abuse were more likely to report that their families were not supportive. These women are also more likely to have had difficult or conflictual relationships with their families prior to the disclosure of their HIV status, thereby complicating the provision of support. While support from most family members might be problematic, research has reported that many women receive relatively high levels of support from their children. One study, for example, found that 62.7% of women received support from their children in contrast with 22 to 49% from other kinds of familial members and 49% from friends (Weiner & Lorber, 1998).

The differential findings regarding support from children and other family or friends is concerning given the fact that support from children is less likely to moderate maternal distress. Klein *et al.* (2000) reported that while more social and emotional support from neighbours and friends predicted decreased psychological distress in HIV-infected (and noninfected) women, there was

some evidence that higher levels of emotional support from children were associated with greater psychological distress. This finding may be indicative of the fact that supportive children tend to act as substitutes in the absence of more adaptive sources of adult support⁸, but that children are unable to effectively meet the emotional needs of their ill parents/caregivers (Klein *et al.*, 2000). Alternatively, mothers may experience their children's support as reflecting the failure of their caregiving role. This interpretation is supported by the fact that higher levels of parenting support have been associated with reduced perceptions of parenting self-competence in HIV-infected women in contrast to noninfected women (Dorsey, Klein & Forehand, 1999a). Moreover, many infected mothers are either reluctant to seek assistance, or resist seeking assistance (Ciambrone, 2003; Thorne, 1990) since they equate soliciting support with being a failure as a caregiver (Freeman, 2004). However, the lack of support for women and mothers is further likely to strain their caregiving capacity, given that support available to the caregiver can improve quality of caregiving, thereby protecting children from maladjustment (Black *et al.*, 1994).

It is noteworthy that in a study of pregnant women in resource poor communities in South Africa, social support scores were generally higher for HIV-infected women (Mfusi & Mahabeer, 2000). While it is uncertain whether this finding has been replicated in studies conducted in high-resource settings such as the United States, it is probable that it is a function of the availability of Mother-to-Child-Transmission (MTCT) Programmes for pregnant women in South Africa. MTCT is a service through which many women are able to access formal support services that were previously unavailable, and follow-up services available to women who test positive have resulted in comparatively high levels of support provision for infected, compared with uninfected, women. Mfusi and Mahabeer's (2000) finding therefore reflects a potential difference between women in developing and developed countries, with an increasingly large percentage of state services in developing countries being targeted at PLWHA, in particular mothers.

Coping strategies

Research on HIV-infected women has shown that they frequently use ineffective coping strategies. These include emotion-focused strategies such as denial (due to refusal to accept their status), concealment (due to fear of abandonment and the desire to avoid placing additional stressors on

⁸ See Keigher *et al.* (2005) on the parental child, in particular young caregivers of mothers with HIV.

uninfected children), and isolation and crying (due to depression and attempts to avoid potential rejection) (Hackl *et al.*, 1997; Uthis, 2000). Koopman *et al.* (2000) found that HIV positive women (and men) reporting the highest levels of perceived stress were those that were most likely to disengage behaviourally and emotionally from coping with illness and to engage in a less secure manner in their interpersonal relationships. This was particularly marked amongst persons with the lowest incomes, however, it should be noted that the levels of education and income in this sample are much higher than that in most other studies with PLWHA. While Riccobono (1995) similarly found that emotion-focused coping strategies were used most frequently, at rates higher than problem-focused or avoidant coping, this strategy predicted much lower levels of perceived stress than in Koopman *et al.* (2000). In addition, these mothers had lower reported levels of depression, and their children had better cognitive functioning and were less likely to seroconvert. It is unclear whether the difference in finding is attributable to the characteristics of the respective samples, the former consisting of a fairly educated group of infected men and women, and the latter a group of HIV positive mother-infant dyads.

Hough *et al.* (2003) found that the greater the severity of an infected mother's symptoms, the more likely she was to use passive, tension-reducing coping strategies such as crying, yelling, excessive eating and sleeping and daydreaming. In contrast with passive strategies, active meaning-making coping was more likely amongst women with higher levels of social support and predicted less emotional distress in women. Reduced emotional distress, in turn, was associated with improved mother-child relationship and less child behaviour problems (*ibid*). Other research on coping has found that the appraisal of stress as a challenge rather than a threat or loss, and more problem-focused coping, tended to be associated with higher role satisfaction amongst HIV-infected caregivers living in Thailand (Uthis, 2000). A study in South Africa also found gender differences in coping strategies amongst recently infected adults, with men more likely to engage in substance use and certain other risky behaviours, while women were likely to use planning and religion to deal with their illness (Olley *et al.*, 2004a).

Stigma and disclosure of HIV status

Among the many challenges faced by HIV-infected mothers that place their emotional well-being at risk, are AIDS-related stigma and decisions regarding disclosure. While disclosure may facilitate access to social support and health benefits, reduce risks of stigma and infecting significant others, and provide an opportunity to openly discuss custody planning (Khan, 2004), the fear of

stigma, rejection, relationship changes, social isolation, violence, and discrimination against the individual and other family members, remain significant barriers (Shaffer *et al.*, 2001; Kirshenbaum & Nevid, 2002; Murphy *et al.*, 2002b; Letteney & Heft LaPorte, 2004).

Clearly, all of the negative consequences of disclosure have potentially adverse effects on women's psychological well-being. In a study with the infected mothers of infants, evidence showed that HIV-related stigma predicted depression in women (Miles *et al.*, 1997). Further, Armistead and colleagues found an association between depression and disclosure, with women who had disclosed to their partner exhibiting fewer symptoms than those who had not (Armistead, Morse, Forehand, Morse & Clark, 1999).

Available research on rates of disclosure amongst mothers has reported that between 28 and 68% of mothers disclosed their HIV status to their children (Armistead *et al.*, 1999; Armistead *et al.*, 2001; Kirshenbaum & Nevid, 2002; Murphy, Steers & Dello Stritto, 2001; Murphy *et al.*, 2002b). In addition, studies have variously reported that 51% of children had been told something about their mothers' illness, although only 13% knew that their mother might die of AIDS (Murphy *et al.*, 2001); and that 3% had not received any information regarding their mother's ill health (Kirshenbaum & Nevid, 2002). It has also been reported in two separate studies that the majority of mothers asked the child to keep their status a secret for fear of repercussions such as stigma and ostracism for both themselves and their child (Kirshenbaum & Nevid, 2002; Murphy *et al.*, 2002c). In one of these, studies, however, one in four mothers identified a "safe person" for the child to discuss the mother's HIV status with (Murphy *et al.*, 2002c).

Several factors have also been associated with either the decision to disclose or the nature of mothers' disclosures to children. Numerous studies have reported that mothers' disclosures regarding their health condition become more detailed as their children get older (Armistead *et al.*, 2001; Kirshenbaum & Nevid, 2002; Rotherham-Borus, Draimin, Reid & Murphy, 1997), and that mothers are more likely to disclose to older children and to girls (Armistead *et al.*, 2001; Shaffer *et al.*, 2001). In Murphy *et al.* (2002b), the average age of children to whom mothers had disclosed was nearly ten years old, while the children in Kirshenbaum and Nevid's (2002) study were significantly younger, at seven years old. The latter study also found an association between disease status and disclosure, with mothers with higher CD-4 cell counts providing more detailed information, while mothers on ART were more likely to disclose the fact that they may die (*ibid*). This is largely confirmed by Armistead *et al.*'s (1999) finding that the likelihood of disclosure increased with mothers' CD4 counts. In contrast, Shaffer *et al.*

(2001) found no association between disclosure and stage of illness, although it should be noted that their approach to conceptualising disclosure was less detailed than that adopted in the former study. With respect to psychosocial factors, research has shown that mothers with higher levels of social support are more likely to disclose to their children (Murphy *et al.*, 2001), while mothers with psychiatric histories are likely to make more detailed disclosures (Kirshenbaum & Nevid, 2002).

Most mothers with HIV/AIDS report carefully weighing the risks and benefits of disclosing their status to others (DeMatteo *et al.*, 2002). However, despite these attempts, research has shown that mothers often perceive the consequences of disclosure as considerably more negative than their children (Murphy *et al.*, 2002b; Shaffer *et al.*, 2001), perhaps resulting in the withholding of information to the child's detriment. Shaffer *et al.* (2001) found that children reported an increase in knowledge about HIV, and no increase in adjustment problems or deterioration in relationship quality with their mothers, mothers perceive an increase in children's externalising problems.

However, three separate analyses found no relationship between child adjustment and mother's disclosure of HIV status (Armistead *et al.*, 2001; Bauman *et al.*, 2002; Forehand *et al.*, 1998b). Higher personal maternal stigma and the mother reporting having a terminal illness were also not predictors (Bauman *et al.*, 2002). While Kirshenbaum and Nevid (2002) found more behaviour problems amongst children who received disclosure about non-specific health problems or were asked to keep status a secret, only 7% of the sample had scores within the clinical range, suggesting that the levels of risk were relatively low. Further, two other studies reported high levels of well-being amongst children with knowledge of their mother's health status, although in one study an improvement was noted after an initial period of adjustment to the disclosure during which behaviour problems were more likely to be present (Murphy *et al.*, 2001; Murphy *et al.*, 2002b). These positive changes included lower levels of aggressiveness (Murphy *et al.*, 2001), better mood (Murphy *et al.*, 2002b) and improved self-esteem over time (Murphy *et al.*, 2001; Murphy *et al.*, 2002b).

Contextual influences in the household and broader environment

Perhaps one of the more important points to emerge from the literature is that, in the poverty environments that are common to the majority of infected

persons, parental HIV/AIDS typically serves as an additional stressor to families and households who are already at-risk. This is clearest in sub-Saharan Africa, the region with the highest HIV prevalence in the world and also one of the poorest regions (UNAIDS, 2004c). In this and other areas where HIV is highly prevalent, many individuals and families also live in single-parent households and contend with the stressors associated with poverty and community violence. Further, it is often poor, black women who are most affected, either by virtue of high rates of infection within this group, or because the disease has a differential social and economic impact on them that compounds the risk. In South Africa, for example, a country with one of the highest HIV prevalence rates in the world, black women must deal with the cumulative effects of gender, race and socio-economic status, a situation that the AIDS epidemic has heightened. Survey data suggests that between 43 and 68% of AIDS-affected households in South Africa are female-headed, with as few as 12.5% of these women having a partner present in the home (Steinberg *et al.*, 2002; UNICEF, 2003; Ziehl & Burns, 2004). Also significant is the fact that these women frequently experience an increased care burden, since both sick men and women tend to be cared for by female relatives (UNAIDS, 2004a). Women are also more likely than men to take in orphaned children (*ibid*).

Aside from the potential effects of HIV/AIDS detailed in this review, the above-mentioned features of the household and broader environment serve as risks to the emotional and psychosocial well-being of caregivers and their children. Consequently, as already noted in some places, often both infected and affected mothers and their children are found to be functioning at levels that are in the clinical range of concern (for example, see Forehand *et al.*, 1998b). In some domains of functioning, this may result in a level of disruption in functioning beyond which the impact of maternal HIV infection does not result in a marked effect. This was the case in some of the research on quality of attachment in mother-infant dyads where marked differences between HIV positive and HIV negative carers were not found (Black *et al.*, 1994). Consequently, the impact of the caregiver's illness on children must be understood within the context of a range of other existent risk and protective factors for both the caregiver and child (Forehand *et al.*, 1998b; Wild, 2001).

Some research has directly addressed the role of environmental factors. For example, in their study of HIV positive men and women, Stewart, Cianfrini and Walker (2005) found an association between self-reported health status and general stress and lack of housing stability, while Koopman *et al.* (2000) found an association between less income and higher levels of perceived stress in infected adults. However, Dutra *et al.* (2000) found no association

between resiliency in children and economic security or family composition, only parenting practices predictive of child outcome. This is perhaps more consistent with Jones *et al.*'s (2002) finding that community risks (gangs in neighbourhood; physical fighting; shootings, knifings or both; killings; and drug use, drug dealing, or both) and income did not have a main effect on child adjustment. Rather, inadequate income and community risks predicted high levels of maternal depressive symptoms which resulted in poor parenting and, ultimately, child adjustment problems. Olley *et al.* (2004b), in a study of persons recently diagnosed with HIV, also found an association between women's depression and negative life events. However, in the absence of a comparison group, there is no evidence that infected women were at greater risk than the general population. Jones *et al.*'s (2002) findings therefore demonstrate that the impact of environmental and household factors on child well-being was mediated, and perhaps moderated, by family processes more proximal to the child. While very few studies have adopted a thoroughly contextual approach in order to directly examine the implications of these findings, some important exceptions have been noted throughout this review.

Conclusions and policy considerations

Perhaps one of the defining features of the literature reviewed is the extent to which the issues it raises are interlinked. While necessary, it is oftentimes reductionistic to articulate clear, linear relationships between any of the model's elements (refer to Figure 1). The relationships are typically bi-directional and the effects depend on a range of other existent factors, for example, stable life conditions, levels of poverty, and history of coping and mental illness. Despite these complexities, several key findings emerge from the review and point to areas which future studies could usefully focus on. A summary of these findings is provided in Box 1.

Box 1. Key findings on maternal well-being, childcare and child well-being in the context of HIV/AIDS

- Children are likely to be faced with a range of material and psychosocial stressors during the course of a caregiver/mother's illness, as well as following her death. These may include disruption of schooling, relocation and increased household responsibility. Since many of these children live in families and households who are already at-risk due to issues of poverty, family fragmentation or unsafe neighbourhoods, parental HIV and AIDS typically serves as an additional stressor that

places child adjustment at further risk.

- The nature of the disease can also result in children experiencing multiple losses, as well as considerable uncertainty, stigma, secrecy and isolation.
- Children of HIV positive mothers are at greater risk for emotional and psychological problems than children of HIV negative mothers, and problems are more likely to manifest as internalising behaviour such as depression than externalising behaviour such as aggression. Children may also under-report their symptoms and problems so that they remain masked from the attention of significant others in their environment.
- Two of the key factors in understanding the pathways to child outcome are: that the stage of the mother/caregivers' illness, rather than HIV status per se, is predictive of disruptions in children's adjustment; and the quality of parenting practices is an important moderating factor.
- HIV positive women and mothers are at greater risk for depressive symptoms than HIV negative women. They also tend to display lower levels of effective parenting behaviours, such as monitoring and discipline, thereby reducing the protective parental / caregiving role.
- While general social problems like stress, housing and social isolation are negatively associated with health status, social support is positively associated with overall quality of life among adults living with HIV and taking antiretroviral therapy. However, HIV infected women and their children received lower levels of socio-emotional support than non-infected mothers and children. Parental support is more protective than extra-familial support for children's psychosocial adjustment, while support from children tends to be associated with maternal distress.
- Disclosure does not appear to have a detrimental effect on the child, but instructions to keep the knowledge a secret appears to be a stressor for some children. Mothers are less likely to disclose their HIV status to boys than to older children or girls.
- Research has shown that several factors related to quality of life can promote adherence to antiretroviral therapy. These include better perceptions of health, higher levels of coping and perceived social support, lower levels of depression, and stable living conditions.

Although many findings have been tested and validated in the North-American context, there remains a dearth of evidence from Africa and other

developing countries, particularly sophisticated empirical studies in the published literature. In South Africa, for example, probably the country in Africa with the highest number of academic researchers in the field of mental health and psychosocial well-being, there are no published studies on the links between parental HIV/AIDS and child adjustment⁹. In contrast, as already noted, the majority of papers reviewed are of studies conducted in the inner-cities of North America. This is especially important given contextual differences between the developed and developing world - in particular the high prevalence of HIV/AIDS across resource-poor communities in the developed world. Contextual factors have been shown to play an important role in mediating the adjustment of children and their HIV-infected carers, therefore the applicability of findings must be examined across different contexts. Further, a range of contextual factors should be considered based on their relevance to the given setting.

One important consideration in this regard is the identity of the infected carer whose health and emotional well-being is conceptualised as being linked to child adjustment. Both empirical and anecdotal evidence indicates that the care of children by non-parents, along with the presence of multiple carers, has been common in black African communities for several generations prior to the impact of HIV/AIDS (Bray, 2003; Stack, 1974; Van der Waal, 1996). As Van der Waal (1996) points out, this produces bonds between parents and their children of a different nature to those common in nuclear families in affluent societies, primarily because they are not centred on any one individual. Thus, children's experiences of 'disruption', and its impact on

⁹ South African research on the psychosocial adjustment of HIV-infected pregnant women (Mfusi & Mahabeer, 2000), the mental health of recently diagnosed men and women (Oley *et al.*, 2004a; 2004b), and the health-related quality of life of persons on HAART (Jelsma *et al.*, 2005) has been cited in this paper. Further, a study on the mental health of AIDS orphans (Wild *et al.*) and a methodological study on the impact of parental HIV/AIDS have just been completed (Swartz *et al.*), and a study with HIV positive mothers and their infants in underway in rural KwaZulu Natal (Stein *et al.*). Details are as follows:

Wild, L. G., Flisher, A. J., Laas, S., & Robertson, B. A. (2005). The psychosocial adjustment of adolescents orphaned in the context of HIV/AIDS. Manuscript submitted for publication.

Swartz, L., Brandt, R., Dawes, A., Bray, R., Mthembu-Salter, L., & Tomlinson, M. (2005). An exploratory study of the impact of primary caregiver HIV infection on caregiving and child developmental outcome in the era of HAART – Report for the Organization for Social Science Research in Eastern and Southern Africa (OSSREA): HIV/AIDS Challenge for Africa Research Programme. Cape Town: Human Sciences Research Council and University of Cape Town.

Stein, Richter, Rochat, *et al.* The impact of HIV during pregnancy on mothers and the subsequent development of their infants.

their well-being, may vary accordingly¹⁰. This poses a challenge for researchers to tease out the relative impact of a parent's HIV status, compared to risks experienced in relation to a carer whose well-being may be more proximal to, and therefore more predictive of the child's adjustment.

Other methodological concerns raised in the review are the failure to draw on ecological approaches that foreground the role of mediating and moderating factors within the child's caregiving environment, and the lack of concordance between mother and children's reports found in some studies. As Forehand *et al.* (2002) note, both mother and children's views may provide valuable sources of information that might be lost if one report is preferred over the other, and the implications for interpreting findings must be considered. This review has attempted to critique the existing literature in light of their attempts or failure to consider the relevance of these two issues.

A third and critically important issue that the literature has failed to address adequately, is the stage of the mother's illness. As noted earlier (in "Methods used to source literature"), most of the research reviewed does not systematically analyse the differential impact on maternal and child well-being of the mother's stage of illness. Moreover, information regarding the stage of study participants' illness and whether or not they are receiving antiretroviral therapy is typically buried in brief descriptions of study samples. In some studies, participant-specific information regarding access to treatment is not even provided, perhaps because the majority of research is produced in the United States where treatment has been widely available since as early as 1996 (Siegel *et al.*, 2004). This is in stark contrast to the situation in developing countries, particularly in sub-Saharan Africa, where HAART reaches only 8% of the adult infected population who need it (World Health Organization, 2005)¹¹. In failing to incorporate stage of illness systematically into studies, the literature also fails to properly address the evidence gathered in this review that the stage of caregiver's illness is a highly important mediating factor for maternal and child well-being.

Although the findings of the review are at times mixed, methodological difficulties that may contribute to the absence of clearer, more unequivocal findings have been noted. Moreover, there is sufficient evidence available to indicate that the well-being of HIV-infected mothers and caregivers – both that associated with their HIV status and their frequently risky environments, undermines the protective role that caregiving otherwise plays, thereby exposing children to a range of risks to their psychological and psychosocial

¹⁰ See Bray and Brandt (forthcoming) for a closer discussion of these issues.

¹¹ See Natrass (2005) for further discussion.

functioning. It is recommended that policy responses take cognisance of children's contexts and the pathways to child outcome when attempting to respond to the HIV/AIDS epidemic. Interventions must not only focus on difficulties associated with the infection, but other stressors in the environment in which families live, such as poverty, crime and violence. An important element of ecologically-sensitive interventions may also be to focus on promoting the social capital of HIV-infected women. This will serve to build positive forms of social networks that promote women's optimal well-being as well as enhancing their role as carers. This will ensure that mothers and caregivers are more physically and emotionally available to their children, thereby better protecting children from poor psychosocial adjustment.

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The CSSR is an umbrella organisation comprising five units:

The **AIDS and Society Research Unit** (ASRU) supports innovative research into the social dimensions of AIDS in South Africa. Special emphasis is placed on exploring the interface between qualitative and quantitative research. By forging creative links between academic research and outreach activities, we hope to improve our understanding of the relationship between AIDS and society and to make a difference to those living with AIDS. Focus areas include: AIDS-stigma, sexual relationships in the age of AIDS, the social and economic factors influencing disclosure (of HIV-status to others), the interface between traditional medicine and biomedicine, and the impact of providing antiretroviral treatment on individuals and households.

The **Data First Resource Unit** ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The **Democracy in Africa Research Unit** (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

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

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