



Joint Learning Initiative on Children and HIV/AIDS JLICA

Learning Group 1 – Strengthening Families

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STRENGTHENING FAMILIES THROUGH HIV/AIDS PREVENTION, TREATMENT, CARE AND SUPPORT – A REVIEW OF THE LITERATURE

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Preface - Learning Group 1: Strengthening Families

The work conducted in Learning Group 1 was based on the fact that families, in all their many forms, are everywhere the primary providers of protection, support and socialization of children and youth, and families exert a very strong influence on children's survival, health, adjustment and educational achievement. This influence tends to be greater under conditions of severe strain, such as is caused by HIV and AIDS, particularly in the context of poverty.

In general, functional families love, rear and protect children and buffer them from negative effects. Functional families are those that have sufficient material and social resources to care for children, the motivation to ensure that children are nurtured and protected, and are part of a community of people who provide one another with mutual assistance. Family environments are especially important for young children. It is well established that multiple risks affect the cognitive, motor and social-emotional development of children and that the quality of parenting, assisted by intervention when needed, can ameliorate such impacts.

From the start of the epidemic, families have absorbed, in better or worse ways, children and other dependents left vulnerable by AIDS-induced deaths, illness, household and livelihood changes, and migration. Similarly, families have contributed, more or less successfully, to the protection of young people from HIV infection. Under the devastating effects of the epidemic, families need to be strengthened – economically, socially and with improved access to services – to enable them to continue, and to improve, their protection and support of children and youth. Families that neglect and abuse children need to be identified and social welfare services must be provided to them.

Families, extended kin, clan and near community are the mainstay of children's protection in the face of the AIDS epidemic - as they have been in poor countries under other severely debilitating social conditions, including war, famine and natural disaster. Only a very small proportion of AIDS-affected children are currently reached by any assistance additional to support they receive from kith and kin. The most scalable strategy for children is to strengthen the capacity of families to provide better care for more children.

The co-chairs, secretariat, lead authors and stakeholders of Learning Group 1 were guided in the work undertaken in the Learning Group by the following key questions. By and large, these are the critical research, policy and programme questions currently being debated in the field.

1. On which children and families should we focus?
2. What evidence is available on which children are vulnerable and what can be done to help them, and how good is the research?
3. What aspects of the HIV/AIDS epidemic impact on children, how and why?
4. How are families changing as a result of adult illness and death associated with HIV and AIDS?
5. In what ways are children's health, education and development affected by the HIV/AIDS epidemic?
6. What does knowledge and experience of other crises teach us about the AIDS response for children and families?
7. What can we learn from carefully evaluated family strengthening efforts in fields other than HIV and AIDS that can be usefully applied in hard hit countries in southern Africa?
8. What programmatic experience has been gained in strengthening families in the HIV/AIDS field?
9. What promising directions are there for the future and what do they suggest?
10. What mistakes have been made and what now needs to be done?

These questions form the structure of the integrated report. As indicated in the Preface, detailed data and references are to be found in the respective LG1 papers.

Twelve detailed review papers constitute the primary evidence base for the conclusions drawn and the recommendations made by Learning Group 1. The papers, their authors in alphabetical order, and their affiliations are listed below.

List of authors, affiliations and paper titles

Authors	Affiliation	Title
Adato, M Bassett, L	International Food Policy Research Institute (IFPRI) – United States of America	What is the potential of cash transfers to strengthen families affected by HIV and AIDS? A review of the evidence on impacts and key policy debates
Belsey, M	Consultant – United States of America	The family as the locus of action to protect and support children affected by or vulnerable to the effects of HIV/AIDS: A conundrum at many levels
Chandan, U Richter, L	Human Sciences Research Council (HSRC) – South Africa	Programmes to strengthen families: Reviewing the evidence from high income countries
Desmond, C	Human Sciences Research Council (HSRC) – South Africa	The costs of inaction
Drimie, S Casale, M	International Food Policy Research Institute (IFPRI), Regional Network on AIDS, Food Security and Livelihoods (RENEWAL), Health Economics and AIDS Research Division (HEARD – South Africa	Families' efforts to secure the future of their children in the context of multiple stresses, including HIV and AIDS
Haour-Knipe, M	Consultant – Switzerland	Dreams and disappointments: Migration and families in the context of HIV and AIDS

Hosegood, V	London School of Hygiene and Tropical Medicine (LSHTM), Human Sciences Research Council (HSRC) – South Africa	Demographic evidence of family and household changes in response to the effects of HIV/AIDS in southern Africa: Implications for efforts to strengthen families
Kimou, J Kouakou, C Assi, P	Ivorian Centre for Economic and Social Research (CIRES), Family Health International (FHI) - Côte d'Ivoire	A review of the socioeconomic impact of antiretroviral therapy on family wellbeing
Madhavan, S DeRose, L	University of Maryland – United States of America	Families and crisis in the developing world: Implications for responding to children affected by HIV/AIDS
Mathambo, V Gibbs, A	Human Sciences Research Council (HSRC) – South Africa	Qualitative accounts of family and household changes in response to the effects of HIV and AIDS: A review with pointers to action
Sherr, L	Royal Free and University College Medical School – United Kingdom	Strengthening families through HIV/AIDS prevention, treatment, care and support
Wakhweya, A Dirks, R Yeboah, K	Family Health International (FHI) – United States of America	Children thrive in families: Family-centred models of care and support for orphans and other vulnerable children affected by HIV and AIDS

**STRENGTHENING FAMILIES
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1. Introduction

Families do not suddenly come into being at the point of the birth of a child. Their roots can be traced much earlier. The entire cultural milieu in which family structures develop and evolve provide a rich tapestry within which childbirth and child care flourishes. This review provides a family-focused analysis of HIV/AIDS programmes and policies. It examines the strengths that families have to offer children in the era of AIDS. It provides insight into the challenges families face, and the ways in which policies and strategy may potentially realign to provide a holistic family approach to HIV prevention treatment and care (Richter, Foster and Sherr 2006).

In many parts of the world, HIV and AIDS has had a dramatic effect on family structure, family resources and family capacity (Seeley et al 1993). Yet, at the same time, it is clear that the family provides a rich resource to combat negative effects of the HIV epidemic and a unit of analysis and provision that has been very much neglected in international strategy (Heyman et al 2007). The reasons for this are complex. Many initiatives in the West emanated from epidemics among gay men or drug users. The more silent epidemic, often concentrated in the least resourced countries, predominates among women, heterosexual couples and children. It is remarkable to observe the balance of attention in the global response to HIV/AIDS and to highlight the general areas of neglect, most notably among children, women and even heterosexual men. This is in sharp contrast to the media attention and calls for rights and equality. All are relatively understudied and underserved. The early responses to HIV in the West were predominantly individualistically based. These approaches often formed the springboard from which HIV strategy in the developing world were addressed – at best with adjusted and applied models – at worst, directly with little change and accommodation. Where did young children fit in within this scenario? What has been studied and established in terms of the needs of this group? The picture is mixed, with many gaps and findings are often quite dispersed.

The needs of children, especially young children are explored in this paper. Strands of knowledge that feed into a family focus will be reviewed. The underlying assumption of this approach is that families provide the social context that has evolved for the protection and rearing of children. Children thrive in families. Strengthening families as a global strategy will provide an invaluable resource and a new pathway. On the other

hand, continued neglect of families may result in short sighted, misdirected approaches which undermine the last stand, the family, in efforts to secure children's wellbeing (UNAIDS 2007), and the long term consequences may be difficult to undo.

This overview also provides an analysis of current programmatic efforts that may handicap appropriate responses to strengthening the capacity of families to care for vulnerable children by way of a series of examples. It attempts to utilize a family focus and explore how the needs of a family approach are reflected or neglected in current policies, programmes and projects for prevention, treatment, care and support for children generally, and vulnerable children specifically. The total piece provides a broad review while the individual sections provide stand-alone coverage of selected in depth topics that contribute to the general concept.

The analysis is based on published literature, established policies and a series of specific analyses of these to elaborate on the issues. There is a history of evidence in general child development that is, all too often, overlooked in the initial and current HIV/AIDS responses. This review will draw on a wider knowledge base to inform potential strategy recommendations and to provide contrast and insight in areas where there has simply been too little quality research or none at all.

The definition of a family approach, used in this review, is based on the concept of family environment in the broadest sense of the term. Although family traditionally encompasses nuclear family in the west, the working definition for the purposes of this review is intended to be broader and include extended family and home-based care provision. This allows for a definition of the family in which the child is linked to carer (s), through kith and/or kin ties and resides within the family/community environment. For many societies extended and reconstituted family arrangements are normative. The idea of the family approach is one based on a system where there is established secure and stable individual focus on a child by an identified individual or set of adults, directly related via blood line or commitment to the individual child within the home based environment. Care arrangements that attempt to mirror this model include fostering and adoption where the blood line may not exist, but a formalized (or informal) arrangement through legal, clan and family, or social service provision, results in the provision of a family environment for the child.

Three key areas have been selected by way of example (although not exhaustive) to examine programmatic features and how they may have handicapped or facilitated appropriate responses to strengthening the capacity of families to care for vulnerable children, or how the oversight or understudy of the area has meant that the issues are lost or under funded in the response to HIV/AIDS and children. These three broad areas selected for coverage are:-

- **HIV prevention in pregnancy.** This area is based on the premise that child development must be viewed from conception rather than from birth. Maternal (and paternal) physical and mental health contribute greatly to the family in which the child is born, and to the integrity of the caregiving environment. HIV prevention in pregnancy benefits children. Sustaining intact families benefits children. Parents, grandparents, siblings and extended family are a rich resource for the new infant.
- **Family approaches to childcare.** This section will cover literature on child development (in the presence of HIV directly and indirectly) and a number of vital child development areas such as environment, parental loss, schooling, nutrition and care. The family can be studied by what is known about families on the one hand, and what is known when family disintegrates, on the other. Parental loss will be explored with a particular focus on what is known and what is not known about the effects of “orphaning” on children. Child development, in the presence of HIV, will be reviewed. The considerations under systematic review are orphan labeling, schooling, nutrition, bereavement, cognitive development, care arrangements and parental mental state.
- **Gender considerations in programmes.** Finally this section will attempt, very tentatively, to raise some of the gender concerns that permeate much of the thinking on children and families, but which may not be highlighted sufficiently in an AIDS response.

Cutting across these three sections will be a theme to examine the neglect of, and how to achieve, family focus in HIV/AIDS policies, programmes and practices

2. HIV prevention in pregnancy

Current Policy

HIV testing in pregnancy has been recommended as international policy. The service is usually offered only to women, and usually only a single test is undertaken. The policy further recommends that those women identified as HIV positive are offered antiretroviral treatment to prevent mother to child transmission.

Key Findings

HIV testing uptake is low in many high prevalence countries. HIV testing is aimed at mothers mostly. Fathers are not included in antenatal HIV testing. Few policies recommend repeat testing in pregnancy. HIV testing, especially PCR tests for infants, is low in availability and roll out. Collection of maternal HIV test results is lower than test uptake. Antiretroviral treatment of HIV infected mothers is low (around 34% of those known to be HIV positive in 2007). HIV treatment for children born with HIV is low in resource-poor countries. Treatment costs are high and roll out strategies often do not include children.

Family considerations

The gaps suggest that a holistic family approach would recommend HIV testing for fathers, and PCR testing for infants. In addition, repeat HIV testing should be given so that women who have unprotected sex and are infected during pregnancy can be offered treatment. Couple testing may help to reduce stigma and fear and may improve the level of return for results. Policies need to provide for the barriers stemming from stigma, affecting decision making in consent to test.

Policies need to urgently address treatment of mothers (and fathers) so as to keep her (them) well and alive to care for their children. These policies should address maternal referral and antiretroviral management of her disease on diagnosis, including a critical questioning of the quality of antiretroviral treatment offered to mothers to maximize efficacy and reduce maternal resistance. This relates specifically to the use of monotherapy, which may have limited efficacy in the short term for preventing vertical transmission, but may jeopardize treatment efficacy for mothers' own health in the longer term. All this occurs in a current environment where uptake of HIV testing and

provision of HIV treatment is low. Treatment for children is hampered by high medication costs, low volume roll out – even when need is established.

Most children are infected with HIV during pregnancy, delivery or breast feeding (UNAIDS & WHO, 2006; McIntyre 2006). Interventions available to prevent transmission include antiretroviral treatment in pregnancy and to the newborn, delivery by caesarean section and avoidance of breast feeding (Gray and McIntyre 2007). In 1994 the first randomized controlled trial was published showing the impact of antiretroviral treatment on such transmission, with a 65% reduction in infant infection in the intervention arm (Connor et al 1994). This trial has revolutionized treatment approaches (Dabis et al 2005, Jackson et al 2003, Shaffer et al 1999, Wiktor et al 1999, Lallemand et al 2004), Limpongsanurak et al 2001, Petra group 2002). The effect has been to endeavour to make such treatments readily available to avoid infant infection (Hudson et al 1999). This was operationalised via programmes to offer HIV testing to all pregnant women, with the idea of identifying positive pregnant women and providing treatment (Suksomboon et al 2007). This straightforward strategy, however, is fraught with policy and implementation challenges (UNAIDS 2007). Clearly the successful implementation of this strategy, in its fullest form, is the single most dramatic intervention currently available to prevent children from being infected with HIV, and as an entry for mothers (and fathers) into treatment and support programmes. In Europe, over the period 1997-2003, HIV positive women have been provided with antiretroviral treatment at an accelerated rate from 5% to 92%. (European Collaborative Study 2005). Transmission rates have been reduced to 0.99% in Europe (ECS 2005), and 2% in the USA (Mofenson 2004). This intervention has been available, with growing refinement, for over 11 years. However, it has two major limitations. The first is that it has failed to be comprehensively rolled out in those settings where the epidemic is most severe. The second is that it is a narrow focused strategy that overlooks parents and family in treatment. It thereby contributes nothing to the long-term sustainability of intact families, HIV prevention, and HIV treatment through family networks. At the same time, individually-oriented services mark women out with diagnosis, stigma, trauma and unmet provision.

Yet such an intervention is not simplistic. In order to treat during pregnancy, HIV needs to be identified. This means a number of logistic steps whereby mothers, and potentially fathers, need to know their HIV status, ideally before conception (Bergenstrom et al 1999), or at least during pregnancy. Once HIV status has been definitively determined, antiretroviral treatment in pregnancy to prevent HIV transmission to the infant needs to be introduced, be accepted and be available. The exact nature of the intervention is still not fully established. Early studies suggested zidovudine monotherapy, whereas later studies propose combination treatments (Dabis et al 2001, Jackson et al 2003, Petra 2002). The management of maternal HIV is another crucial element of this equation - to reduce illness and to maximize CD4 count and reduce viral load at the time of delivery (McIntyre 2006). This has been clearly established as policy, but is not reflected in current practice (WHO 2004, Hawkins et al (BHIVA) 2005, USPHS 2005). As HIV can be transmitted during breast feeding, there is a need to continue prevention efforts until the baby is weaned. In resource poor settings this is a challenge. There is a hiatus in clear, implementable recommendations, and little research has been done to make breastfeeding, the feeding option of choice, safer.

As a result of the early intervention trials (Connor et al 1994), programmes offering HIV testing to all pregnant women were launched in many countries. There is much debate on the procedures associated with such testing in pregnancy. How should the issue be raised? Should the tests be optional or routine? Should the paradigm on offer be one of “opt in” or “opt out”? Who should do the counselling and how should this be carried out?

In developing settings it raises questions in relation to the quality and effectiveness of HIV testing in pregnancy, the focus and recipients of the testing, the providers and protocols of such testing, and the link between testing outcome and action. This action includes antiretroviral treatment, mode of delivery, type of feeding. For HIV positive women this link needs to be towards treatment and ultimately prevention. For HIV negative women this would be an opportunity for HIV prevention intervention, given time and expertise constraints.

If health care is to nurture the new family at this point, it needs to address:-

1. The quality of implementation of such programmes (couples rather than women only, quality of testing, quality of counselling, linking with antiretroviral treatment services, uptake and adherence to such treatment, impact on the infant).
2. The physical and mental health of the mother, father, infant and other children and adults in the close family environment
3. The unintended effects of such programmes need to be catalogued, such as
 - a. the focus on women rather than couples,
 - b. the treatment of women to prevent transmission but not to sustain their own health (possible prevention of transmission to the infant, but illness and death of the untreated mother in early infancy),
 - c. stigma associated with HIV and its ramifications on human behaviour – such as the person first tested often (erroneously) assumed to be first infected with consequent violence, rejection and relationship trauma. Societal censure which may affect willingness to avoid breastfeeding (formula feeding may lead to suspicions about HIV status)
 - d. the issue of non-adherence to medical routines resulting in missed antiretroviral treatment
 - e. the pros and cons of stand alone unintegrated HIV testing services in ante-natal care
 - f. potential hazards of the treatment on subsequent resistance profiles of the treated women. (Palmer et al 2006)
 - g. teratogenic effects of antiretroviral treatment on the developing foetus.
 - h. The implications for ART exposure on uninfected infants in the long term and specifically on infection and treatment in their adult life.
 - i. quality standards of the health care system to deliver HIV testing in time with accuracy; antiretroviral treatment on time and in the right amount, infant testing to provide feedback to the parents, feeding provision to avoid infection via breast feeding (or exclusive breastfeeding, or (as Coodvadia is investigating) provision of antiretrovirals during breastfeeding.
 - j. The lack of emotional support services for families facing the trauma of HIV diagnosis and its ramifications

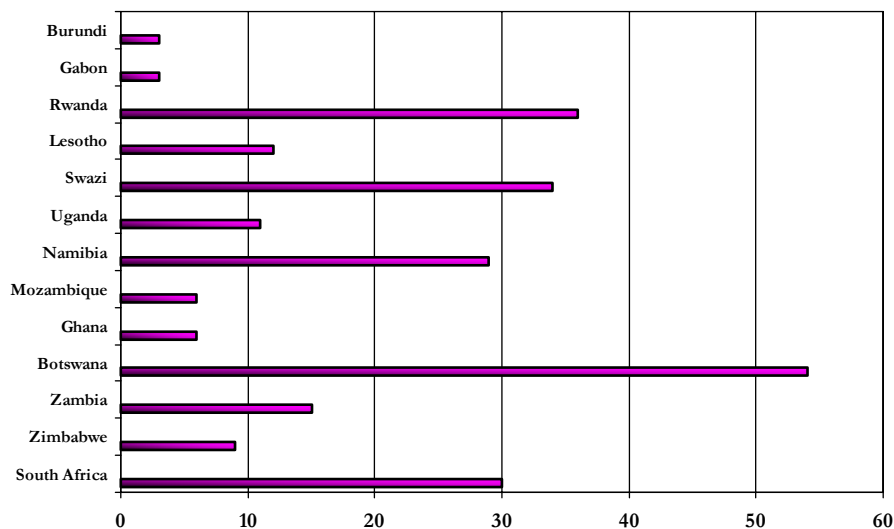
2.1 Implementation of HIV prevention programmes in pregnancy

By 2005, 9 years after the first reported effects of antiretroviral treatment in prevention of vertical transmission, the World Health Organisation published comprehensive country data giving numbers of women tested for HIV during pregnancy, estimated numbers of HIV positive women, and actual numbers of women receiving antiretroviral treatment during pregnancy. The figures were exceedingly low. From this data 13 countries in Africa with widespread epidemics are summarized in the tables below.

2.2 Uptake of ART in HIV positive pregnant women in Africa

The table below, drawn from WHO country data (2005) shows the percentage uptake of antiretroviral therapy for Pregnant HIV positive women for 13 African countries (Burundi, Gabon, Rwanda, Lesotho, Swaziland, Uganda, Namibia, Mozambique, Ghana, Botswana, Zambia, Zimbabwe and South Africa).

Figure 1. Percentage uptake of ART for Pregnant HIV+ve Women



Data based on 13 country data from WHO report (2005).

This graph shows the poor implementation of established interventions for prevention of mother-to-child transmission during pregnancy. Botswana has the highest reported uptake, but this is still under 60%. These figures also probably represent a gross

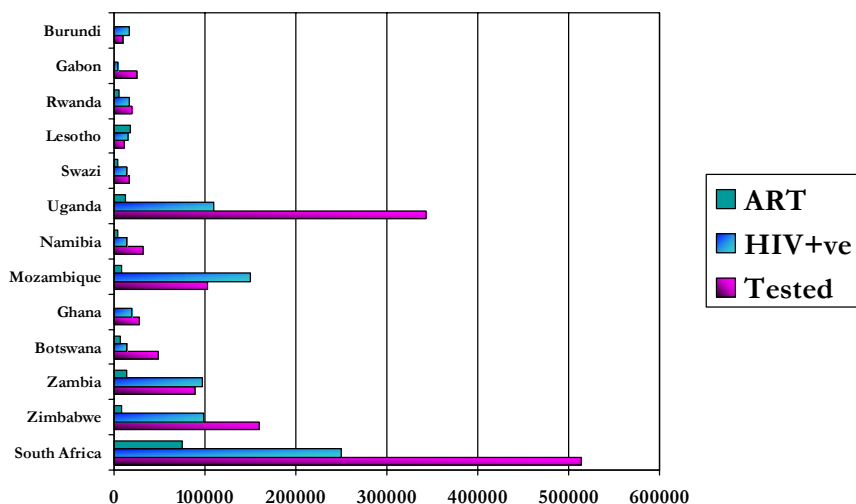
underestimation given that they refer only to women, known to be HIV+, and thus reflect the effective reach of antenatal HIV testing programme. The figures for women who are not aware of their HIV status, but who could obviously benefit from intervention, are therefore not included in this analysis. These figures are in sharp contrast to Western data where universal HIV testing in pregnancy result in close on 90% uptake in some studies in the UK with higher HIV prevalence (Conaty et al, Sherr et al 2006), UK with lower HIV prevalence (Stokes et al 2007) and high uptake in the US (Anderson et al 2007), Australia (80% - Grover et al 2005). Uptake followed universal policy (Townsend 2003) who showed that after introduction of UK policy for nationwide Obstetric units, 69% of Units reported over 80% pregnant women take up antenatal HIV testing. For those women who are diagnosed with HIV during pregnancy, the uptake of interventions is high in resource rich countries.

High uptake is possible in an African setting (see example Urban et al 2004 who demonstrated a 90% uptake of antenatal HIV testing in a South African setting, with an 86% uptake of treatment for those who tested positive). Botswana also shows that national policies and full scale implementation can result in 78% uptake of VCT during pregnancy and 56% uptake of interventions for those testing HIV positive (Creek et al 2007).

2.3 HIV testing

The figure below, covering the same 13 African countries drawn from WHO country report (2005) shows the numbers of women reported to test for HIV during pregnancy, the proportion who are HIV positive, and the uptake of ART during pregnancy. The two figures below set out the numbers who test HIV+ve and numbers who take up ART. The first figure provides data on 13 countries, and the second figure is a repeat, but excludes South Africa where the numbers are so high that the other 13 countries are difficult to visualize. The data is the same, the scale differs on the graphs.

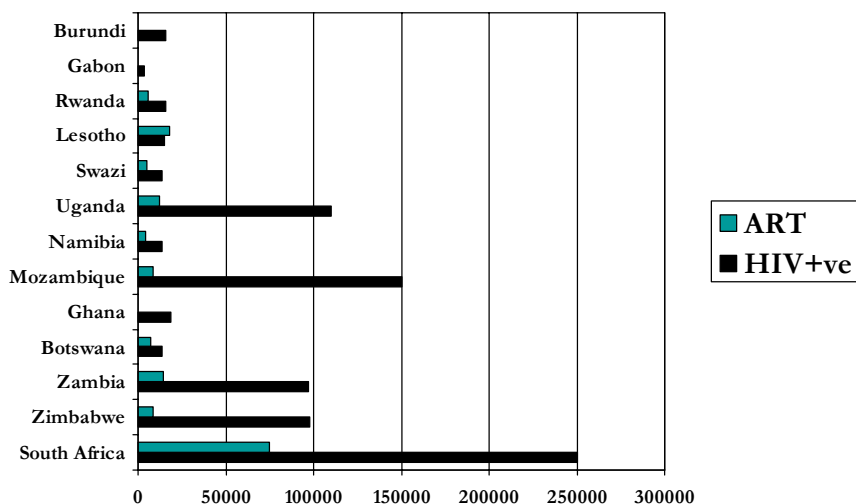
Figure 2. 13 African countries – Women HIV test, HIV+ve and receiving antiretroviral treatment including South Africa



Data based on 13 country data from WHO report (2005).

These data, drawn from country estimates, reveal that across the 13 countries, 1,398,039 pregnant women were tested for HIV. Of these 816,600 (58.4%) were recorded as HIV positive. Given that the proportion is grossly over the national prevalence estimates, it would appear that HIV testing in pregnancy may be targeting very high risk women; alternatively, those who believe they may be HIV positive are coming forward for testing. This may be directly triggered from a desire to avail themselves of antiretroviral treatment to prevent transmission to their baby. Sadly, of those who are established as HIV positive in these 13 countries, only 19.6% are reported to receive ART; 80.4% of those women with established HIV in pregnancy do not receive ART. The figures by individual country are set out below. This is clearly a missed opportunity to prevent infection among both parents and children.

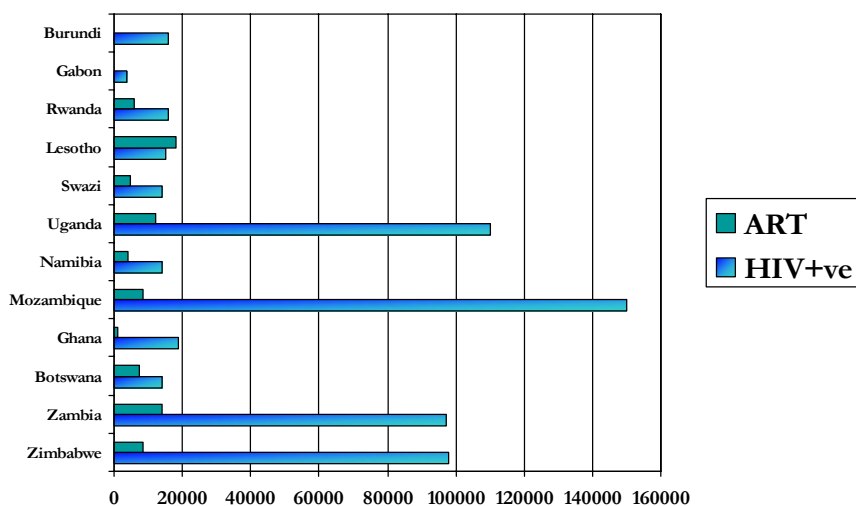
Figure 3. 13 African countries – Women who test HIV+ve and receive antiretroviral treatment



Data based on 13 country data from WHO report (2005).

This graph clearly highlights that in every country the numbers of women receiving antiretroviral treatment is well below the numbers with established HIV infection. The two graphs below repeat the data, with South Africa excluded, as the numbers in that country are so high that it is difficult to observe the distribution in the remainder.

Figure 4 - 12 African countries – Women who test HIV+ve and receiving antiretroviral treatment –South Africa excluded



Data based on 13 country data from WHO report (2005).

Full uptake would render these lines equal. Any discrepancy shows a failure to reach HIV+ pregnant woman and her partner, and a failure of intervention for the unborn child.

It is also important to note that these women are receiving antiretroviral treatment to prevent transmission to the infant, **and not** treatment for their own HIV disease management. The situation thus shows that many mothers with established HIV in pregnancy are not receiving prophylactic ART to prevent infant infection. Furthermore, they are not receiving ART treatment for their own disease, to ensure their longevity and good health in the early years of mothering. The situation is compounded by the findings that there is a modicum of resistance possible for women exposed to ART in pregnancy to prevent infant infection, which may affect the long term efficacy and drug resistance profile for their own treatment (Phillips 2001). This has resulted in the development of what is called MTCT+, in which women are also treated for their own infection (Abrams et al 2007). This provision is made available in 9 countries with epidemics (Cameroon, Cote d'Ivoire, Kenya, Mozambique, Rwanda, South Africa, Thailand, Uganda and Zambia – under the Mailman School of Public Health initiative). This ideal standard of care reaches even fewer pregnant HIV positive women than standard PMTCT, but is clearly the future pathway, with PMTCT providing a gateway to HIV treatment (Abrams et al 2007)

Keeping a family intact, well and functioning is in the best interests of all – especially the young child, as well as for breaking through family and community concentrations of infection. A family approach to HIV management would urgently address this situation. HIV testing in pregnancy should be available for all women. Their partners should also be entitled, and encouraged to take up HIV testing to ensure that discordancy is picked up, to help ensure that transmission during this and any subsequent pregnancy is avoided, and to enable all HIV+ members of the family to be treated for opportunistic infections and with ART when they are eligible. A family approach would also ensure that maternal health was on an equal priority footing to infant health. Preventing HIV infection in a newborn is vital. Keeping the mother (and father, or other care providers) of that newborn alive and well is equally vital.

2.4 Stumbling blocks to HIV interventions in pregnancy

The offer and provision of HIV testing in pregnancy has proven to be more complex than originally thought. There need to be skills and training to discuss HIV testing and it is unclear who is best qualified and available to do this task. Should it be nurses, midwives, doctors, counsellors or lay providers?

Test refusal is common and a number of initiatives have explored ways of enhancing test uptake such as opt in/opt out provision, group/couple (Farquhar et al 2004) and individual counselling. (Voluntary HIV testing study group 2000)

Knowledge of results has proven problematic. It is well documented that many women agree to an HIV test, but do not collect their results. It is unclear whether this is due to practical obstacles (return to the clinic, time taken for the results) or emotional hurdles (reluctance and ill prepared to receive the results, fears of rejection/recrimination or illness, coercion to test). Rapid testing (see for example, South Africa) may be one solution to ensuring higher levels of result collection.

Uptake of treatment is not automatic. In centres with sophisticated provision, uptake is high (ECS 2005). The data above (Figures 1-4) clearly shows that in resource poor settings, uptake is generally low (McIntyre 2006). Despite establishing HIV status, treatment uptake is not always automatic. This can be as a result of multiple hurdles including provider related barriers (availability of compounds, organisational infrastructure), and patient related hurdles (reluctance, fear, misunderstanding).

Although HIV prevention during childbirth may be achieved, many infants are infected via breastfeeding (Bulteel and Henderson 2007, Newell 2004, Coutsoadis 2004), with reported increases in transmission rates through breastfeeding varying between 14% and 17.9% (Bulteel and Henderson 2007, see below). WHO report that overall, breastfeeding adds a 5-20% risk of HIV infection to the infant. In centres where feeding alternatives are safe and available, such infections are limited. However in poverty stricken areas, feeding alternatives are simply not available. A variety of options have been studied to ameliorate transmission during breastfeeding. These include exclusive breast feeding, treatment of the mother to reduce infectivity, heat treatment of expressed

breast milk and early weaning (Newell 2004, Coutsooudis 2004, McIntyre 2005). Where safe alternatives are not available, current WHO advice is for exclusive breast-feeding.

Summary of data on breastfeeding and infant risk

WHO report that overall, breast-feeding adds a 5-20% risk of HIV infection to the infant.

The most recent review (Bulteel and Henderson, 2007) covered 22 papers (including 5 meta analysis) that reached inclusion criteria.

Transmission considerations included method of feeding (exclusive versus mixed), maternal risk, duration of feeding, presence of breast pathology (mostly mastitis), and infant factors (such as presence of oral candida).

Rates of transmission of HIV were affected by breastfeeding:

- Bobat et al (1997 – South Africa): 15% increase in transmission rate via breastfeeding.
- Dunn et al (1998 – various): Transmission rate of 29%, a 14% increase in transmission rate added by breast-feeding at 2 years.
- Fawzi (2002 – Tanzania): 17.9% increase in transmission rate via breastfeeding.
- Nduati (2000 – Kenya): Breast-feeding transmission of 36.7% versus formula feeding of 20.5% at 2 years. Breast feeding adding 16.2% chance of transmission to the infant.
- Tess et al (1998 – Brazil): 2.2 fold increase in transmission for breastfeeding.
- The European Collaborative Study reports a 2.25 odds ration of infection for breast-feeding versus never breast-fed.

In many settings, infants are not tested for HIV with a definitive test at the earliest possible stage so that families know of the efficacy of the interventions. This often means that many parents live with uncertainty.

The narrow focus of the PMTCT programme addresses the singular issue of prevention of mother-to-child infection, but does not direct itself to the broader family issue of prevention and healthy productive developmental environments. The approach, albeit highly effective, is based on an individualistic medical model of care. Hurdles in the roll out policy have triggered the response of “opt out” and “provider initiated” testing. These developments continue the single issue and individualistic approach and fail to address family needs. They may increase uptake of testing, but as the treatment of already established HIV positive pregnant mothers is reaching only a minority of such women, there needs to be a dramatic rethink of policy in the best interest of the child, parents and other adult caregivers, and the cycle and reproduction of infection and transmission.

2.5 Lessons from a family focus

HIV prevention in pregnancy policies were informed by a well meaning medical model that has been effective in the approach to other diseases. This provided a solid evidence base for the efficacy of interventions and provided a medical care environment within which the offer of a test, the provision of antiretroviral treatment and prevention advice, and the implementation of ancillary strategies such as caesarean section, avoidance of breast-feeding were incorporated. Yet the reality, after 11 years of experience and knowledge gained is an alarmingly low roll out, a social barrier to HIV testing and result collection, a less than perfect uptake of treatment, a resultant failure to avoid new infections in infants on the vast scale that is potentially possible, and a missed opportunity to reach out to prevent, treat and support connected people (such as the family) who are affected by the epidemic.

A family focused approach would realign some of the policies. Firstly pregnancy, and the creation of family care for a child, occurs within a couple. Thus couple testing and integrated HIV testing services have a much better chance of ensuring social acceptability and reducing stigma. There is also a gender bias in offering testing to mothers only, which jeopardizes the family in the long run. If the mother is HIV negative and the father HIV positive, pregnancy is a time when condoms are probably not used and the potential for infection during pregnancy is thus increased. If the HIV status of the father is addressed, then HIV prevention at this time can be attempted, and

treatment for opportunistic infections initiated (Weinhardt et al 1999, Arthur et al 2007). New infection is associated with high viral load and thereby with heightened transmission. Furthermore, such expanded policies will help to protect the family and enable them to address HIV infection jointly. Studies have shown that when couples are tested, the feared rejection is not the norm (Grinstead et al 2001).

A family focused approach would suggest integrated HIV testing services within maternity care generally. Indeed it would recommend that HIV is incorporated in pre-pregnancy services as well - such as family planning (Bergstrom et al 1999) ¹³ and termination clinics (Bergstrom et al 1999b) or Well-Baby clinics. The family focus would also ensure that evidence gathering was longitudinal. Families tend to have more than one child, and the impact on subsequent pregnancies should be noted. This is particularly pertinent with regard to issues such as caesarean section and previous neonatal death.

Many programmes that provide HIV testing and interventions for pregnant women have incomplete follow up. There is commonly an absence of HIV testing of the infant to establish categorical serostatus. Where only antibody testing is available, this needs to be over extended time periods as the antibody test does not discriminate between infant and maternal antibodies and may test positive yet not denote infant infection. Currently, follow up and feedback up to 18 months is required. More expensive and accurate polymerase chain reaction (PCR) tests can establish infant status at 6 weeks. Treatment roll out programmes need to address the costs and availability of such PCR tests within the package of available provision. The burden of uncertainty weighs heavily on the family and may affect parenting dramatically. Knowledge of an infant's status may increase parental commitment to invest in the child's care and treatment.

Only 9% of HIV positive women were receiving antiretroviral treatment in 2004, and this has recently risen to 34% in 2007. The fact that around 66% of those women with established HIV infection are not receiving antiretroviral treatment needs urgent attention. The fact that not all women have an HIV test available to them during pregnancy is also a cause for concern. The current international target is for 80% of pregnant women to be reached by a PMTCT programme, and 50% to receive

antiretroviral treatment. The figure below shows the relative achievements of 13 African countries.

Table 1. Selection of African countries providing data on pregnant women and PMTCT programmes, as well as ARV reach (from UN data (Shisana) 2006)

Country	% of pregnant women on PMTCT Program	% Receiving ARVs
Target	80%	50%
Angola	2.3%	6.0%
Botswana	-	85.0%
DRC	-	4.0%
Lesotho	5.1%	14.0%
Madagascar	0.0%	-
Malawi	2.3%¹	20.0%
Mozambique	3.4%	9.0%
Namibia	25.0%	35.0%
South Africa	14.6%	21.0%
Swaziland	11.9%	31.0%
Tanzania	-	7.0%
Zambia	4.0%	27.0%
Zimbabwe	4.4%	8.0%

The short term thinking around antiretroviral treatment in pregnancy is focused on the best interest of the child by preventing transmission in a narrow medical model. Yet failure to treat both mother and father as indicated by a family approach would ensure not only HIV infection free infants, but also avoid parental death in early childhood and the occurrence of orphaning.

The use of monotherapy may have specific consequences for the later treatment and potency of antiretroviral treatment for an HIV positive mother. The literature is well established that exposure to monotherapy is associated with subsequent resistance (Phillips 2001). A family approach needs to include the best interests of the mother, father and child/children in the equation.

A clear message from the current detailed information available is that counselling testing and treatment, based at the individual is currently not the key strategy that will have a major impact on turning this epidemic around. Interventions have been available for over 10 years now, and the focus at the individual level has not made a dramatic difference. Higher-level approaches are needed to integrate this knowledge and provide an efficient effective response to protect families.

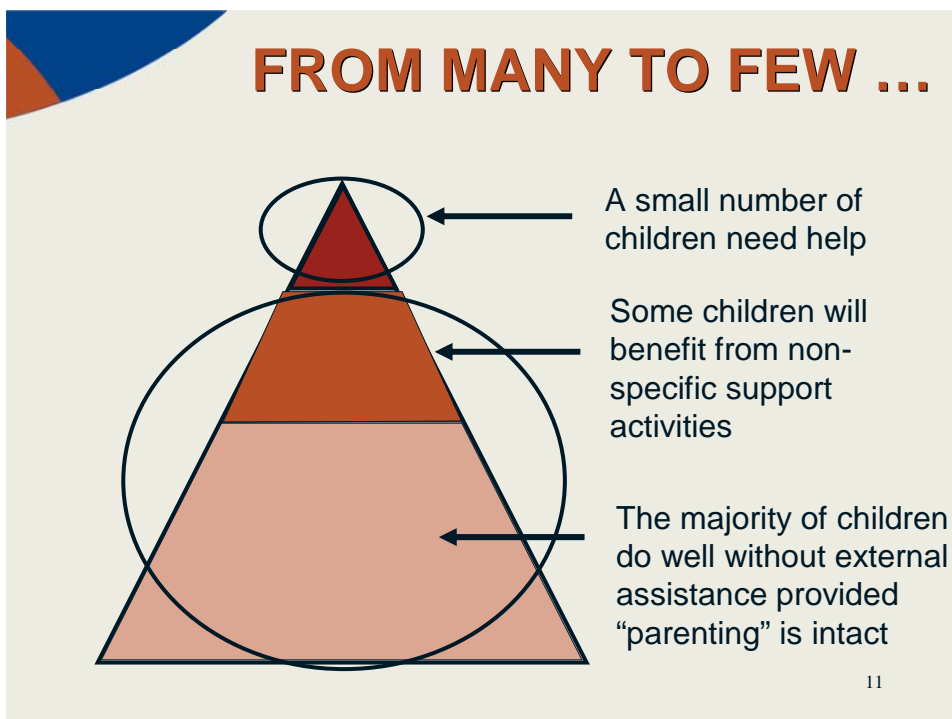
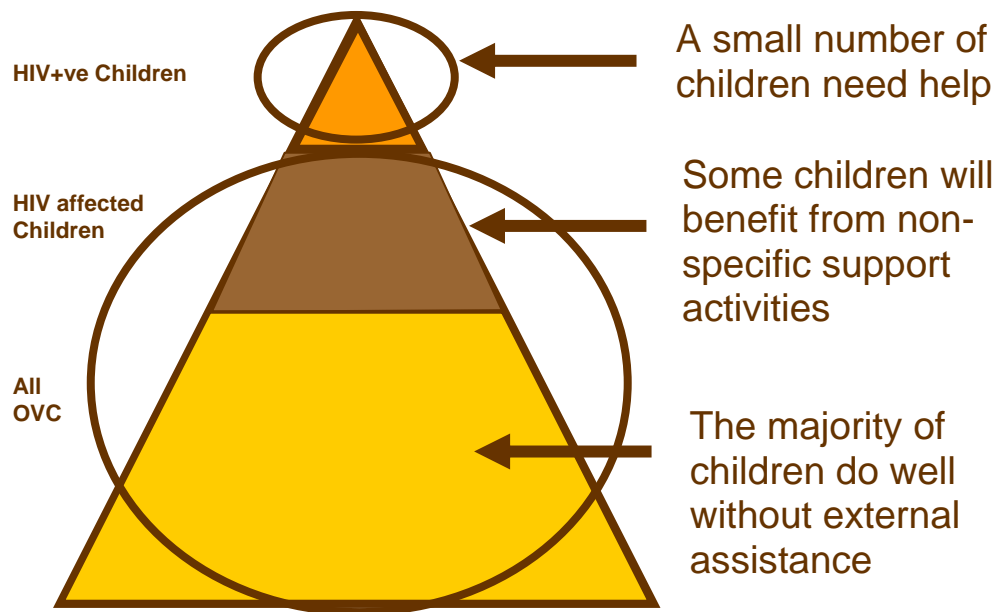
3. Family approaches to child care

This section provides an overview of policy issues relating to childcare. Child development within a family focus provides the environment within which the child can grow, flourish, learn and adapt. Eight elements of child development will be systematically reviewed and summarized. The reviews will examine the literature and evidence base on the topic, and formulate the conclusions in terms of a family approach to the child and implications for policy. The areas are:-

1. Treatment of HIV positive children
2. Policy around orphan definitions and problems that may arise
3. Institutionalised care and child development
4. Mobility, separation and child development
5. Schooling and child development
6. Nutrition, HIV and child development
7. Bereavement
8. Cognitive development and HIV
9. Parental mental state

HIV positive children represent the tip of the iceberg of need for children affected by HIV. UNICEF provides a helpful diagram showing the range of need.

Figure 5. Range of Need for Children and HIV (adapted from Richter L, Toronto IAC presentation 2006)



As HIV permeates many communities, particularly in Africa, the range of children affected can be summarized as:-

- **Children living with HIV/AIDS**
- **Orphans**
- **Children living with sick caregivers**
- **Children taken into family fostering**
- **Children in households that foster children**
- **All children in communities affected by HIV/AIDS**
- **All children & families in extremely poor communities**

Depending on the point of entry into the problem, responses can vary from individual therapeutic emergency approaches, to community based development approaches (Richter Foster and Sherr 2006). A family approach based at the community level will incorporate HIV positive children. However, it is important that if HIV infection is not prevented, and HIV positive children are living in the community, that the understanding? Of these children is clarified.

3.1 Treatment availability for HIV positive children

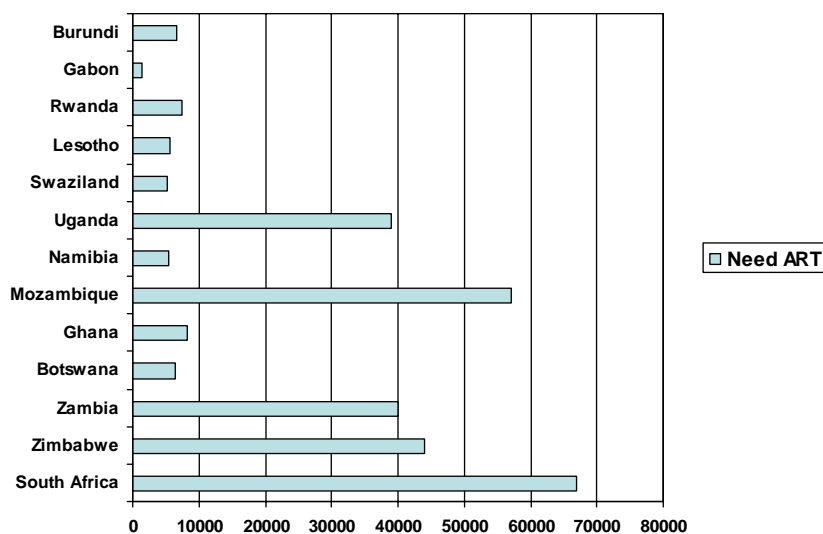
Within the family, it is important to follow through how HIV positive children fare. The UNAIDS Global Fund and the WHO 3x5 programmes are both examples of unprecedented international endeavours to deliver antiretroviral treatment globally. Yet it is remarkable that such endeavours lag in terms of provision for children generally and young children specifically. The UNAIDS Report (Children and AIDS – a Stocktaking report), notes that on 4% of children who need cotrimoxazole prophylaxis are in receipt of this intervention, and approximately only 10% of children who require antiretroviral therapy are in receipt of medication. Medication and compounds that are tailored to children have lagged behind in pharmaceutical research and provision. Furthermore when they do exist, they are said to be up to four times more costly than similar adult formulations. Although the best strategy for children is to avoid infection in the first place, for those who are infected, treatment options lag behind adult provision (Little et al 2007).

If a child is HIV positive from birth, then there is probably multiple infection in the family. A family approach to treatment availability, treatment provision and care would ensure that all members are included in provision, as such an approach allows for the needs of both HIV positive and HIV negative family members to be addressed holistically.

Especially in resource poor settings, treatment for children is lacking. This is even true where treatment access has been initiated for adults by programmes such as the WHO 3x5 initiative or those funded by PEPFAR or the Global Fund. In December 2006, WHO announced an initiative to “make medicines child size” (WHO 2007), clearly a good initial step for treatment access for children.

The table below (based on WHO figures 2005) examines antiretroviral need across the 13 African countries for children, based on nationally provided data.

Figure 6 – 13 African countries – estimates for children needing Antiretroviral treatment



Data based on 13 country data from WHO report (2005)

These WHO estimates clearly show the high need for antiretroviral treatment across the 13 countries, much of which is totally unmet at present. The data indicates that, in total for the 13 Africa high prevalence countries, 293 400 children are estimated to be in need

of antiretroviral treatment. The passage of time and the absence of effective widespread intervention to prevent transmission of HIV to the unborn child means that, in the intervening period, these figures can only have increased.

The situation is exacerbated by the lack of key indicators in national monitoring systems for children. Thus the need cannot be accurately established, let alone responded to. For those children who do receive treatment, its efficacy is dependant on adherence to complex lifelong regimes with a range of side effects. Uniquely, an adult mediates child adherence. Thus the knowledge and understanding of HIV adherence in adults is not entirely relevant for children. A recent systematic review of adherence among children (Simoni et al 2007) identified 50 studies for review. Of these 8 provided interventions for improving adherence. Measurement of adherence differed between studies (self report for older children, parental/caregiver report, clinician assessment; medical chart review; clinic attendance; pill count; pharmacy refill records; electronic drug monitoring (EDM); behavioural observation (such as directly observed therapy (DOT) (sometimes during hospitalization); resistance testing; and therapeutic impact Overall the findings were mixed and difficult to compare given various methodologies. Complete and constant adherence was not universal.

Interventions to promote adherence in adults have been evaluated and a number of effective programmes are well documented (Simoni et al 2006, Amico et al 2006). Adherence in children is extremely difficult to measure, with self-report, medication refill, carer report all being used (Byrne et al 2002, Watson et al 1999, Katko et al 2001, Farley et al 2003, van Rossum et al 2002, Mellins et al 2004). Of the 32 studies identified in the Simoni review, 69% were USA based and thus difficult to generalize to resource-poor settings. A summary of factors associated with adherence in children related to medication (dose frequency and compound), patient factors and caregiver factors. The authors highlight difficulties that HIV positive parents/caregivers may have. Furthermore they were only able to identify one randomized controlled trial of an intervention (Berrien et al 2004). Thus, once again, crucial information on children and treatment simply is not to hand, highlighting the research vacuum to support quality care of children.

3.2 Focus on orphans – when is a child called an ‘AIDS Orphan’ – confusion over definitions and implications for care

Current Policy

Policy is driven by where provision is needed and currently this includes all vulnerable children, not just those who have been orphaned. This enhances reach for interventions, but means that the evidence base is clouded, making it difficult to distinguish which children have which needs. Research warns of growing numbers of orphans and a host of negative ramifications for the future.

Key Findings

A systematic review of studies shows mixed use of definitions, with only 3% of studies including loss of biological mother and father, and 1 including loss of carer. Of 383 studies identified through literature and conference abstract searches on key word (orphan), only 18 were published and had a control group. Lack of clarity makes interpretation of overall data difficult. Studies do not employ the same measures. Overall consistent negative effects of orphanhood on psychosocial parameters were noted in all but one study. Studies do not adequately separate HIV affects from parenting effects or poverty by failing to monitor HIV status of children studied. Studies do not adequately determine that AIDS was the cause of death for the parent by basing the classification on verbal autopsy (often lacking the rigour usually demanded) at best or assumption at worst. Studies do not adequately use agreed or shared measures. Studies do not use adequate research design. Few are controlled and few have sufficient sample size.

Family considerations.

A family focus would separate definitions for provision and definitions for research. There is a gap in the data base and a lack of clarity on the protective effects of a surviving parent or a quality carer. There is little study on the effects of carer death, which needs to be included with a wider definition of parenting styles. Parenting is ill defined and different models of parenting may need to be articulated. The findings suggest the importance for children experiencing parental illness or death need to have psychosocial needs provided for as well as practical provision such as finance, schooling, healthcare and nurturing. Problems relate to separations, trauma, loss, bereavement and care.

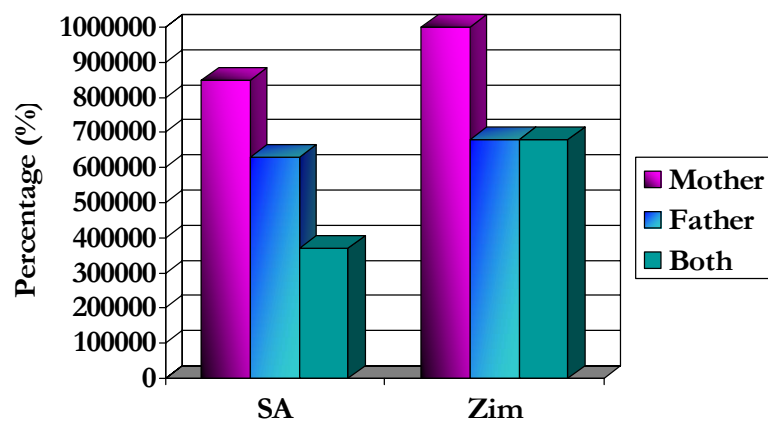
“Hindsight provides an opportunity to reflect on the road traveled and the unintended detours taken along the way. The first detour was an excessive emphasis placed on the category of orphaned children in HIV and AIDS programming and policy. Whilst not negating the suffering of children who lose their parents by any cause “orphans” are a kind of shorthand for highlighting the cumulative community impact of the epidemic, following the waves of infection and illness. However the success in promoting orphans as the bellwether of the impact of the epidemic on children and communities has had a number of unintended consequences. The preoccupation with orphan numbers has led to efforts being put into enumeration and registration without action, as well as to the proliferation of the confusing and stigmatizing term “AIDS orphan” by both agencies and the media. Children whose parents are presumed to have died of AIDS are often thought to be HIV+ve themselves, stigmatized, excluded from school and denied treatment when they are sick. The preoccupation with orphans has meant that the plight of children living with sick parents has been overlooked. While we have been concerned with the category of orphans, vulnerable children – the VC in the acronym OVC – have been largely invisible.” Richter Foster and Sherr – 2006

The detour of focusing on AIDS orphans is further compounded by the fact that the actual definitions of an orphan used are very mixed, and thus any information and learning that may emerged from the evidence base is clouded. In order to understand vulnerability, the protective effects of surviving parents, the quality of antecedent and subsequent care and potential effects of multiple bereavement, it is important to gather together the existing literature on “AIDS Orphans” to allow it to feed into the evidence base and move forward.

What is a child an AIDS orphan – how do we rationally define this term, which is fraught with such emotional significance, and how do we avoid the unintentional stigmatizing effects on children? AIDS orphan is a relatively new concept. The USAID coined the technical term of an AIDS orphan as any child whose mother or father had died (2002, 2004). Estimates were also made of the number of children whose parents were likely to have died as a result of AIDS, based on national prevalence, mortality, causes of death and the like (Children on the Brink).

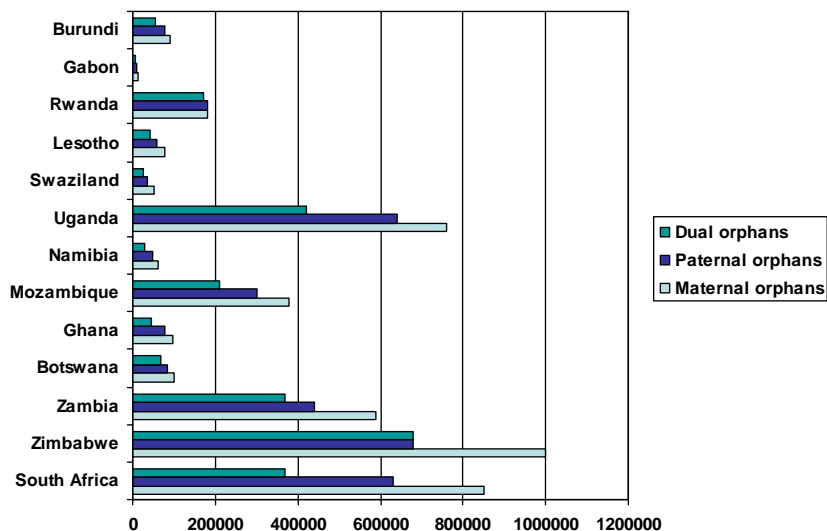
Generally, in English, an orphan is defined as a child who has experienced the death of both parents. Among non-Western people an orphan is often defined as a person without social relations. A closer scrutiny of practice reveals that some definitions include only maternal death, while others limit the age of the child to 15 years and below. There have been quotes of 15-25 million children under 18 years who have lost 1 or both parents to AIDS (UNAIDS). The tables below set out the estimates for parental death – showing mother, father and both.

Figure 7 – Orphan estimates for SA and Zimbabwe 2005



Data from WHO 2005 Source

Figure 8 – Orphan estimates for 11 African countries

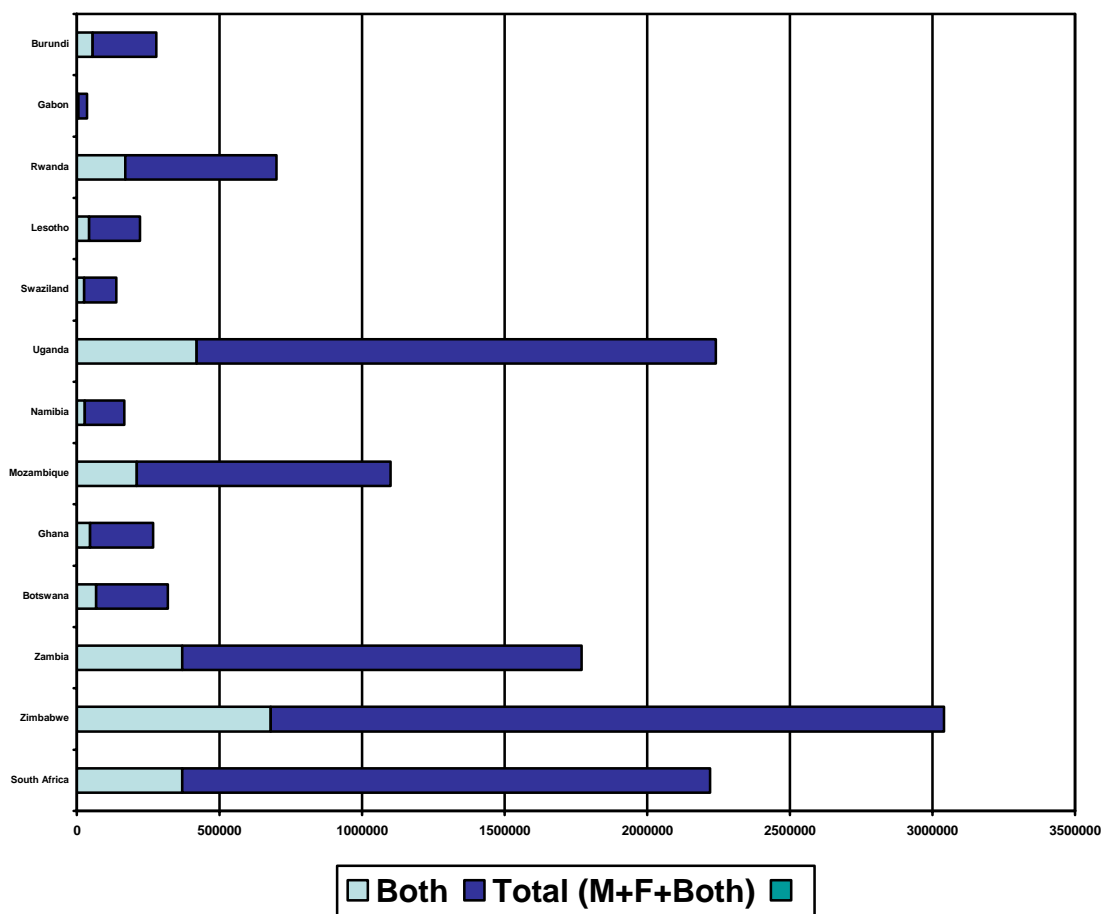


Data from WHO 2005 country data

These estimates, based on the WHO report data, show high orphaning, with all countries showing higher rates of maternal death than paternal death. It also sets out the differentiation between paternal, maternal death and dual parental death.

The data shows, that for the 13 countries, the average proportion of double orphan for the group who have lost a parent is 24.8%. Thus three quarters of children listed in the 13 countries under the orphan category have a surviving parent, while 24.8% have experienced a double bereavement and have no surviving biological parent. Some of this data may need to be subject to more detailed scrutiny and international analysis to establish full and accurate rates.

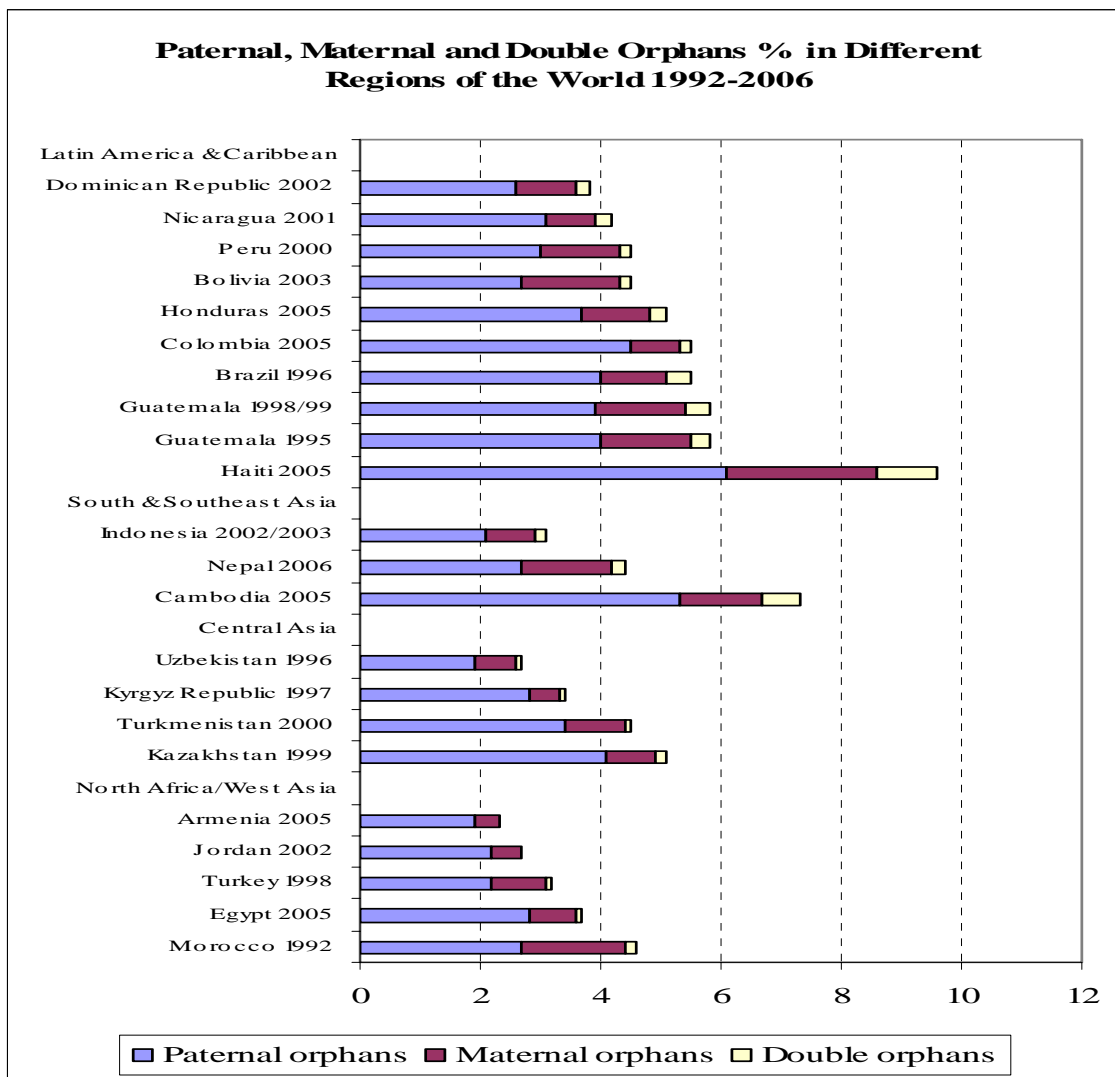
Figure 9 – Proportion of children categorized as Orphans who have experienced loss of both parents



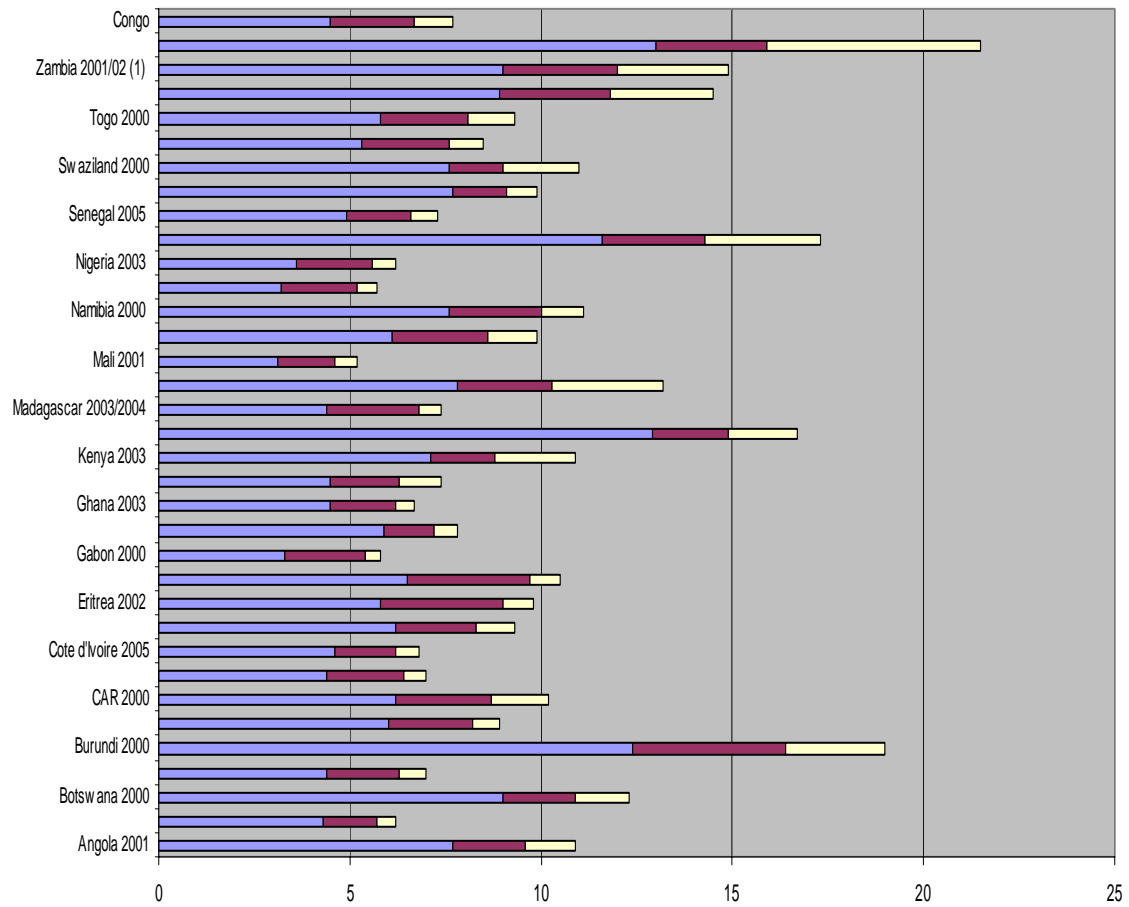
There may well be differences in outcome between loss of a mother, loss of a father or loss of both parents. The purpose of this review is not to provide further labelling burdens to a child, but to clarify the definition and to document the implications for child outcomes according to such definitions.

The data from Belsey (JLICA LG1), is reproduced here to show some of the clearer findings in terms of maternal, paternal and double parental death.

Figure 9a and 9b (data from Belsey, M., LG1 on Parental death status for children)



Paternal, Maternal and Double Orphans



Essentially the term Orphans and Vulnerable Children (OVC) was invoked from a policy perspective to ensure the inclusion of all vulnerable children (regardless of involvement of AIDS) into mitigation programmes, and to underline the varied needs of children over time prior and subsequent to parental death. An early focus purely on orphans often meant that those children caring for sick or dying parents were not included in the umbrella of support provided for those labelled as “AIDS Orphans”, despite their great need (Foster and Williamson 2000). Children in AIDS affected households may also need assistance as economic, social and health issues affect their lives. AIDS and HIV in a family or community result in a host of vulnerabilities, often linked to the direct as well as the indirect effects of the disease, acting in concert with historical and contemporary conditions, such as poverty, separation, economic decline, stigma, social isolation and community impact (Snider 2006). The term “Orphan and Vulnerable Children” also avoided potentially stigmatizing orphans while ensuring the inclusion of this group in needs and provision (Richter et al 2006). From a programmatic point of view this has made enormous sense. There are however, those who may also argue, with some cynicism, that there was a donor appeal associated with orphans and this could be used in order to generate resources for all affected children (Richter et al 2006). Such benefit needs to be carefully weighed against exclusive orphan provision that is not supported by the research literature, such as orphanage and other forms of non-family residential care. Resources that are diverted to building orphanages are misplaced and misguided. There is a wide and robust literature detailing the poor outcomes of institutionalised children. These negative effects have been reported in many areas of children’s development (MacLean, 2003; Smyke, Koga, Johnson et al, 2007). Institutions, even in resource rich countries, such as the United States and the United Kingdom, often provide too little and poor quality social support and food, leading to malnutrition (e.g. Rutter & the ERA Study Team, 1998). Children may also suffer other physical and material deprivation. Institutionalisation has a negative effect on the physical development of children and psychosocial development (MacLean, 2003; Wilson, 2003; Smyke et al, 2007; Rutter & the ERA Study Team, 1998; See Richter review 2004 for more detail on interactions on institutional care).

From a psychological point of view, as well as a research and programme perspective, the blurring of the concepts around “who is an orphan” may result in a lack of clarity. Calling a child an orphan presumes, in colloquial understanding, that a child is

disadvantaged, taking into account complex constituent contexts (see Smedslund – how psychologists empirically investigate concepts that have already been given meaning in language; e.g. 1991). On closer scrutiny, there are many different definitions of the concept of orphan including the absence of a carer and often referring to acute poverty (Bray & Brandt 2007). Psychologists propose that a child with no parents (orphan) differs considerably from a child who has the resources, love and bonds of a surviving parent or long-term loving caregiver (often in Africa, a grandmother or an aunt). Similarly a child with no carer, or no adult carer, may face different difficulties to those with a foster caregiver. A child who has experienced the death of one parent may be differently bereaved from a child who has experienced the death of both parents. Such a child may have endured months of extended exposure to illness and grief as well as associated separations, economic hardships, stigma, trauma and threat. Need to take account of the huge father absence in Africa – see our book *Baba: men and fatherhood in South Africa*

The psychological literature would also see merit in understanding differences (if they exist) between maternal and paternal death. Such an understanding may be fed back into policy so that differential needs and provisions are made available and fine tuned. Indeed a psychological approach would go further to explore the remaining and responding care arrangements and to examine how they affect child outcomes (e.g. Rutter et al, 1998, 1999). Essentially there is solid evidence underscoring the importance of quality of care (irrespective of source) that may pertain to this situation. Rutter has clearly demonstrated that the quality of subsequent care is the best predictor of positive outcome after traumatic loss.

The current situation is one fraught with a lack of clarity over definitions. This means that there is a lack of solid empirical evidence to make statements about the various sub-groups. It may be time to revisit the concept of definitions to aid both future research and applied project work and to ensure that policy is evidence-driven. This analysis sets out to ascertain

- Firstly, how often and in what manner the term orphan is defined within the children and HIV/AIDS literature.

- Secondly to provide a systematic review of the psychological and physical effects of various 'orphan' definitions on child outcomes.

Methods

A systematic search was undertaken to generate studies on HIV/AIDS and Orphans. The key words 'Orphan', 'HIV', AIDS and 'child/ren' were used. Searches were conducted among published journal articles in the medical and social science indexes up until February 2007. Two additional searches were carried out utilising abstracts from the International AIDS Conferences in Bangkok (2004) and Toronto (2006).

All studies identified with relevant key words were then read and sorted for inclusion of only those where empirical data gathering was carried out. The final included group was coded on six factors:

Definition used

Empirical data collection (presence or absence)

Focus of research – Medical/Psychosocial/both or other;

Methodology – quantitative, qualitative or mixed;

Presence of a control group

Continent of publication

The definition phase included all papers. The systematic review of findings included only full articles. This methodology allowed for two outcomes:-

1. ***An overview of definitions used for orphans across studies.*** All papers were sorted to provide details on how children were coded as orphans.
2. ***A systematic review of implications of orphaning for children.*** The second stage of the systematic review explored effects of orphaning on physical and psychological outcomes. All outcomes covered in the studies were listed and subsequently coded into themes. The outcomes were then analysed according to orphan definition and the nature of study (empirical versus non empirical).

3. ***The final summary*** emerging from the systematic overview included only full journal articles, which were conducted in an empirical way and included a control group.

Results

Search outcome

The search in the medical and social science indexes generated 360 studies with the term 'orphan' and 'AIDS' as keywords. These were then sifted and coded for inclusion of any article that provided empirical data gathering on this target population. This resulted in 198 papers, 56 of which were purely descriptive and opinion-based. The remaining 142 papers were incorporated into the first stage analysis.

The two most recent international AIDS Conferences (Toronto 2006 and Bangkok 2004) have electronic abstract databases that were also searched. There were 10,126 abstracts submitted to Toronto (data base supplied courtesy of the International AIDS Society for academic analysis of work related to children.) 344 studies contained the keyword 'orphan'. All 344 abstracts were read and sorted for those that were relevant and contained some form of data, revealing a base of 166 abstracts. The database for the Bangkok (2004) conference contained 8 057 abstracts in total. Of these 298 contained the keyword orphan. These were read and sorted according to abstracts with empirical data, revealing 75 studies in total.

The initial reading generated 383 studies available for coding (table 1). Note was taken of multiple papers by authors on the same population (Cluver et al, Rotherham Borus et al etc).

Table 2. Search results for papers containing the word “Orphan; HIV/AIDS”

Abstract Location	Total N of papers generated	Relevant N (after detailed reading)
Medical and Social Science indices	360	142 (39.4%)
Toronto AIDS conference	344	166 (48.3%)
Bangkok AIDS conference	298	75 (25.2%)
		N = 383

Orphan definitions

The majority of studies (n=273, 71.3%) did not differentiate or clearly define the concept of orphan. Those that did, used a variety of definitions, namely one or both parents died n=64, 16.7%; both parents died n=13 (3.4%), mother died n=23, (6.0%); father died (n=3, (.8%); or multiple definitions used within the study (including death of primary caregiver), n=7, 1.9%). Few gave the age ranges included to clarify the aspect of “child”. Of those that did, under 19 years and under 15 years were reported. The data is set out in figure 1.

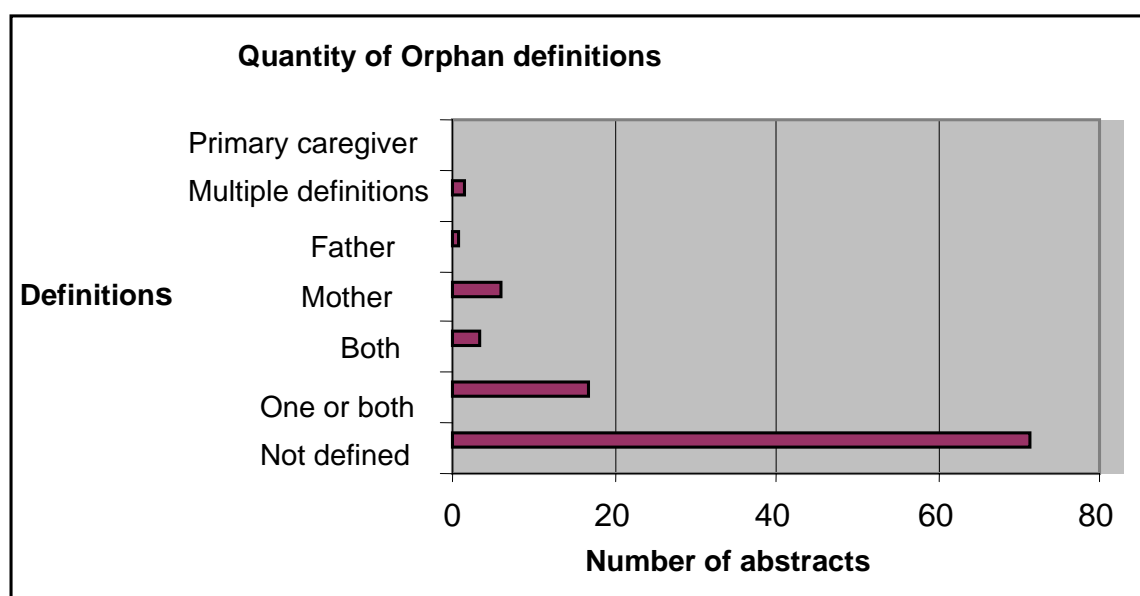
Figure 10. Frequency of orphan definitions used

Table 3. Frequency of orphan definitions used

	Frequency	Percent %
Not defined	273	71.3
One or both parents	64	16.7
Both parents only	13	3.4
Mother	23	6.0
Father	3	.8
Multiple definition	6	1.6
Primary caregiver death	1	.3
TOTAL	383	100.0

The majority of orphans are concentrated in endemic areas of HIV spread, most notably Africa, Asia and South America. 59% of studies emanated from Africa, 12.3% from Europe, 7.6% from Asia, 18% from North America, 2.3% from South America and only 0.3% from Australasia

Systematic review of impact of orphanhood

The second stage involved classifying the findings for negative psychological and physical outcomes related to being an orphan. Of the 383 studies, 188 described psychological outcomes. Of these, only 57 were empirical studies citing actual data to support conclusions about psychological outcomes. Of these 188, 67 described physical outcomes, of which only 18 were empirical studies

Negative Outcomes

Outcomes were coded as physical or psychological for the 383 papers. A separate analysis was conducted for each. All psychological effects listed in the 383 abstracts were recorded. Seventy-four concepts were derived, and these were then clustered into nine prominent themes, namely

- Trauma/ Stress/ Grief
- Stigma/Discrimination
- Internalising and externalizing problems
- Lack of basic needs – food shelter, education, resources, finances

- Abuse – sexual physical or emotional
- Developmental issues
- Lack of nurture / support
- Taking responsibility of adults
- Lack of rights

The frequency of impact on these 9 themes are set out for the empirical and non empirical studies separately, and according to study orphan definition. The empirical studies (table 6) showed 33 studies did not define their criteria, 2 studies defined an Orphan as a child whose both parents had died, while 15 studies defined an orphan as a child who had experienced at least one parental death, but could have experienced both parental deaths. Only 2 empirical studies that highlighted a negative psychological aspect to being an orphan coded for double orphan.

A similar overview for physical effects was collated for the studies, generating 34 listed outcomes, which were clustered into 5 themes. These included

- Treatment
 - Availability
 - Adherence
 - Expenses
- Lack of basic needs – malnutrition/sanitation
- Infection risk
 - HIV/STI
 - Others (e.g. opportunistic)
- Problems in medical organisation
- Mortality

67 (17.5%) studies stated a negative physical outcome of which 18 provided empirical data. All were subjected to coding analysis, listing the themes and breaking these down according to orphan definition. Ten studies did not define the orphan group, while 5 included single or double orphans into one category. As with the psychological findings, most identified a lack of basic needs. However, no empirical papers defined the term orphan.

Table 4. Effects of Orphanhood

Orphan Definition:	Not defined	Defined as both	Defined as 1 or both	Not defined	Defined as both	Defined as 1 or both
Psychological Effects	Psychological Empirical (n = 57)			Psychological Not Empirical (N=131)		
N	33	2	15	99	3	22
1. Trauma, Stress, Grief	3	-	-	12	-	3
2. Stigma, discrimination	3	-	-	13	1	2
3. Internalising & Externalizing problems	3	-	3	6	-	1
4. Lack of basic needs – food, shelter, education (due to lack of resources/ finances)	10	-	5	29	1	7
5. Abuse – sexual, physical, emotional	3	1	2	8	-	1
6. Developmental issues	2	-	2	4	-	1
7. Lack of nurture, support	5	-	3	17	1	4
8. Taking responsibility of adults	1	-	-	4	-	1
9. Lack of rights	3	-	-	6	-	2
Physical effects	Physical Empirical (n = 18)			Physical not empirical (n = 49)		
N	10	0	5	32	2	11
1. Treatment availability	-	-	1	10	-	2
2. Treatment compliance	-	-	-	3	1	-
3. Treatment expense	1	-	-	2	-	1
4. Lack of basic needs – malnutrition, sanitation	3	-	2	7	-	5
5. Infection risk – HIV, STD	1	-	1	6	-	-
6. Infection risk – others e.g. opportunistic	3	-	-	1	1	1
7. Problems in medical organisation	-	-	1	2	-	1
8. Mortality	2	-	-	1	-	1

Systematic review of effects of Orphaning on outcome indicators

The final stage of analysis examined the 47 (33.1%) studies that were both empirical and published in full. Of these studies, only 17 were identified which used a control group. The table below (table 4) sets out the 17 studies and whether there was a difference found between the HIV orphan group and the control group.

Table 5. Systematic review of HIV Orphan studies according to definition and child outcome measures

	Study	Place	Sample	Orphan Definition	Measures	Sig Negative Diff noted
1.	Atwine et al (2005)	Uganda	123 vs. 110 control	“Orphan defined as a child having one or both parents dead due to AIDS”	Demographics Household size Beck Youth Inventories (distress) Self concept Anxiety Depression Anger Disruptive behaviour Stressor inventory (non standardised) – chores, hunger, treatment, loss, health, school attendance, support	No Yes Yes No Yes Yes Yes Yes Yes
2.	Bhargava (05)	Ethiopia	1000 Maternal Orphan	Maternal orphans (but orphans with both parents deceased were also included).	Economic Demographic Morbidity Vaccination Food conditions Unequal distribution of food School participation 60 Items MMPI (emotional/social adjustment)	Yes Yes No No Yes (particularly girls)
3.	Bicego G, et al (2003)	5 country		Children under 15 whose mother, father or both have died	Orphan rate Household structure Education	Yes
4.	Blignaut, E (2007)	South Africa	87 HIV orphans vs. HIV adults	Residents of home for abandoned/ orphaned children	Demographics Oral Swab	Yes

5.	Cluver, L et al (2006)	South Africa	30 orphans and 30 controls	No specific definition (control children had “not experienced a parent dying”)	Demographics Strengths and Difficulties (SDQ) - Prosocial Behaviour - Conduct problems Peer Relationships No good friends Hunger Violence School attendance Hyperactivity Concentration Nightmares Somatic symptoms Impact of events scale (PTSD – Orphans only)	No No No No Yes No No No No Yes Yes Yes n/a
6.	Crampin et al (2003)	Malawi	1106 offspring 197 HIV +ve 396 HIV-	Death of mother	Mortality/morbidity Anthropometric measures	Yes
7.	Diamond et al (1990)		+ve vs –ve			Yes
8.	Forehand and Pelton (1999)	USA	20 orphans 40 control	Maternal death	Demographics health status Transition characteristics Child psychosocial adjustment Aggressive behaviour of CBCL (Achenbach 1991) Children’s Depression Inventory (Kovacs 1981)	No
9.	Gregson et al (2005)	Zimbabwe	1523	“Under 19, orphan, has a parent HIV+ve or ill, lives in a household where death in past year.	Sociodemographic Sexual relationships STI Symptoms/Teenage Pregnancy HIV status Parental survival Maternal orphans 2x adverse outcome	Yes Yes Yes Yes
10	Lindblade et al (2003)	Kenya	1190 <6yr	Maternal, paternal or double orphans	Illness history, Parenting Bednets Health Indicators Weight/weight for height	Yes No No Yes

11.	Makame et al (2002)		41 orphans, 41 non-orphans	Children who had lost one or both parents	Arithmetic test (WRAT) Internalizing problems – Rand mental health inventory (sampled) Positive effect Beck Depression Inventory (items) Suicidal ideation School attendance Experience of punishment, reward Hunger Problem list Separation from siblings	Yes Yes Yes Yes No + Yes Yes
12.	Manuel (02)	Mozambique	76 Orphan 74 Non orphan			Yes
13.	Masmas et al (2004)	Guinea-Bissau	128 rural 192 urban Control 808.	Child who survived its biological mother, irrespective of survival status of father.	Demographic variables Prior to death of mother Socioeconomic measures Sibling caretaking Movement between households Health and nutrition Schooling Hospitalisations Vaccinations Arm circumference measures Caretaking, residence and structure	Yes No Yes Yes No
14.	Monasch et al (2004)	40 SSA		Child under 15 years, mother or father or both have died.	Survival status Residence Schooling Child labour	Yes Yes
15.	Nyamuka pa (2006)	Zimbabwe	5,321 children (12-17 yrs)		Psychological disorders Social connectedness (CBC, RMH and Beck informed)	
16.	Nyamuka pa C, (2005)	Zimbabwe	2402 orphans	Paternal, maternal and double orphans	Demographics School attendance/completion Household composition	Yes No Yes
17.	Pelton J et al (2005)	USA	105			Yes

18	Poulter et al (1996) (unpublished)	Zambia	22 orphan, 66+ve parent, 75 control			Yes
19	Sarker M, et al (2005)			A child under 18 years lost father, mother or both.	Demographics Socioeconomic background Orphan status Sick during 2 weeks previous Morbidity history health care seeking Nutrition Height and length;weight	Yes Yes No No No
20	Sengendo and Nambi (1997)	Uganda	193 orphan, 29 non orphan		Norwicki-Strickland Locus of Control Depression	Yes

These studies clearly show a systematic detrimental effect on both psychological and physical measures for children affected by AIDS. Some studies provided solid definitions of parental AIDS (e.g. the Rotherham Borus where study population was gathered from the children of medically diagnosed HIV positive parents). However, other studies gave unclear or inadequate definitions of AIDS. This was usually report or verbal autopsy measures, not confirmed by medical or biological markers (eg Cluver). Orphaning. The effects may be exacerbated by poverty, but the use of control groups clearly indicate that poverty is not the key mechanism accounting for these effects.

Control groups and their composition have also not been clearly articulated. Clearly the quality of the control group is vital in assessing the confidence and relevance of the findings. These varied from orphans compared to non orphans gathered from similar population sites, orphans due to HIV/AIDS compared to orphans due to other causes (Cluver et al) and comparisons according to which parent (or both) had died.

There is a lack of definitions and children with maternal, paternal or parental death are included in different ways in the studies. Cut off ages vary dramatically as well, with 15 years and 19 years being commonly used. There is a lack of consistency on measures used to explore well being, psychological functioning, mood, depression, social connectedness and mental health. Physical measures, such as growth and development,

nutrition and housing are easier to capture and compare across studies. Not a single study provided data that could be verified against another study. Many studies used a complex basket of measures, and the studies were mixed. When power calculations were carried out, these tended to be based on a single measure. Thus the studies may have been underpowered to explore all the measures used.

The blurring of definition categories masks the specific contribution of maternal or paternal loss, any protective effects from a parent alive, or the full impact of the death of both parents. One key study (Gregson et al) shows clear impact of paternal/maternal or parental death and goes further to show differential effects on male and female children. This clarity needs to be replicated in other studies. The array of measures used shows a total lack of standardisation and renders the studies difficult in terms of systematic review or meta-analysis and limits the extent to which findings can be generalized.

Careful reading of the controlled studies points to a much more complex picture. Although there are some consistent detrimental effects of orphaning, there are also some surprises, and some studies seek to find differences on certain outcomes and do not find these (e.g. Cluver et al, Bhargava et al). They tentatively explore protective factors, and these seem all to be associated with family factors and quality of care.

When differences between maternal, paternal or parental death are separated out, studies do show differential impacts. They are too few in number to provide a combined overall finding, but clearly indicate that when studies conflate these separate groups they are misleading. On the measures used, and in the few studies where these are examined, maternal death has a direct effect on specific outcomes such as school attendance and risk behaviour. The studies also point to the importance of gender considerations where differential effects for girls and boys are noted. Similarly the gender of the deceased parent seems to have an impact.

The overriding finding from the research is that very few studies clearly define the term orphan within their work. When definitions are available, there was a variety used. Only 3.4% of studies defined and included double orphans only. Thus it is very difficult for the literature to provide systematic overview, as the studies are simply not comparable. There is undoubtedly a need to refine definitions and report samples studied with clarity.

In the absence of a consensus, standardised measures and controlled studies the evidence base on the impact of orphanhood is limited and piecemeal. There is a clear finding, from all studies reviewed (with one exception) that when control groups are used, whatever measures are employed standardised, derived or specifically created) there are significant differences whereby orphaned children have detrimental outcomes. Yet a detailed examination of the studies shows a mixed picture and points to the need to understand the absence of effect or protective factors where children rally.

The systematic review of studies shows a high number of psychological and physical negative impacts of being in the group labelled 'orphans' (however defined). It must be noted that there are other confounding factors, such as poverty and HIV status, which may not have been controlled for in the empirical studies, and may have contributed to significance between orphan cohorts. It is also important to note that despite a significant effect, there are still a variety of definitions being used, and therefore it does not identify which particular children are the ones which need the support. Few studies look at strengths or positive outcomes.

This blurred picture renders the literature difficult to navigate. It is important that definitions for evidence gathering are not confused with definitions for support and resources. The political need for inclusion of a wide range of children into the provision arena has ensured many children benefit from support and also stigma is avoided. Yet at the same time this approach within research has limited the clarity of the evidence base. There is a need for a coordinated approach to measurement for children. In the absence of such rigour the evidence base is difficult to interpret. The emerging messages within the controlled studies suggest that this situation ought to be remedied at an international level and as a matter of high priority.

3.3 Institutional care and child development

Current Policy

Policy is generally mixed and country specific. There is an emerging trend of institutionalised provision, which runs counter to findings beyond the HIV/AIDS arena.

Key Findings

Research into the effects of institutional care within a HIV/AIDS context is scarce. There is good evidence from the wider literature that institutionalised care should not be the focus of provision for HIV affected children.

Family Considerations

Family care can enhance individual, family & community capital. Orphan programmes must support, not supplant, parenting & reach those in greatest need. A pathway between families, community, programmes and services, and state provision should be established in terms of orphan and childcare. Children have a better chance of being free of HIV directly and the burdens of HIV within a well-resourced family that is able to protect its own children. Ensuring families and communities are the focus for orphan care rather than institutions is essential to secure psychosocial health and cultural belonging for orphaned children.

Orphan programmes

This review will provide a brief analysis of one section of care provision for orphans, namely institutionalised or non-family residential care, which is outside of a family context. Such orphan programmes may alienate rather than integrate all children. This section will provide an overview of institutionalized care versus family care and examine evidence base on care provision. This element of the report will provide some analysis from existing child development literature exploring the benefits and limitations of institutionalized care. This will be used to explore the extent to which long-term knowledge in areas outside of HIV infection may be used to inform strategy from an evidence base.

The role of institutionalised care in caring for orphans in Africa is a prominent one. Foreign funding and staff are still being used to build and staff orphanages rather than for community based resource projects (Drew, Makufa & Foster, 1998). Despite the move to non-family orphan care, very few evaluations of this approach have been conducted and the evidence base within the sub-Saharan African and HIV/AIDS context is scarce. This lack requires consultation of the ample wider literature on the effects of institutional care on children.

Institutionalised care outcomes – literature overview

There is a wide and robust literature detailing the poor outcomes of institutionalised children. These outcomes are found in all areas of development (MacLean, 2003; Smyke, Koga, Johnson et al, 2007).

Physical outcomes

Institutions, particularly in Eastern Europe, often provide too little and poor quality food, leading to malnutrition (e.g. Rutter & the ERA Study Team, 1998). Children may also suffer other physical and material deprivation. Institutionalisation has a negative effect on the physical development of children (MacLean, 2003; Wilson, 2003; Smyke et al, 2007; Rutter & the ERA Study Team, 1998). For example, institutionalised children lose one month of linear growth for every 3 months spent in institutionalised care (Johnson, 2000; as cited in Wilson, 2003). Also, older studies, of institutions probably more like the ones in Africa, also showed increased morbidity and mortality. However, children can make a remarkable physical recovery once adopted out of an institution into improved conditions (Vorria, Papaligoura, Sarafidou et al, 2006; Rutter & the ERA Study Team, 1998). In Africa, some authors argue, given the poverty of communities, living in an institution may even be beneficial for nutrition and physical development (Panpanich, Brabin, Gonani & Graham, 1999). Yet another strategy, based on the generalised international literature would be to address the poverty of the community, rather than the relative benefits of an institution.

Cognitive outcomes

Cognitive and language deficits have been consistently reported in institutionalised children (Smyke et al, 2007; Vorria et al, 2006; Kaler & Freeman, 1994; Rutter & the ERA Study Team, 1998). Castle, Groothues, Bredenkamp et al (1999) found the higher the rating of psychological deprivation experienced in the orphanage, the lower children's IQ scores, and this was independent of malnutrition status. A meta-analysis by Van Ijzendoorn, Juffer & Klein Poelhuis (2005) found that the cognitive development of adopted children can recover to a large extent but language abilities and school performance may remain delayed. These effects may compound both the cognitive and language deficits associated with HIV infection in positive children, and related poverty effects associated with orphanhood, such as malnutrition.

Psychosocial and Emotional-Behavioural outcomes

Psychological, social and emotional deprivation may be the most important and universal problem of institutional care, and be worse affected than cognitive development (Wilson, 2003). The quality of children's relationships with others, particularly an adult caregiver, is an important factor in healthy psychological development (Vygotsky, 1978). Even in those orphanages with caring staff, the child: adult ratio is necessarily far lower not only lower, but shift work, staff turnover, disinterest in children etc than found in households meaning children receive less than optimal levels of attention and social interaction from adults (Camras, Perlman, Wismer Fries & Pollack, 2006), whilst staff rotation patterns reduce caregiver stability. The importance of continuity and bonding/loving adults may be disrupted. Children housed in same-age groups also lack older peers to provide 'scaffolding' opportunities for development (c.f. Vygotsky, 1978). The psychosocial effects of institutionalisation are more permanent than the physical effects (Wilson 2003), and may be more important in predicting later development than malnutrition alone (Rutter & the ERA Study Team, 1998). Yet, they are less researched in Africa and in terms of the HIV/AIDS epidemic.

Deficits in social functioning have been widely reported (Smyke et al, 2007; Kaler & Freeman, 1994). Emotional expression is often disturbed: institutionalised children show less positive affect and more negative affect (Smyke et al, 2007). Additionally, these

children show significant difficulties in emotional understanding (Wisner Fries and Pollack, 2004; Vorria et al, 2006; Camras et al, 2006). Higher emotional understanding is predicted by maternal elaborative conversational style in the context of secure attachment (Ontai & Thompson, 2002): these are two factors lacking in an institutional environment.

Bowlby's (1951) attachment concept, which aimed to link early social relationships and later psychosocial functioning, was based on the inability of institutionalised children to form secure attachment relationships. Attachment difficulties in institutionalised children have been consistently reported (e.g. Vorria et al, 2006; O'Connor, Marvin, Rutter, et al, 2003). These attachment difficulties have been linked to the 'indiscriminate friendliness' of institutionalised children toward all adults, irrespective of their familiarity or the care they provide (e.g. Tizard & Hodges, 1978). This behaviour persists long after leaving the orphanage (MacLean, 2003) and is associated with other behavioural problems, particularly attentional difficulties (MacLean, 2003). The potential links to HIV risk exposure behaviours have not been systematically studied in the context of the HIV epidemic.

Further behavioural problems reported in institutionalised children include overeating and stereotyped behaviour (Fisher, Ames, Chisholm, & Savoie, 1997). Higher internalising and externalising behaviour scores are reported in children three years after leaving institutionalised care by some authors (MacLean 2003). Institutionalised children who still have contact with their relatives show less positive affect and have higher rates of aggression compared with those who have no such contact (Nielsen, Coleman, Guinn & Robb, 2004). The extreme socio-emotional and behavioural problems of some institutionalised children have even been described as a "quasi-autistic" syndrome (Rutter, Andersen-Wood, Beckett et al, 1999). The amelioration of effects by relative links is a finding that needs to be underscored in relation to HIV care in the presence of multiple deaths.

Potential benefits

Some studies argue that foreign-run institutions can offer some developmental benefits to orphans in Africa, particularly in terms of immediate physical requirements. Nathan, Nerlander, Dixon et al (2003) found survival at 3 years old was higher for institutionalised HIV-infected children (70%) than for those living in the community (11%). Orphans living in an orphanage in Malawi were more likely to have their physical and material needs met compared to those living in a foster home (Zimmerman, 2005). However, these studies fail to take into account the longer term psychosocial and cognitive effects which need urgent study. Since 55% of the Malawian population live below the poverty line (CIA, 2004), this finding reflects the inconsistency of care between foster homes.

Food variety, quantity and stability in Malawian orphanages have been observed to be superior to that in foster homes (Zimmerman, 2005; Panpanich et al, 1999). Correspondingly, orphanage children aged over 5 were less wasted and stunted than those in foster care (Panpanich et al, 1999). This single study is in contrast to the more robust studies. For example an analysis of UNICEF surveys that collected nutritional status data from institutionalised children found that children in orphanages in Malawi and Jamaica *were* nutritionally worse off than those in households (Rivers et al, 2004). Panpanich and colleagues (1999) interestingly found no significant difference between the nutritional status of fostered orphaned children and non-orphans, indicating the community foster care was adequate and did not differentiate or negatively affect orphaned children. Similarly, studies have found no difference between fostered orphans and non-orphans in health status and care, school attendance, lodging and sanitation facilities, and clothing (Lindblade, Odhiambo, Rosen & DeCock, 2003; Masmus, Jensen, da Silva, Hoj, Sandstrom, and Aaby, 2004; Kamali, Seeley, Nunn et al, 1996). Some authors suggest that fostered children may be stigmatised and unfairly treated in favour of biological children (e.g. Zimmerman, 2005; Cluver & Gardner, 2007), but whilst this may be the case in isolated households, current evidence does not support this conviction (Masmus et al, 2004). Foster care in Africa is unlikely to exceed the standard of physical and material provision achieved by orphanages but, crucially, orphans in foster care receive the same standard of care as non-orphans in the same community. In addition, foster care in a family environment is likely to offer many benefits that

institutional care cannot, particularly for psychosocial development and cultural integration. It is possible that a family will inherently provide a loving and nurturing environment that an institution cannot. The importance of the interactions between caregiver and child has been clearly demonstrated by Richter (2004), who identifies the importance of caregiver sensitivity and individual responsiveness to the child and highlights the need to support nurturing caregiver-child relationships ideally within a family and continuous environment.

In a comprehensive review of the wider literature, MacLean (2003) identifies age of admission quality of care and duration of institutionalisation as important factors in the severity and permanence of the deficits associated with orphanage care. Furthermore, the detrimental effect of institutional care on development is greatest when the post-institutional environment is high risk (MacLean, 2003). This has clear implications for institutionalised orphans in Africa, who leave orphanages with few connections to their families, communities and culture, and face an environment of poverty, HIV/AIDS epidemic and political unrest. A long-term dependency is frequently described among individuals who leave orphanages and then subsequently seek work in them. As treatment becomes more available and effective, HIV positive children living in orphanages are beginning to live into adulthood, raising issues of reintegration into their communities that have not previously been considered. Life in an orphanage does not however necessarily doom children to poor outcomes as adults (MacLean, 2003). While for one Malawian orphanage, “almost 100% of their former residents who were over 18 were living self-sufficient, well-adjusted lives” (Zimmerman, 2005), there is clearly need for quantifiable evidence before any conclusions can be drawn.

Zimmerman (2005) suggests that institutional care is a good short-term solution to allow African communities to recover and rebuild. However, if this strategy were to be successful, institutions would actually need to become part of the long-term strategy rather than their current isolated position, funded and run independently of any community efforts. This is important – how sustainable are care institutions? For example, Mozambique has many orphanages established by foreigners during the war, that no longer receive regular funding, and where children now live in dire conditions. Zimmerman (2005) also suggests “A more relevant question to ask is “How much money would it cost to raise a child in a foster home at the same standard of care found in an

orphanage?”” (p. 908). The author goes on to suggest that orphanages offer greater value for money from this perspective. Given the evidence to suggest the ‘standard of care’ in orphanages is not optimally balanced across the material-psychosocial plane to ensure healthy child development, and that the experience of institutionalised children is difficult to compare directly with that of fostered children in the community, this may not be a relevant question in terms of long-term policy.

The long-term strategies for the care of orphans in Africa need to take more into account than simply cost-per-head. A number of community-based volunteer interventions have been successful in providing both material and psychosocial support to foster families and the whole community (Kidman, Petrow & Heymann, 2007; Foster, 2007; Drew et al, 1998). This type of intervention is both sustainable and economical, and given current evidence in determinants of healthy psychological development should be the focus of efforts to care for orphans and other vulnerable children in Africa.

Institutional Care Evaluations of Children Affected by HIV in Africa

The above literature is drawn heavily from the international literature on outcomes of institutionalised children, and where African studies are included the evaluative data on orphanages is either purely qualitative (e.g. Zimmerman, 2005) or focussed heavily on one (usually physical) outcome (Panpanich et al, 1999; Nathan et al, 2003). The overwhelming message from the established evidence base is that this approach is not in the interests of healthy child development, and this has been the major impetus in the closure of institutions worldwide. Despite this, orphanage care continues to be supported in sub-Saharan Africa, and yet their effects are not empirically evaluated. A recent paper by Schenk and Michaelis (2008) reviewed relevant psychosocial evaluations of institutionally based care for orphans and other vulnerable children worldwide. The review found only three papers focussed specifically on evaluating the institutional care of HIV-affected children in sub-Saharan Africa. None have been published in the academic literature. One article published in the grey literature reports only qualitative case-study data (Abdulla et al, 2007), one study is yet to be completed (Whetten, in progress) and one appeared as an abstract in the International AIDS Conference in 2004 (Powell et al, 2004), reporting no quantitative data. Whilst the Whetten study (in progress) aims to address the literature gap once completed, currently no single

comprehensive empirical evaluation of the effect of institutional care on HIV-affected children in Africa has yet been published.

3.4 Mobility/Separation and child development

Current Policy

There is no clear policy relating to mobility and separation of children – something the Zoë's Ark issue in Chad recently highlighted.

Key Findings

Analysis of the international child development literature indicates that mobility and separation appear to be key factors in development. Research from within the HIV/AIDS context is lacking. HIV/AIDS has the potential to disrupt stability, increase mobility as families fracture, disperse and vary their economic and social structure. Child-parent/caregiver and child-sibling separation is a risk within the unfolding HIV epidemic. This can result from hospitalisations, illness, death and dispersal.

Family considerations

A family approach would encourage policy and programmes to address mobility and separation in the provision for children. This should range from access and accompaniment in hospital care, to provision for children in the presence of illness and death. Sibling separation should also be avoided. However, planned mobility within the African context can sometimes have positive effects on children and families.

A stable family or home environment is an important factor in the healthy psychological development of children and family instability in childhood may result in a variety of negative outcomes. Two key elements of family stability can be identified that impact upon child development and adjustment: caregiver stability and residential stability (Adam, 2004).

Separation from a parent (e.g. through death, divorce) in childhood has been associated with a higher likelihood of attempted suicide amongst adults (Adam, Bouckoms and Streiner, 1982), and with poorer educational attainment (Ermisch and Francesconi, 2001). Similarly, residential instability has been associated with educational difficulties

and behavioural problems (Wood, Halfon, Scarlata, Newacheck & Nessim, 1993; Pribesh & Downey 1999). However, it is particularly the *degree* of instability that children face which predicts children's developmental adjustment (e.g. Ackerman et al, 1999). Using a random sample of African American female adolescents from a high-poverty neighbourhood, Adam and Chase-Lansdale (2002) found that higher number of separations from caregivers were significantly associated with higher levels of internalizing problems, and educational and sexual adjustment difficulties in adolescence, after controlling for confounding factors. In particular, adjustment problems were significantly associated with separations from both temporary *and* long-term caregivers, and with separations occurring in both early and middle childhood, *and* adolescence. Separations from long-term caregivers in early childhood were most detrimental (Adam & Chase-Lansdale, 2002). Although the correlational results cannot imply direction of causation, the study highlights the importance of taking the degree of disruptions over time into account, rather than simply a 'snapshot' of a child's home environment. Similarly, Forman and Davies (2003) found family instability increases adolescents' risk for internalizing and externalizing behaviours.

A positive relationship was found also between frequency of residential moves and number of adjustment problems the Adam and Chase-Lansdale study (2002). Similarly, higher numbers of residential moves was found to increase the likelihood of detrimental health behaviours including teenage pregnancy, early sexual initiation, smoking, alcoholism, depressed affect and attempted suicide in a large retrospective cohort study (Dong, Anda, et al, 2005). However, the authors suggest this and other associations between residential moves and poor outcomes can be explained by other adverse childhood experiences. A large cohort study by Gilman et al (2003) has identified that both parental instability and high residential instability (more than 3 moves by age 7) were related to elevated lifetime risk of major depression, and were most pronounced of depression with onset by 14 years of age.

Children who grow up in foster care in developed countries often experience high levels of both caregiver and residential insecurity. Negative psychological and behavioural outcomes have been identified in these children. Rubin et al (2004) found that foster placement instability, in terms of both multiple placements and episodic foster care, were independently associated with a higher risk of being a mental health service user.

Rubin et al (2007) found that, independent of a child's baseline problems, the placement instability experienced as a foster child had a significant impact on behavioural well-being. As many as one third of children failed to establish any placement stability in the first 18 months of foster care, and this increased their risk of behavioural problems by up to 63% compared with those who achieved some placement stability. Similarly, Lawrence et al (2006) found that children placed in foster care had significantly higher levels of behavioural difficulties both during care and following release from care, when compared to both maltreated children who remained in their homes, and to non-maltreated and non-fostered children with similar at-risk demographics. Juvenile delinquency is also associated with boys, but not girls, who experience placement instability in foster care (Ryan and Testa, 2003). However, some research has showed that placement instability for the first 8 months of care does not adversely affect children's psychosocial well-being (Barber and Delfabbro, 2003). Another important aspect of the stable home environment for children is the relationship with their siblings. Separation from siblings removes an important developmental factor. Furthermore, separation from siblings during foster care is associated with a higher likelihood of placement disruption (Leathers, 2005), leaving children vulnerable to the abovementioned negative developmental outcomes.

Family instability has been proposed as a mediating variable to explain associations between poor developmental outcomes and poverty. Adam (2004) indicated the need for future research to focus on the interaction between home quality and stability over time – is a high-quality often-disrupted environment more deleterious for development than a low quality stable one? This may have implications for foster care in developed countries, but also for interventions in Africa: whilst some degree of mobility may be inevitable, it might be useful to design programmes to focus more on either quality or stability.

The African situation

Children in Africa commonly experience both caregiver instability and residential mobility. Although migration can occur for a number of reasons, it is a widespread coping strategy following a parental death in a household, a frequent occurrence in the context of the AIDS epidemic (Operario, et al 2007). A study by Young and Ansell (2003)

found that, in Malawi, 58% of children had moved at least once, with parental death being the greatest reason for migration. Parental death increases risk of household mobility by nearly two-fold (Ford & Hosegood, 2005). Urassa and colleagues (2001) found that in 44% of cases where the head had died, all members moved out of a household. However, whether or not the death was from AIDS did not affect mobility, and indeed, others have found mobility following a death of AIDS to be lower than from other causes (Ford & Hosegood, 2005). The authors speculate that families coping with AIDS may have longer to prepare care plans than those experiencing deaths from more immediate causes.

Children may also be affected by residential and caregiver mobility before they are orphaned, for example by moving to care for sick relatives or due to poverty from illness or death in the family (Young & Ansell, 2003). Similarly, parental death has long-term as well as immediate effects on child mobility (Ford & Hosegood, 2005). Multiple moves can occur, for example due to further deaths or increased poverty following extra burden on households. Siblings may be separated to reduce the likelihood of subsequent moves. Orphans often go to live with close relatives in the same community (Young and Ansell, 2003) but may have to move further afield to reach relatives able to care for them. Children may also be fostered or adopted, or even admitted into an orphanage, which itself may have deleterious effects on development (see above). The developmental outcome of these children may depend on the way they are accepted into their new homes – for example, whether they are integrated or seen as inferior to biological children in the household (Young & Ansell, 2003; Ford & Hosegood, 2005). Important work by Hosegood has also shown that it is often the youngest children who are most mobile.

Unfortunately, there often is no other choice than for children to move in this environment. Furthermore, moves are generally carefully planned by caregivers to be as positive for orphans as possible (Ford & Hosegood, 2005). Bray and Brandt (2007) explore the possibility that residential and caregiver mobility is not necessarily detrimental to development in the light of anthropological and psychological notions of 'home'. 'Home' in both a social and an emotional sense is related to an individual's feeling of belonging, and this makes it possible to feel 'at home' in a number of different physical spaces (Rapport & Dawson, 1998; as cited in Bray & Brandt, 2007). Stable and

continuous aspects of children's lives, such as their relationships with others, family ties and familiarity with various surroundings, may make it possible for physical mobility to be ameliorated by emotional belonging. Furthermore, cultural differences mean that having several different but equal caregivers is not uncommon in African communities. Similarly, movement of children is often beneficial, and children go to spend shorter or very long periods with relatives to strengthen family ties, to provide company for a lonely adult, to help out in the house, or to get opportunities e.g. for education. Hence, moving between caregivers might not have the detrimental effect that might be expected in Western cultures.

There is a paucity of research on the effects of caregiver and residential instability on African children's development. Given the outcomes demonstrated in developed countries, the level of instability faced in Africa and the number of other negative factors involved in the AIDS epidemic context, it must surely be important to investigate exactly how these moves are affecting children as they develop. Some of the studies discuss separation in general, while the psychologists may want to explore similarities and differences between separation from place and separation from person(s).

A family perspective would encourage a wide definition of family, an appreciation of the cultural practices that determine kith and kin ties, cultural responsibility and place of care. Interventions and reactions to HIV related disruption should be aimed at keeping such family intact, and ensuring that mobility and separation are minimized. Where they do occur, the circumstances and provisions around such mobility and separation has an effect on quality of adaptation and effects on children.

3.5 Schooling, HIV and development

Current Policy

Schooling provision is the subject of a variety of policies in countries affected by widespread HIV. The ideal forms cover universal provision free of charge to the child/family.

Policy advances, such as the Education for All Campaign, are separate from HIV/AIDS policies, but have enormous implications for children affected and are a good example of joined up thinking.

Key Findings

HIV can have direct and indirect effects on school attendance and school quality provision. Schooling is a single key element in future attainment.

Family Considerations

Schooling provision is of benefit to children and particular attention needs to be focused on barriers to school attendance within a family so that these can be overcome.

Several potential outcomes of the AIDS epidemic on the schooling of children have been proposed. Enrolment and attendance rates may be lower in countries with high HIV prevalence as a result of increased poverty, increased mortality of both children and adults, and decreased fertility levels. It is also suggested that children's performance once in school may be poorer, and drop-out rates higher, due to psychological and physical burdens at home and stigma at school (Bennell, 2005). However, there is a lack of empirical evidence to support these assumptions. For example, analysis of empirical studies from Botswana, Malawi and Uganda shows little evidence of discrimination towards orphans in school (Bennell, 2005). The relationship between schooling and parental status is rather more complex than often supposed.

Researchers hypothesise that some children will be more susceptible to poor schooling outcomes than others as a consequence of the AIDS epidemic. These children can fall into four groups: HIV-infected children, orphans, fostered children and children living with an ill caregiver. Because it is estimated that less than 1% of school-age children are HIV-infected (Bennell, 2005), most research has concentrated on determining whether orphans and other vulnerable children are at increased risk of poor schooling compared with less affected children.

Some studies have found a negative effect of orphanhood on schooling (e.g. Evans and Miguel, 2007; Mishra, 2005; Bhargava, 2005; Ainsworth et al, 2005; Kamali et al, 1996; Yamano & Jayne, 2005). The definition of orphanhood is variously defined (see table 7 below). Orphans may be up to 20% more likely than non-orphans not to attend school (Monasch and Boerma, 2004; Yamano and Jayne, 2005). Orphans are less likely to be enrolled in school than the non-orphans that they live with, even after controlling for the

effects of poverty (Case et al, 2004, Case & Ardington, 2005). Orphans were more likely to experience interruption to their schooling than non-orphans in Botswana, Malawi and Uganda (Bennell, 2005). In terms of grade repetition, Bicego et al (2003) found that, after controlling for confounding factors, orphans were half as likely to be at correct grade level as non-orphans at age 6-10 and two-thirds as likely at age 11-14. Sharma (2006) also found that the likelihood of dropping out of school for orphans in Malawi is higher as their grade level increases.

However, some authors have found no effect of orphanhood. There was no difference in school enrolment between orphans, children with an ill caregiver, and other children in Rwanda and Zambia (Chatterji et al, 2005). In contrast to Bicego and colleagues (2003), Ainsworth et al (2005) found no evidence that attendance of older children (11-14 years) in primary school was affected by orphanhood. Some authors have even found an *advantage* in school attendance for some orphans (e.g. Akresh, 2004). This may be as a direct result of school support programmes available to orphans. However, there is a good argument that universal provision would obviate the need for special treatment. Contrary to usual assumptions and reports that double orphans fare worst in schooling outcomes (Monasch and Boerma, 2004), double orphans had better school attendance than non-orphans in Uganda and Botswana (Bennell, 2005) and better school completion rates in Zimbabwe (Nyamukapa & Gregson, 2005).

However, simply looking at a 'snapshot' of the attendance of orphans against non-orphans may not reveal important patterns of vulnerability. Orphans and other vulnerable children are inevitably intertwined, given that children living with an ill caregiver will become orphans when the caregiver dies. Which parent dies is also important, although those experiencing a single parent death may well face a double loss if HIV has affected both parents and there is no treatment availability: HIV prevalence among surviving parents of orphans is 4-5 times higher than non-orphans (Busingye et al, 2003). These different stages of vulnerability are likely to have different implications. These different stages of vulnerability are likely to have different implications. Longitudinal research, which crucially enables researchers to control for fixed differences across households, has investigated the difference in schooling before and after parental death, and hence the complicated path between being a 'vulnerable child'

and becoming an 'orphan'. Furthermore, several authors have identified differences between the effects on school of death of a mother or a father.

Effect of orphanhood definition

Ainsworth and colleagues (2005) performed a multivariate analysis of the pattern of parental mortality and school attendance and enrolment in Tanzania, where approximately half of children, nationally, are not enrolled. After controlling for a number of confounding variables, the authors found being a *maternal* orphan was associated with late enrolment. Similarly, the longitudinal study of Case & Ardington (2005) in South Africa found the death of a mother was a strong predictor of poor schooling outcomes: maternal orphans were less likely to be enrolled at all, and completed significantly fewer years of schooling with less money spent on their education, when compared to the non-orphaned children they lived with. Maternal orphans in Botswana are significantly more likely than other orphans and non-orphans to have ever repeated a school grade (Bennell, 2005). Maternal orphans in Zimbabwe have significantly lower primary school completion rates than other children, whilst female paternal or double orphans were found to have the highest levels of school completion (Nyamukapa & Gregson, 2005). The authors suggest this is due to increased residence in female-headed households, and greater access to external resources, whereas maternal orphans suffer from poor support from fathers and stepmothers, and ineligibility for welfare due to living in higher SES households – which shows how complicated it is. Furthermore, Bhargava (2005) found that the presence or absence of a father had no effect on school participation after maternal death. Similarly, a father's death has no causal association with poor educational outcomes – the only correlation between these factors arises because paternal death is an indicator of household poverty (Case & Ardington, 2005). However, other research conversely indicates that paternal orphans, not maternal orphans, may be worst affected: Ainsworth too Absenteeism in Malawi is significantly higher in female paternal orphans and double orphans but not maternal orphans, while paternal orphans are most at risk of repeating a school grade in Uganda (Bennell, 2005). Others have found no significant differential effects of maternal and paternal death (Monasch and Boerma, 2004).

Maternal death is additionally associated with poorer school participation *prior* to the death (Bhargava, 2005). Evans and Miguel (2007) also found a significant decrease in school attendance before parental death, followed by an even larger decrease following the death. Again the authors noted the effect was worst for maternal deaths, and for those with a poor baseline academic performance record. In the 3-6 months before an adult death, Ainsworth and colleagues (2005) noted that children who *did* attend school spent significantly fewer hours in school. Attendance in these children overall returned to normal after the death. Bhargava (2005) identified that school participation before maternal death was a significant predictor of participation subsequently, with those attending school prior to maternal death 3.5 times more likely to attend afterwards. Ainsworth et al (2005) also noted that girls were affected differently to boys: a large decline in hours spent at school was observed for girls in the 6 months following a mother's (or both parents) death, but not for boys. Similarly, Bhargava (2005) found that girls were significantly less likely than boys to attend school following a maternal death in Ethiopia. On the contrary, Yamano and Jayne (2005) found no effect on girls' school attendance following a death, only a large effect on boys from poor households. Poverty is an important factor in schooling outcome: income and good feeding and clothing conditions are significant predictors of school participation following maternal death (Bhargava, 2005). Children in poor households were 33% less likely than those from non-poor homes to attend school in the two years prior to an adult death (Yamano and Jayne, 2005). Bhargava (2005) also identified that participation in income-generating work more than doubled following a maternal death for all orphans, and that this reduced their likelihood of attending school by ~80%. This pattern is echoed in Malawi, where a mother's death increased need for female child labour (Bennell, 2005). However, in Uganda, it was a father's death that increased need for child labour (Bennell, 2005). Nevertheless, Case et al (2004) found that orphans fared significantly worse than their non-orphaned host siblings independent of poverty.

Need to stress context – by country, by urban/rural etc

Bhargava (2005) also investigated differences in schooling outcome depending on the cause of maternal death, and found that AIDS orphans (those whose mother died of AIDS) were *more* likely than non-AIDS orphans to be attending school. The author doesn't offer any suggestions as to why this pattern occurs. It is conceivable that a death from AIDS allows families enough time to make alternative arrangements for children in

a way that a sudden death might not. Further investigation needs to be made. Having HIV-infected parents makes children significantly *less* likely to attend school than those with uninfected parents (Mishra, 2005), however children living with a single, uninfected parent are worst off, being less likely to attend school than children of HIV-infected parents who still live together. Where orphans live may have a significant influence on schooling, independent of their actual parental status: Sharma (2006) found that orphans living with a single parent or grandparents were significantly less likely to attend school than orphans living with other relatives. However, simply being an orphan had no effect on school attendance. Akresh (2004) found that all children, orphaned or otherwise, living in fostering households were more likely to be enrolled in school than other children, and there were no difference in the enrolment of fostered children and their host siblings. Conversely, Case and colleagues (2003) suggest that orphans do fare systematically worse than non-orphans on schooling outcomes, and this effect is worst when they live with non-relatives.

What are the possible explanations for this very mixed picture of the effect of parental illness and death on schooling? Even in high-prevalence African countries, only up to 5% children were two-parent or maternal orphans in the mid-late 1990s (Bennell, 2005). Although this number is set to increase, the rate of growth in numbers of orphans is less than often proposed, and this rate has actually decreased in countries such as Tanzania and Uganda since it peaked in 1998. We might therefore not expect large changes in enrolment and dropout rates as a result of parental status changes. Within-country factors are also important. For example, Botswana has a strong schooling culture. The provision of school meals and the preferable environment of school compared to home may promote positive schooling outcomes. Furthermore, there is not a simple association between HIV prevalence and school attendance and enrolment among orphans and non-orphans. This may be due to governmental efforts to boost schooling outcomes by introducing free or cheaper schooling in high prevalence countries (HPCs) (Bennell, 2005). For example, a three-fold increase occurred in Ugandan enrolments at the same time that the AIDS epidemic seemed to peak in the late 1990s, following the launch of free primary schooling. Information from DHS statistics show that both repetition and dropout rates for Uganda, Malawi and Botswana also dropped significantly during the late 1990s (Bennell, 2005). DHS statistics suggest that overall, orphans are slightly more vulnerable to poor school outcomes but overall risk is small in

most countries (Bennell, 2005; Case et al 2003). Given that effects vary widely between countries, future efforts should concentrate on identifying which children are particularly vulnerable in individual communities and tailoring interventions accordingly.

Systematic review

A systematic review of the literature on the effect of schooling outcomes for children affected by HIV, revealed 15 key studies where these variables were monitored, a control group was reported, and empirical data was available. These studies are summarized in the two tables below:-

Table 6. Studies on Schooling and HIV affected children

Study	Country	Sample	Negative effect (yes/no)	Detail
Ainsworth, M., et al (2005).	Tanzania	Kagera health and development survey – longitudinal survey from 1991-1994. 757 households completed all rounds. 62 primary schools.	Yes	<i>Enrolment</i> Older children unaffected (7-14 yrs) Poverty has effect
Akresh, R. (2004).	Burkina Faso	Survey of 606 household heads and their 812 wives. 300 paired households that had exchanged a foster child between 1998-2000	No	<i>Enrolment</i> All children, orphaned, fostered or host siblings, living in fostering households were more likely to be enrolled in school than other children.
Bennell, P. (2005)	Uganda, Malawi, Botswana	Review and analysis of empirical studies, DHS surveys.	Yes	<i>Absenteeism</i> <i>Grade repetition</i> <i>Dropping out</i> Differences in the patterns across the three countries
Bhargava, A. (2005).	Ethiopia	The National Survey of Prevalence and Characteristics of Orphans Ethiopia 01/02 Minnesota Multiphasic	Yes	Participation Participation before death sig. Predictor of participation afterwards

		Personality Inventory-2 (MMPI) ~n=1000 orphans		
Bicego, G., et al (2003).	Zim, Kenya, Tanz, Ghana, Niger	DHS surveys 1995-2000	Yes	<i>Correct grade level</i>
Case, A. & Ardington, C. (2005).	South Africa	Longitudinal data from a demographic surveillance area office. HSE surveys. ~20,000 children	Yes	<i>Enrolment</i> Years completed <i>Money spent</i> Effect independent of poverty
Case, A., et al (2004).	10 SSA-	19 DHS studies (Ghana, Kenya, Malawi, Moz, Namib, Niger, Tanz, Uganda, Zambia, Zimbabwe)	Yes	<i>Enrolment</i> Effect is worst when orphans live with non-relatives Effect independent of poverty
Chatterji, M., et al. (2005).	Rwanda Zambia	Survey <i>Zambia:</i> 496 primary caregivers 504 children 563 adolescents <i>Rwanda:</i> 570 primary caregivers 656 children 402 adolescents	No	<i>Enrolment</i> Compared orphans, children with chronically ill caregiver, and other children. No differences found. No controlling for confounding factors
Evans, D.K. & Miguel, E. (2007).	Kenya	7815 children with completed questionnaire data and parental mortality data	Yes	<i>Participation</i>
Kamali, A., et al (1996)	Uganda	Rural population cohort 10,000 people 52% under 15 yrs Demographic, socio-economic, serological	Yes	<i>Attendance</i> Greater effect at later age
Mishra, V., Arnold, F. et al. (2005).	Kenya	The 2003 KDHS. 9865 households. Population-based nationally-representative surveys link individual HIV test results with the behavioural, social and demographic indicators included in the survey.	Yes	<i>Attendance</i> HIV-infected parents = sig. Less likely to attend school Single, uninfected parent are worst off of everybody
Monasch, R. & Boerma, J.T. (2004).	40 SSA	23 MICS surveys 14 DHS surveys	Yes	<i>Attendance</i>
Nyamukapa, C.	Zimbabwe	First round data from	Yes	Completion rates

& Gregson, S. (2005).		Manicaland study. 8399 households. 2402 children of primary school completion age.		
Sharma, M.P. (2006).	Malawi	Longitudinal. 5 rounds between 2000 & 2004. 534 rural households.	Yes	<i>Dropping out</i> Living with single parent /grandparents = sig. Less likely to attend school than living with other relatives
Yamano, T. & Jayne, T.S. (2005).	Kenya	3-year panel of rural household surveys. 1266 households included in all 3 surveys.	Yes	<i>Attendance</i> Poverty sig. Effect

Table 7. School studies (n=15) summarized according to type of orphan (Maternal/Paternal/Double), gender (male/female) and findings

Study (date, place)	Negative effects by Type (Maternal, Paternal, Double)	Negative effect by Gender (M, F)	Nature of Control group?	Comments
Ainsworth et al (2005) Tanzania	M	F	Y Non-orphans	Enrolment Poverty has effect
Akresh (2004) Burkina Faso	-	-	Y Host siblings Non-fostered biological siblings	Enrolment Advantage for fostered and fostering children. No difference between orphans, host siblings and other fostered children
Bennell (2005) Review			Y Non-orphans	Absenteeism <i>Grade repetition</i> <i>Dropping out</i>
(Botswana)	M (<i>repeated grade</i>) M, D (<i>drop out</i>)	-		Double orphans sig. Better attendance
(Uganda)	P (<i>repeated grade</i>) M, D (<i>drop out</i>)	-		Double orphans sig. Better attendance

(Malawi)	P, D (<i>absenteeism</i>) D (<i>repeated grade</i>) P (<i>repeated grade</i>)	F M F		
Bhargava (2005) Ethiopia	M	F	Y? Non-AIDS orphans	<i>Participation</i> AIDS orphans sig. Better participation than non-AIDS orphans Income-generating work >for all orphans, reduced attendance 80%
Bicego et al (2003) 17 countries	M, D	-	Y Non-orphans	Correct grade level Younger orphans worst affected
Case & Ardington (2005) South Africa	M	No Diff.	Y Non-orphans in same household	<i>Enrolment</i> Years completed <i>Money spent</i>
Case et al (2004) 10 countries	D	No Diff.	Y Non orphans	Enrolment Older orphans worst affected Effect independent of poverty
Chatterji et al (2005) Zambia/Rwanda	-	-	Y Vulnerable children Other children	Enrolment
Evans and Miguel (2007) Kenya	M	No Diff.	Y Non-orphans	Participation
Kamali et al (1996) Uganda	-	-	Y Non-orphans	Attendance
Mishra et al (2005) Kenya	M, P	F	Y Children of HIV-+ve parents Children of HIV-ve	Attendance Double orphans sig. Better than M or P orphans
Monasch & Boerma (2004) Review	D	No Diff.	Y Non-orphans	Attendance No diff between M&P

Nyamukapa & Gregson (2005) Zimbabwe	M	M	Y Non-orphans	Completion rates Female paternal & double sig. <i>Better</i> than non-orphans
Sharma (2006) Malawi	-	F	Y Non-orphans	Dropping out Effect increases as grade level increases
Yamano and Jayne (2005)	-	F (before death) M (after death)	Y Children not experiencing adult mortality	Attendance Poverty sig. Effect

Thirteen of the 15 controlled studies identified a negative effect of orphanhood on at least one aspect of schooling. Control and comparison groups vary, and the age of the child/children may be a factor. Poverty is an overriding issue. Age appears to be a factor, but may be mediated by age cut off for free school provision and age-related caring duties within a household. It also appears that the gender of the child as well as the gender of the adult who has died has an important effect on outcome. As such studies should always keep a note on gender and policies should have specific gender related provision.

3.6 HIV nutrition and development

Current Policy

General policies on nutrition are available and vary. Few are integrated with HIV policies.

Key Findings

Systematic data is needed. The specific nutritional requirements for sick children are often poorly provided for. Adverse outcomes from malnutrition are noted, however developmental catch-up from improved nutrition is possible.

Family Considerations

An integrated approach to nutrition provision, poverty and HIV would be an advantage. Nutritional needs are crucial for children's development and growth, and nutrition is affected by HIV on many levels, including via household livelihoods and food security (see Drimie, 2005).

Good nutrition in childhood is a key factor in healthy development, and there is a wide and robust literature on adverse outcomes for malnourished children. Outcomes include short stature and poorer educational attainment (e.g. Alderman, Hoddinott & Kinsey, 2006), long-term cognitive and motor function impairment (e.g. Liu et al, 2003; Grantham-McGregor et al, 2000), and long-term behavioural problems (Grantham-McGregor et al, 2000). Such deficits give children a lesser chance to lead a productive life, with lower earning capabilities and higher birth complications (Bridge et al, 2006).

Evidence from countries outside Africa shows that orphans may be at risk for poorer nutrition and health. Fisher and colleagues (1997) studied Romanian orphanage children adopted to Canada. They found that 85% of children had a reported medical condition at adoption, and while these greatly improved over the following 3 years, adopted children still had significantly more medical problems than other children. Several authors have found that at least half of post-institutionalised children fall below the 5th percentile for weight and height (Morison et al, 1995; Benoit et al, 1996; Rutter and the ERA Study Team, 1998) and these delays persist up to 3 years after adoption (Rutter and the ERA Study Team, 1998; Chugani et al, 2001). A review by MacLean (2003) identifies that evidence consistently shows that institutionalised orphans are more likely to be malnourished, small and in poorer health.

The situation for orphans in Africa is exacerbated by extreme poverty, long-standing food insecurity and under-nutrition, and the AIDS epidemic. Both orphans and other vulnerable children (such as those in AIDS-affected households) may be at an increased risk for poor health and nutrition because they are more likely to be extremely poor, may receive less care, and may themselves be HIV infected (Watts et al, 2007). However, the evidence is equivocal as to whether orphans and other vulnerable children (OVC) are at a significant disadvantage compared with non-orphaned children: Many recent studies have failed to find any difference between the nutritional and health status of these two groups (Bridge et al, 2006; Chatterji et al, 2005; Crampin et al, 2003; Lindblade et al, 2003; Masmas et al, 2004a; Mishra et al, 2005; Panpanich et al, 1999; Sarker et al, 2005). Rivers et al (2004) analyzed 13 DHS, 17 MICS II, and 6 UNICEF surveys and 6 C-SAFE/WFP datasets, covering a large proportion of sub-Saharan African countries. After controlling for a number of potential confounders, including age differences and

remaining parents in or outside the household, the authors found no difference between the nutritional and health status of orphans compared with non-orphans.

This growing body of evidence is strengthened by associated findings for both nutritional and health measures. For example, in cross-sectional study of approximately 1000 orphans in Ethiopia (Bhargava, 2005) the author found no significant difference in whether food was distributed unequally in orphan households compared with non-orphan households, and in Malawi, malnutrition was not associated with the length of orphans' stay with extended family (Panpanich et al, 1999). Two studies found no difference in the health seeking behaviours of orphans and vulnerable children and non-orphans (Bridge et al, 2006; Sarker et al, 2005), while Panpanich and colleagues (1999) found that illness was actually reported more frequently in non-orphans, when comparing them with both village orphans and non-orphans. A study conducted in 1991 in the same district as that studied by Bridge et al (2006) did conversely find that children from AIDS affected households did have a significantly lower nutritional status compared to other children in the community (Mugisha, 1993). However, it has been suggested that the pervasive nature of poverty and the AIDS crisis means that all children in a community are now equally affected by poor nutrition and health (c.f. the Ripple Effect, Barnett & Whiteside (2002) as cited in Bridge et al, 2006). For example, Bridge and colleagues (2006) found that stunting rates were extremely high in Uganda at 54% and rising quickly, with no difference between orphans and non-orphans, despite Uganda's adequate food supplies. The effect was worst in Western Uganda, where the AIDS crisis is also worst.

However, some current evidence still points towards poorer health and nutritional outcomes for orphaned or vulnerable children. A large cross-sectional study of over 30,000 children in Zimbabwe found that orphans and vulnerable children were more likely than non-orphans to have recently had diarrhoea or an acute respiratory infection, and were more likely to be stunted or underweight (Watts et al, 2007). Furthermore, and contrary to the 'Ripple Effect' suggestion, the authors adjusted the results for the effects of extreme poverty and found that orphans and vulnerable children remained at a significantly greater risk for chronic malnutrition. The authors suggest that a mechanism such as stigma might contribute to this differential in health status and that further research should aim to investigate such mechanisms.

Other studies provide some support for this conclusion. For example, despite overall measures suggesting no difference between orphans and vulnerable children and non-orphans, Lindblade and colleagues did find that wasting (weight for height, <-2 z scores) was significantly higher in orphans, particularly paternal orphans and those who lost apparent over a year ago. In contrast to the finding of Panpanich et al (1999), orphans in Uganda were ill significantly more often than non-orphans in the past fortnight (Sarker et al, 2005) and length of disease episodes were found to be significantly greater in children from AIDS affected homes (Bridge et al, 2006).

The story for orphans living in orphanages rather than in communities is rather more mixed. Few studies have investigated children in Africa, but Panpanich et al (1999) found that orphanage children over 5 were less stunted and wasted than both non-orphans and village orphans. Although younger orphanage children were more likely than the other two groups to be undernourished and stunted, older orphanage children had the best nutrition of all three groups. More information on duration of stay might help to explain this pattern, but it is possible that young children admitted to orphanages are nutritionally disadvantaged from their previous community environment, and only the worst off are admitted to care. Indeed, food variety, quantity and stability in Malawian orphanages are superior to that in foster homes (Zimmerman, 2005; Panpanich et al, 1999). However, conversely, Rivers et al (2004) found that children in orphanages in Malawi and Jamaica were nutritionally worse off than those in households.

At the extreme end of health status, orphans (defined here as maternal orphans) are more likely to die than non-orphans, particularly if aged under 2 years (Masmas et al, 2004b). Children of HIV+ mothers are more likely to die than those of HIV- mothers, which may be due to both direct (vertical transmission) and indirect mechanisms (Crampin et al, 2003). This finding is in contrast to that of Kamali et al (1996) who controlled for HIV+ orphans, since seropositivity rates are higher among orphans than non-orphans, and found no significant difference between the mortality of orphans and non-orphans.

A mixed picture

The equivocal evidence on the health and nutritional status of orphans and vulnerable children in Africa may be due to a number of factors. While most studies endeavoured to control for confounding factors, there is little consistency: for example, most failed to control for poverty and for parental or child HIV infection. Potential differences between different groups of orphans might be obscured, and overall differences might be dampened, by failing to control for such variables. Illustrating this, in comparing the difference between AIDS orphans and non-AIDS orphans, Bhargava (2005) found that the number of days that children were critically ill was more for AIDS orphans, and that a lower proportion of AIDS orphans reported their feeding conditions in foster care were satisfactory. Similarly, it is apparent that we cannot draw conclusions on all African countries from results from one. Chatterji and colleagues (2005) conducted a study of over 2000 children in both Rwanda and Zambia, investigating the differences between orphans, non-orphans with a chronically ill parent/caregiver, and other children. Their results indicated that in both Rwanda and Zambia lower proportions of orphans and children with an ill parent have indicators of good health. However, whilst in Rwanda orphans and vulnerable children were found to have a lower food intake than other children, no difference between the three groups was found in Zambia.

The study of Rivers et al (2004) clearly demonstrates the need to control for a variety of factors. In addition to analyzing results by country and age, the authors also coded children into 9 different categories based on their parental status. Among their findings was the result that fostered children whose parents were still alive but not living with them were significantly better off than all other groups of children in terms of anthropometry. Similarly, another study investigated the impact of having HIV-infected parents still together versus having a single uninfected mother (Mishra et al, 2005). Children of HIV infected parents were more likely to be underweight and wasted and less likely to receive treatment for diarrhoea than those of non-infected parents, but children of non-infected single mothers were the worst off overall in terms of nutrition and schooling. However, the association of poor health and nutrition with mother's HIV status is not always observed (Crampin et al, 2003). Unfortunately, with the exception of Rivers et al (2004) and Lindblade et al (2003), the vast majority of literature on orphans and vulnerable children in Africa does not clearly define what is meant by the term

'orphan' (Sherr et al, 2008), let alone investigate the differential effects between such groups as maternal, paternal and double orphans, and those with absent but living parents. 'Vulnerable children' are similarly ill-defined. Clarification of which outcomes relate to which groups of children will help to disentangle the mixed evidence on health and nutrition. It is clear that distinguishing between various groups of orphaned and vulnerable children is a key consideration for future research.

Fourteen studies on HIV Children and Nutrition were identified with control groups and empirical data. These studies are summarized below clearly setting out nutritional effects when these were observed. Ten studies recorded no nutritional effects in comparison to control groups, while four studies noted such effects. However most of the studies themselves (12/14) did not control for child HIV status, let alone parental HIV status.

Table 8. Nutrition and HIV

Study author	Country	Sample	Negative Nutrition/ Health effect (Yes/No)	Was Child HIV Status controlled for (Yes/No)
Bhargava, A. (2005).	Ethiopia	The National Survey of Prevalence & Characteristics of Orphans in Ethiopia (2001-02). ~1000 orphans had complete details Non-orphans and Non-AIDS orphans controls	No	No (But parent HIV status controlled for)
Bridge, A. et al. (2006).	Uganda	Cross-sectional, questionnaire and anthropometric measures. 205 homes sampled Children in AIDS-affected homes vs. children in non-AIDS-affected homes	No	No
Chatterji, M., et al. (2005)..	Rwanda & Zambia	Survey Zambia: 496 primary caregivers 504 children 563 adolescents Rwanda: 570 primary caregivers 656 children	Yes	No

		402 adolescents Orphans Children with a chronically ill caregiver Other children		
Crampin, A.C., et al. (2003).	Malawi	Population survey 1106 children included Non-orphans control group	No (Yes – for mortality of children of HIV-positive mothers)	No (But Parental HIV status controlled for)
Kamali, A., et al (1996).	Uganda	Rural population cohort 10,000 people 52% under 15 yrs Demographic, socio-economic, serological surveys Non-orphan controls	No (Mortality)	Yes
Lindblade, K.A., et al (2003).	Kenya	Cross-sectional survey and examination, 1999 with follow up in 2000 1347 children at baseline, 78.3% follow up. Non-orphan controls	No	No
Masmas, T.N., et al. (2004a).	Guinea-Bissau	~1100 interviews (300 case children, 800 non-orphan controls)	No	No
Masmas, T.N., et al (2004b).	Guinea-Bissau	~1100 interviews (300 case children, 800 non-orphan controls)	Yes (Mortality)	No
Mishra, V., Arnold, F. et al. (2005).	Kenya	The 2003 KDHS. 9865 households. One of the first population-based nationally representative surveys to link individual HIV test results with the behavioural, social and demographic indicators included in the survey. Non-orphaned, non-fostered controls	No	No (But parental HIV status controlled for)
Panpanich, R., et al (1999)..	Malawi	Cross-sectional study 76 orphanage children 137 village orphans 80 village non-orphans	No (Between village orphans and non-orphans)	No (17% of orphanage children only were tested for)

				HIV. 3 were HIV+)
Rivers, J., et al (2004).	Botswana Uganda Malawi	Analysis of: 30 DHS and MICS II surveys 2 Sub-national UNICEF surveys 6 C-SAFE/WFP Non-orphan controls	No	No
Ryder, et al . (1994).	Zaire	466 HIV+ women, their children and the fathers 606 HIV- women, their children and the fathers	No	Yes
Sarker, M., et al (2005).	Uganda	Cross-sectional survey 241 orphans 278 non-orphan controls	No	No
Watts, H., et al (2007).	Zimbabwe	Analysis of data from ~30,000 children Non-orphan controls	Yes	No

3.7 Bereavement and child development

Current Policy

There are few specific policies concerning bereavement and handling for children generally, let alone within the HIV provision.

Key Findings

Bereavement literature is mostly handled by categorising the child as bereaved (orphaned in some form), or by measuring the length of time since bereavement, subsequent care arrangements and impact on developmental and outcome factors. Very little emotional and mental health is studied and thus findings to inform policy and provision are limited.

Family Considerations

The importance of the carer in child development is paramount and a family approach would necessitate the study and provision in the event of bereavement. Fully functioning families need mental health resources and care and this would be prioritised in research and policy.

A child's parents and primary carers have a fundamental influence on their healthy development. The loss of one or both parents as a child is therefore likely to negatively affect the child in a number of different ways, such as the potential loss of residential and caregiver stability, and increased risk of poverty (Richter, 2004). However, the bereavement may also adversely affect children's mental health – have to take account of who the child lives with e.g. in Africa, children may be reared by grandparents because either or both mother and father are migrant workers who the child only sees every few months. A comprehensive review by Dowdney (2000) identifies a variety of psychological effects of parental death in children. In the short term, children frequently suffer feelings of sadness, confusion, despair and distress. The review found that children may even experience mild depression in the year following the death, but that more serious psychiatric disorders are rare and certainly not inevitable. However, non-specific emotional and behavioural disturbance were common, and characterised by symptoms such as anxiety, depressive symptoms, and angry outbursts. For example, teachers rated bereaved children as having significantly more emotional and behavioural problems, being more anxious and depressed, and having more attention difficulties (Dowdney et al, 1999). Similarly, a review by Tremblay and Israel (1998) found that children who experience parental death are more likely to have behavioural problems. In the long term, these children were also more likely to suffer adult depression. Bereavement may be complicated by the cause of parental death being AIDS (Siegel and Gorey, 1994).

In a large longitudinal study, Rotherham-Borus and colleagues (2005, 2006) investigated the adjustment of adolescents of parents living with HIV at 3 and 6 years from baseline. Parental death by three years predicted more sexual risk behaviours and reduced positive expectations for adulthood. A follow-up article also identified a significant association between parental death and depression, which was worse for older adolescents (Lee et al, 2007). Adolescents of PWH also had high rates of lifetime and recent anxiety disorders, where lifetime depressive disorders were associated with parental bereavement, prior traumatic exposure, and being female (Lester et al, 2006). Conversely, Forehand et al (1999) did not find an increase in children's psychosocial adjustment problems between the six months prior to and six months after the death of their mother from AIDS. However, the small sample size and short follow-up period may limit this conclusion, and further, the lack of problem *increase* may have masked

the consistently higher number of difficulties faced by children with a mother with AIDS.

Tremblay and Israel (1998) conclude from their review of the literature that parental death makes a child vulnerable to psychological difficulties, rather than causing these problems directly. A number of factors have been found to mediate the association between parental death and mental and behavioural outcome. For example, the highest rates of disturbance are found in children from less stable backgrounds (Dowdney, 2000). Other risk factors include poor family relationships and communication, negative influence from role models, stressful life events, low self-esteem and traumatic death circumstances (Christ & Christ, 2006; Lee et al, 2007, Dowdney, 2000). Conversely, protective factors include a competent remaining caregiver, higher SES, peer acceptance, and the opportunity to talk openly about the deceased (Christ & Christ, 2006). More broadly, strong parent-child relationships before and after death, stability of family circumstances, and availability of social support exert a protective effect (Tremblay & Israel, 1998; Lee et al, 2007). Rotherham-Borus and colleagues (2006) observed parent-child bonding (PWH) at baseline was associated with less later emotional distress, less sexual risk taking and greater expectations for the future. They also found that their randomised controlled trialled family intervention had significant indirect and direct protective effects against substance use over 6 years. Wolchik, Tein, Sandler and Ayers (2006) propose both a cross-sectional model and a longitudinal model to describe the influence of stressors and caregiver-child relationship quality on the psychological outcome of bereaved children at three time periods. The authors found that stressors, mediated by fear of abandonment, but not the quality of the parent-child relationship, affects subsequent mental health.

An African perspective

These risk and protective factors are likely to have important implications for African AIDS orphans. For example, these children are surrounded by poverty, face disruptions and a lack of social support services, and often experience caregiver and residential instability following a potentially traumatic illness and death from AIDS. Furthermore, many African cultures discourage talking about death to children, meaning orphans may never get to discuss their feelings, and even not be told that their parent has died This is

not universally true – Vuyiswa will also address this. The research on this topic to date has been shamefully ethnocentric. Italians and other southern Europeans also tend not to discuss death openly, practices which also pertain in parts of the East (Wood et al, 2006). Understandably, efforts to support orphans have been concentrated on meeting their physical and material needs following their parents' death – again this is not necessarily true – there are accounts of family members showing a child who has lost a parent additional care and affection to mitigate the sorrow felt by the child. Research has largely neglected to investigate the psychological effects of being orphaned by the AIDS epidemic in Africa; evidence from developed countries, whilst offering some insight, cannot be generalized to the unique African contexts. Since one third of the world's orphans are sub-Saharan African AIDS orphans, and the number of orphaned children from AIDS is likely to be 5.7 million by 2015 (Cluver and Gardner, 2006), understanding how bereavement is affecting these children is vitally important to anticipate short and long term consequences for both individuals and whole communities.

A large cross-sectional study (n=11,904) of young people in South Africa found the prevalence of parental death was 27.3% (3% with both parents deceased). After controlling for socio-demographic factors, parental death was associated with HIV positive status in females and, in males, with having recent unprotected sex (Operario et al, 2007). Similarly, Gregson and colleagues (2005) found that orphans and vulnerable young women in Zimbabwe had a higher prevalence of HIV infection, had more STI symptoms, were more likely to have had a teenage pregnancy, and were less likely to have received any secondary education. This is a very good argument for adopting a family approach, as HIV/AIDS clusters in families (for all kinds of reasons, with both intrinsic and extrinsic risk, just as it clusters in communities for the same reasons).

It is conceivable that this relationship might be mediated by mental health state: indeed, Shrier and colleagues (2001) found that depressive symptoms in adolescents were associated with condom non-use and a higher risk of having an STI. Of the few studies to investigate the effect of bereavement and orphanhood in Africa on mental health outcome, there is some consensus that orphans are more likely to have adverse outcomes. A qualitative study by Sengendo and Nambi (1997) identified feelings of loss of hope, sadness and helplessness in children whose parents were sick or died, and anger and depression in those adopted. Children living with widowed fathers or alone

were significantly more depressed than other children. In more recent research, after controlling for background factors, Atwine and colleagues (2005) found orphans had higher levels of anxiety and depression than controls. Higher depression levels were associated with smaller household sizes; the authors postulate that fewer household members might mean less emotional support, highlighting the importance of the extended family system and support over and above material aid. Similarly, after controlling for stressors, AIDS orphans had significantly more internalising problems than non-orphans, and were more likely to have considered suicide in the past year (Makame et al, 2002). Bhargava (2005) also found that orphans scored lower on the emotional and social adjustment scales than non-orphans, and girls fared worst. Furthermore AIDS orphans had lower scores on social adjustment compared with non-AIDS orphans. However, conversely, Cluver and Gardner (2006) did not find that orphans had higher levels of self-reported emotional and behavioural problems compared with non-orphans. Orphans did however have remarkably high levels of PTSD (Post Traumatic Stress Disorder) symptoms (non-orphans were not assessed on these items), more somatic physical symptoms, and were less likely to have a good friend. Cluver and Gardner (2007) present a clear graphic description of potential protective and risk factors for emotional and behavioural problems, based on their qualitative study of children orphaned by AIDS in Cape Town. The authors identify a number of factors already reported in the literature like those above, but place emphasis on the risk factors of multiple bereavement, and stigma both in the home and among children's peers. These two factors are discussed below.

Culture is an important factor in the response to illness and death. Death is considered taboo in Africa, and especially an inappropriate topic for children (Stein, 2003). Any communication about a death is minimal and often through indirect language and euphemism (Wood et al, 2006), or belief that the dead stay with us as ancestors and therefore don't really die. Similarly, the stigma surrounding HIV/AIDS means it is also often referred to indirectly, compounding the problem when the death is from AIDS (Sherr). Even in Western societies, families may be wary of disclosing the reason for illness and death to children, given the stigma they could face (Stein, 2003). An AIDS death in Africa may also be seen as a 'bad' death and spoken about even less (Wood et al, 2006). Indeed, children may not even be told that their parent has died (Wood et al, 2006). Existing studies indicate a tendency for African children to have internalised

symptoms of grief (Wood et al, 2006; Makame et al, 2002). Orphans report a higher frequency of somatic physical symptoms (such as stomach-aches, headaches) than non-orphans (Cluver & Gardner, 2006), so it is possible that orphans express psychological distress through somatic symptoms. Somatisation may be a culturally appropriate expression of emotional distress (Stein, 2003); silence is interpreted as a sign of strength (Wood et al, 2006). However, quiet children are seen as those coping well, which may mean caregivers do not provide adequate emotional support (Wood et al, 2006). It is clearly important to be aware of differences in coping style: Western practices may not be most beneficial to all cultures. However, teenagers in Zimbabwe express desire to be able to talk openly about deaths from AIDS in their community (Wood et al, 2006). Children and adolescents may feel betrayed if not told about their parent's illness or death, and this breach of trust might damage the familial relationships that are so important for emotional support. There is some consensus that it is more beneficial to support children through illness and death, rather than protect them from it because the most frightening thing for children is to "...know something unspoken is terribly wrong" (Stein, 2003). If bereaved children do experience any outward grieving, it may be further restricted due to the increasing number and frequency of deaths in AIDS affected communities. Makame and colleagues (2002) suggest that less and less time for grieving is being 'allocated' as death becomes more commonplace.

Multiple Bereavements

The AIDS epidemic now means many children face multiple bereavements in their family, therefore possibly incurring recurrent psychological damage (Makame et al, 2002). Wood et al (2006) also suggest that vulnerability of children created by parental/familial death lies on a continuum, where it increases as more people die. In addition to multiple bereavements, children may start to grieve before their parents or family members actually die. Forehand et al (1999) note that their failure to find an increase in psychosocial adjustment problems in children following maternal death may have been due to the high levels of difficulties present at the baseline assessment, prior to the mother's death. Rotherham-Borus et al (2005) found that the emotional distress of adolescents of PWH was highest over a year before their parent died, and actually

declined as the death approached and afterwards. Depression, however, did rise immediately following the death, remaining elevated for about a year.

Sixteen studies examining bereavement and HIV have been identified in the literature. There is very little consistency across studies in order to provide a comprehensive overview. For the purpose of this review, two analyses of the 16 studies were undertaken. Firstly a qualitative coding was carried out where all studies were inspected and coded for protective or risk factors identified. These are then summarized in the table below. This will provide a state of the art analysis of the factors currently under study by HIV researchers. From this list standardized and systematic concepts can be explored in future research.

Table 10. Protective and Risk factors identified in the literature

Protective factors	Risk factors
Competent remaining caregiver Higher SES	Residential and caregiver instability Remaining parental psychological morbidity
Peer acceptance Opportunity to talk openly about the deceased	Traumatic parental death Poor family relationships
Strong parent-child relationships Stability of family circumstances	Poor family communication Negative influence from role models
Availability of social support	Stressful life events
Secondary education	Low self esteem
Attending school	Fear of abandonment
Access to medical care	Stigma
	Poverty
	Multiple bereavement
	Family conflict
	Lack of medical care

Table 11 below then summarises the 16 studies in terms of the measures utilized and findings. Twelve of the 16 studies record some form of emotional impact of bereavement. A variety of measures are used, so comparisons are difficult. The most commonly used item in outcome is the Child Behaviour Checklist. The literature also points to the fact that with children, variation can be found depending on which adult completes the inventory. Thus there is a complete lack of consistency of measurement, let alone standardized methodology in recording data and defining populations. It can be seen that very little work directly on bereavement is undertaken and thus there is a

paucity of detailed understanding of the mental health ramifications and needs in this area, despite the high profile presence of AIDS related bereavement for young children.

Table 11. Key studies investigating the psychological/emotional and behavioural effects of parental death/bereavement on children

Study	Country	Sample (age)	Emotional impact (Y/N) and how measured	Behavioural Impact (Y/N) and how measured
Atwine, B., Cantor-Graae, E., Bajunirwe, F. (2005).	Uganda	11-15yrs 123 case children 110 controls	Y Beck Youth Inventories of Emotional and Social Impairment (BYI)	-
Bhargava, A. (2005).	Ethiopia	10 yrs + ~1000 children (half AIDS orphans, half non-AIDS orphans)	Y Minnesota Multiphasic Personality Inventory-2 (MMPI)	-
Cluver, L. & Gardner, F. (2006).	South Africa	6-19 yrs 30 case/30 matched controls	N SDQ IES-8	N SDQ IES-8
Dowdney, L., et al (1999).	UK	2-16 yrs 16 boys 29 girls Matched controls	Y Parents child behaviour checklist Teachers report form	Y Parents child behaviour checklist Teachers report form
Forehand, R. et al (1999).	USA	6-11 yrs 20 case children 40 controls	N Interview Child report GPA CBCL CDI	-
Gregson S, et al. (2005).	Zimbabwe	15-18 yrs 1523 teenagers population survey	-	Y Census data Individual interview
Lee, S., et al (2007).	USA	11-18 yrs 206 adolescents with PWH	Y Brief Symptom Inventory	Y Self-report

		intervention group 207 adolescents with PWH no intervention control group		
Lester, P., et al. (2006).	USA	12-18 yrs 423 adolescents Intervention vs. no intervention	Y BSI Self report CIDI	-
Makame, V., et al (2002).	Tanzania	10-14 yrs 41 orphans 41 matched controls	Y 21 items adapted from Rand Mental Health and Beck Depression inventories Questionnaire	-
Operario, D., et al. (2007)	South Africa	15-24 yrs 11,904 cases	-	Y Survey Oral fluid samples
Rotherham-Borus, et al. (2006).	USA	11-18 yrs Longitudinal 6 year study 288 adolescents participated at all three stages (Intervention vs. no intervention)	Y BSI Self-report Interview	Y Self-report Interview
Rotherham-Borus, et al (2005).	USA	11-18 yrs Longitudinal 6 year study 414 adolescents	Y Brief Symptom Inventory (BSI; for mental distress) Dealing-with-Illness Questionnaire	Y Self-report of problem behaviours CJS reports
Sengendo, J. & Nambi, J. (1997).	Uganda	172 Orphans (6-20yrs) 24 controls	Y In-depth interview Focus-groups Depression scale (non-validated)	-
Tremblay, G.C., & Israel, A.C. (1998).	USA	Literature review	Y Literature review	Y Literature review
Wolchik, S.A., et al (2006).	USA	Mean age 11.46	Y General Life Events	Y General Life

		339 cases Longitudinal	<p>schedule for Children Child Report of Parenting Behaviour Inventory (CRPBI) (Among others)</p> <p>Coping efficacy scale Self Perception for Children scale Fear of Abandonment scale</p> <p>CBCL CDI R-CMAS Youth Self-report</p>	<p>Events schedule for Children Child Report of Parenting Behaviour Inventory (CRPBI) (Among others)</p> <p>Coping efficacy scale Self Perception for Children scale Fear of Abandonment scale</p> <p>CBCL CDI R-CMAS Youth Self- report</p>
Wood, K., Chase, E. & Aggleton, P. (2006).	Zimbabwe	7-22 yrs 56 orphans and vulnerable children 41 adults	Y Qualitative: household case studies and semi- structured interviews (Not empirical data)	Y Qualitative: household case studies and semi- structured interviews (Not empirical data)

The evidence available indicates that the mental health of children in Africa may be at particular risk as a result of multiple bereavements. In addition to the negative psychological effects of the material and physical strains that the death of a parent presents, their culture may restrict African children from grieving effectively. The result is high levels of psycho-emotional difficulties in childhood, possibly continuing into adulthood, which in turn are associated with negative health behaviours. Future interventions might focus on provision for mental health support for children around grief and loss and providing systematic tools and measurement to improve the evidence base. As individual level mental health services are unlikely to reach many children in countries where neither education nor health care reaches everyone, perhaps our

recommendation should be for public education on how to help children, and mental health services for the most disturbed children

3.8 Cognitive development and child HIV

Current Policy

There is very little policy in terms of cognitive development and provision.

Key Findings

The systematic review reveals the complexity of understanding cognitive implications of HIV on the child. Infected children may have virus effects, environmental effects or a complex mixture. Affected children may have virus exposure effects and environmental effects. Uninfected and non-exposed children may have environmental effects.

Family Considerations

A family approach would underline the importance of understanding and providing input for cognitive development in the presence of HIV. There is a clear need for international agreement on key indicators and for these to be included in child studies.

Systematic review of cognitive development and child HIV

HIV can permeate the blood brain barrier. There has been good reason to study the impact of HIV on cognitive development of children infected or exposed to the virus. However, the concept is complex, given that cognitive development is not purely biologically determined, and environmental factors contribute considerably to such development. Furthermore the presence of HIV in a child often signifies family infection and cognitive outcomes may be affected by a multitude of factors including parental health, illness or death, child health, illness, opportunistic infections, drug treatment side effects, economic effects, separation, emotional state, isolation, stigma, availability of schooling, stress, trauma and bereavement. The environment within which the child develops may be altered directly or indirectly as a result of HIV in the family. Parental illness and death may dramatically impact on the child's experience, nurturing and learning environment. Constant absences and family trauma have a role to play. It is well established in the literature (Downey et al, Sherr et al, Stein et al) that parental

mood may affect child development. HIV infection, single and multiple bereavement may all affect parental mood and thus add additional burdens to the progress of development for the child.

Child development literature has clearly established that infant development is intricately bound up with subsequent development and capabilities. Early experiences affects subsequent internalizing, maturation, achievement and emotional qualities. The literature has shown relationships between development and parental mood (depression, anxiety, eating disorders, mental illness), social state (poverty, access to education, school and home socio-economic conditions) and health (access to schooling, immunization, health care and nutrition). HIV and AIDS can dramatically affect all these levels – and more. The clearest distinction needs to be made between children who are infected with HIV themselves and those who are exposed to the virus in utero, but are not affected, those who are uninfected but live within a family where HIV is present, and the uninfected who may not HIV in their direct family, but live in areas of high prevalence where HIV touches their everyday lives. At each of these levels, the multiple ways in which young children are affected accumulate. It is probably true to say that in societies where seroprevalence is high (most of sub-Saharan Africa for example), all children are affected by HIV/AIDS – the question is simply one of degree. The entry point of HIV/AIDS and the extent to which young children are affected may differ, as may the responses and capacities (Sherr 2005).

From the beginning of the AIDS epidemic neurological problems in children have been reported and were predicted to have overwhelming consequences (Armstrong 1993). Belman et al (1988) and Burns (1992) showed in early work that there were neurological implications of HIV infection for young children. Data from autopsy revealed that 90 percent of children showed neurological abnormalities. Yet the mechanisms and implications of such relationships are difficult to establish. Autopsy data also does not allow one to differentiate between findings, which are caused by HIV pathogenesis or are treatment-related. Scarmato et al (1996) described different patterns of atrophy in the brains of children with AIDS. This suggests that the disease may affect the tissue in some way. Brouwers et al (1995) studied computed tomographic brain-scan abnormalities in 87 children and rated abnormalities with intelligence test and social emotional behaviour ratings. Calcifications were associated with greater delays in neurocognitive

development. In an examination of the European data describing the first presenting AIDS defining illness (Sherr 1997) significantly more children are diagnosed with neurological impairment (2.32%) than adolescents (.56%).

The true incidence, range and content of childhood neurological problems associated with HIV is unclear with some writers claiming it is underreported (Turner 1993) while others show a widely divergent range depending on the place where studies are carried out. In the USA rates reported are as high as 90% compared to European children where rates recorded are closer to 20-30% (Msellati et al 1993, European Collaborative Study 1996). There are a wide range of methodological problems associated with the description and diagnosis of neurological problems in children with HIV. Some cohort studies are drawn from clinic populations, which disproportionately include those with impairment who have been diagnosed with HIV disease on the appearance of neurological symptoms. The more sophisticated studies compare HIV positive children born to HIV positive mothers and use either HIV negative children born to positive mothers, or HIV negative siblings as comparison groups. Such studies are more reliable given they account for the potential developmental impact of an ill, dying or absent mother and developmental disruption of family illness and disease management. Other methodological problems surround some of the major risks associated with maternal infection in the first place. For example, in Europe (Spain, France, Italy and Portugal specifically), maternal drug use is a major route of HIV infection and may itself affect development. Other categories of maternal infection, such as migration from areas of high prevalence, may also affect cognitive development in young children if such parents are ill, migrants, isolated from wider family, economically disadvantaged and having a home (and first) language which differs from the test centre and the test items. The range of test inventories used is problematic in itself, but often involves translation and translocation and therefore validity and accurate normative data are questionable.

Few studies have designs that are sufficiently sophisticated to control for problems such as low birthweight and premature delivery, which are factors commonly associated with HIV positive children and also well noted in the literature as possible contributors to developmental differences. Among some cohorts, there are multiple problems and it is difficult to differentiate these and the extent to which they contribute to findings. Examples include children with HIV and Haemophilia (Hilgartner et al 1993) or parental

drug use. Some studies use retrospective analysis (Mok et al 1996), and very few report that the assessors are blind to the sero-status of the child.

No systematic review has currently been undertaken to explore and collate the neuropsychological effects of HIV on child development. There are a number of review papers focusing specifically on psychological distress (Lwin and Melvin 2001, Futterman et al 2000, Roberts 2000, Pontrelli et al 1999, Nichols and Abrams 2002). The limitations with the review papers to date is the difficulty in coordinating measures of development, the absence and presence of control groups in studies, the wide age range of children studied, and the inclusion or exclusion of children who initially test HIV positive but sero-revert. Such children are HIV exposed, but not HIV positive and they may differ from children who are not HIV exposed.

This systematic review examines papers on neuro-cognitive development and HIV in children and provides a detailed review, exploring place, findings and limitations. By taking account of the limitations it is possible determine the overall direction of studies as well as understanding the literature gaps and the direction of future research.

This review examines research on cognitive development and HIV in children and provides a detailed review, exploring place, findings and limitations.

Method

A systematic search was conducted utilizing medline, social science abstracts and research data bases. The key words for research included “child/children, HIV/AIDS, development, cognitive development, neurological”. The search time frame included published works from 1988 to beginning of 2007. The key electronic databases used were Medline and Psychinfo. Studies had to meet the following inclusion criteria to be included in the overview:-

1. Include children with HIV infection
2. Carry out at least one systematic measure of cognitive functioning
3. Report on place of study, sample size, age of children and outcome measures.

Results

From this search, 54 studies were identified and included in the systematic review. In terms of understanding measures and outcomes, all studies are included. For conclusions only those with control groups are examined. .

Where are the studies based and can the findings generalize?

The data is highly North American biased (63%), and the interaction of drug use and HIV cannot be discounted from North American settings. Thus it may be difficult to generalize findings to non-drug using populations. Europe (France n=2, Italy n=3, UK n=1, Hungary n=1) account for 13% of the studies and there are only 7 from Africa and 2 from South America where the vast majority of children with HIV are found.

Table 12. Geographic source of study

North America	USA	34
	Canada	2
Europe	France	2
	Italy	3
	United Kingdom	1
	Hungary	1
Africa	Uganda	3
	Cote d'Ivoire	1
	South Africa	1
	Zaire	1
	Rwanda	1
South America	Brazil	2
Asia	India	1
	Thailand	1

Comparison/control groups

Of the 54 studies identified, 13 (24%) had no control groups. Within this set, one compared early and late infection, and another mild versus severe illness in children. Ten studies (18.5%) utilized three groups, HIV positive, HIV negative and sero-reverters (children born to HIV positive mothers, who did not have established HIV infection on follow up). Eighteen studies (33%) compared HIV positive children with HIV negative

children. Various levels of control in the selection of HIV negative children were reported. A further 10 studies (18.5%) compared HIV positive children to those who sero-reverted only.

Thus comparison and control groups vary from none, HIV exposed but uninfected controls and population controls (such as siblings or peers). Methodological problems abound. Some groups are drawn from clinic samples resulting in an overrepresentation of illness and the severe end of the spectrum – risking finding more problems than in a community sample. The various comparison groups also show that effect is not restricted to virus exposure, and family factors, environmental factors and treatment factors all have a part to play.

Table 13. Studies on the effect of HIV on Cognitive Development

Study	Place	Sample Size (N)	Cases & controls	Findings		
				No difference	HIV detrimental effect	Mixed findings
1. Aylward et al (1992)	USA	96 infants aged between 5.5 & 24 months.	- 12 HIV+ - 45 HIV- - 39 seroreverters		X	
2. Bachanas P et al (2001)	USA	68 children aged 6-16 & their caregivers.	- 36 HIV+ - 32 demographically matched HIV-		X	
3. Bagenda et al (2006)	Uganda	107 children aged 6-12 years	- 28 HIV + - 42 seroreverters - 37 HIV -			X
4. Bell et al (1997)	Côte d'Ivoire	Autopsy of 155 children	- 78 HIV+ - 77 frequency matched HIV-		X	
5. Belman et al (1996)	USA	Prospective study of 247 children from birth to 2 years.	- 32 HIV+ - 99 seroreverters - 116 controls born to uninfected women		X	
6. Bisiacchi et al (2000)	Italy	42 children	- 29 HIV+ - 13 seroreverters		X	

7. Blanchette et al (2001)	Canada	50 infants.	25 HIV+ vertically transmitted 25 seroreverters		X	
8. Blanchette et al (2002)	Canada	25 school-aged children	- 14 HIV+ vertically transmitted. - 11 HIV- siblings of HIV+ children.		X	
9. Bobat et al (2001)	South Africa	141 children followed-up from birth to childhood	- 48 HIV+ - 93 seroreverters		X	
10. Boivin et al 1995	Zaire	50 children aged under 2 years.	- 14 HIV+ - 20 Reverters - 16 Control		X	
11. Bruck I et al (2001)	Brazil	150 children	- 43 HIV+ - 40 Reverters - 67 Controls		X	
12. Chase et al (1995)	USA	51 children from birth to 30 months.	24 HIV + 27 Reverters		X	
13. Chase et al (2000)	USA	421 infants <30 months	- 77 HIV + - 344 HIV -		X	
14. Cohen et al (1991)	USA	48 children who had received neonatal blood transfusions.	- 15 HIV+ - 33 HIV-		X	
15. Coplan et al (1998)	USA	Children aged 6 weeks to 45 months.	- 9 HIV+ - 69 seropositive but HIV-		X	
16. Coscia et al (2001)	USA	43 caregivers and their children aged 2.5 to 12 years.	No controls		X	
17. Depas et al (1995)	France	8 HIV + children aged 2.5 to 5.5 years.	No controls		X	
18. Drotar et al (1997)	Uganda	436 infants assessed from 6-24 months	- 79 HIV + - 241 seroreverters - 116 HIV -			
19. Esposito et al (1999)	Italy	117	39 HIV- seroreverter 78 Controls with no family history of HIV		X	

20. Fishkin et al (2000)	USA	80 children aged 3 to 5.	40 HIV + 40 HIV- matched on ethnicity, age, sex & prenatal drug exposure.			X
21. Foster et al (2006)	UK	62 children <3yrs	No controls 31 HIV+ mild disease 31 HIV+ severe disease		X	
22. Fowler et al (2000)	USA	595	114 HIV+ 481 HIV-		X	
23. Frank E et al (1997)	USA	27 HIV+ children aged 6 to 17 years.	No controls		X	
24. Gay et al (1995)	USA	Prospective study: 126 infants born to HIV+, non-drug using mothers.	28 HIV+ 98 seroreverters		X	
25. Grover et al (2007)	India	Random sampling of 441 6-11 yr olds	140 HIV infected 301 controls		X	
26. Havens J et al (1994)	USA	60 school-aged children. Sample consisted of non-referred children exposed to maternal drug addiction.	- 26 HIV+ - 14 Reverters - 20 Controls (non-HIV exposed)		X	
27. Hooper S et al (1993)	USA	46 male children aged 4 to 19 with hemophilia.	- 18 HIV+ - 20 HIV-	X		
28. Hooper et al (1997)	USA	58 male adolescents with hemophilia.	25 HIV+ 33 HIV-	X		
29. Knight et al (2000)	USA	45 infants ages 3-30 months; 67% were prenatally drug-exposed.	20 HIV+ 25 HIV- seroreverters		X	

30. Kollar et al (2004)	Hungary	9 HIV+	No controls			
31. Levenson et al (1992)	USA	49 school-aged children.	41 HIV+ 8 seroreverters		X	
32. Lindsey et al (2006)	USA	1204 infants from 1-3 yrs	1059 HIV- 145 HIV+		X	
33. Llorente et al (2003)	USA	157 HIV+ infants			X	
34. Lobato et al (1995)	USA	1811 HIV Infected children	No controls			
35. Macmillan et al (2001)	USA	1094 infants	- 147 HIV+ - 383 Drug exposed		X	
36. Martin et al (2006)	USA	41 children	No controls		X	
37. McKinney r & Robertson J (1993)	USA	170 aged not less than 25 ½ months. All referred for HIV antibody status.	- 62 HIV+ - 108 HIV-		X	
38. Mellins et al (2003)	USA	307 children	- 96 HIV+ - 211 seroreverters		X	
39. Mialky et al (2001)	USA	85 school-age patients	No controls		X	
40. Msellati et al (1993)	Rwanda	436 children (6, 12, 18 & 24 months old)	- 218 born to HIV+ mother (50 HIV+) - 218 born to HIV- mother		X	
41. Ndugwe et al (1997)	Uganda	436	79 HIV+ 241 HIV- 116 HIV- born to HIV- mother		X	
42. Nozyce et al (1994)	USA	181	- 21 HIV+ - 65 Reverters - 95 HIV- born to HIV- mothers (controls)		X	
43. Nozyce et al (2005)	USA	274 children aged 2-17yrs	No controls – all HIV+		X	
44. Piazza et al (1995)	Italy	138 children	- 58 HIV+ - 80 Seroreverters		X	

45. Pilowsky et al (2001)	USA	73 children of injection drug users, aged 4 to 12 years.	Groups unclear		X	
46. Pollack et al (1996)	USA	65 infants born to women at risk of HIV.	- HIV+ - seroreverters - HIV- born to HIV- mothers		X	
47. Scafidi et al (1997)	USA	48	- HIV exposed children - not HIV exposed children		X	
48. Smith et al (2000)	USA	114 HIV+	- early infected infants - late infected infants		X	
49. Smith et al (2006)	USA	117 HIV+	- 33 HIV+ class C symptoms - 84 HIV+ not class C - 422 HIV-			X
50. Tahan et al (2006)	Brazil	88 HIV+	- 84 HIV- (seroreverters)		X	
51. Tardieu et al (1995)	France	33 HIV+			X	
52. Vanprapar et al (2005)	Thailand	16 HIV+ aged 12-34 months	No controls	X		
53. Watkins et al (2000)	USA	7 to 19 year old males with hemophilia.	- 66 HIV- - 79 HIV+ well - 28 HIV+ ill		X	
54. Whitt et al (1993)	USA	63 children & adolescents with hemophilia	25 HIV+ 38 HIV-			X

Three studies found no effect of HIV on cognitive outcomes. Four studies had mixed effects (some negative and some positive). The remaining (81%) studies all recorded a detrimental effect of HIV on outcome measures, whatever they were.

Measurement tools currently under use

The measurements used vary, but in general show a consistent finding of subtle effects, but less validation of gross effects of HIV on the developing child. One problem is the

wide range of measurements used, the variation between standardized and study specific measures and the lack of internationally agreed instruments. The table below sets out the measures used to highlight this problem.

Table 14. Measures used to assess cognitive functioning of children with HIV

Study	Place	Formal measures	Other measures	Gender Identified
Aylward et al (1992)	USA	Bayley Scales of Infant Development	Mental Development Index & Psychomotor Development Index	No (abstract only)
Bachanas P et al (2001)	USA	Psychological adjustment; health locus of control; coping	Caregiver completed measures of their own & child's psychological adjustment	No
Bagenda et al (2006)	Uganda	Kaufman Assessment Battery (K-ABC) Wide Range Achievement (WRAT-3) Various sensory tests (5 domains)	Health status – height and weight	No
Bell et al (1997)	Côte d'Ivoire	Various: neuropathology		No (abstract only)
Belman et al (1996)	USA	Serial neurologic examinations (8 domains) & head circumference measures		No
Bisiacchi et al (2000)	Italy	Neuropsychological tests, e.g. executive function impairments, memory & visuo-praxic deficits.		28 males 14 females
Blanchette et al (2001)	Canada	Bayley Scales of Infant Development	CT scans	29 males 22 females
Blanchette et al (2002)	Canada	Intelligence, language; memory; motor development; cognitive dev.; academic achievement.		No (abstract only)

Bobat et al (2001)	South Africa	Physical measures, e.g. weight-for-age and length-for-age.		No
Boivin et al 1995	Zaire	Denver Developmental Screening Test	Kaufman Assessment Battery for Children & Early Childhood Screening Profiles.	No
Bruck I et al (2001)	Brazil	Denver Developmental Screening Test; Clinical Adaptive Test/Clinical Linguistic & Auditory Milestone Scale.		42% boys 58% girls No difference found
Chase et al (1995)	USA	Bayley Scales of Infant Development		No (abstract only)
Chase et al (2000)	USA	Bayley Scales of Infant Development – Mental and Psychomotor Scales	Maternal HIV history	No
Cohen et al (1991)	USA	Neuropsychological development, e.g. school achievement, motor speed, visual scanning & cognitive flexibility.		50% each sex
Coplan et al (1998)	USA	Language development: Mean Early Language Milestone Scale; ELM-2 Global Language; Bayley scales of Infant Development; McCarthy Scales		36% male 42% female
Coscia et al (2001)	USA	Cognitive functioning: IQ		19 boys 24 girls
Depas et al (1995)	France	Cerebral function		3 boys 5 girls
Drotar et al (1997)	Uganda	Bayley Scales of Infant Development – Mental and Psychomotor Scales Fagen test of Infant Intelligence	Neurological assessments Care giver-child interaction observed	No

Esposito et al (1999)	Italy	Child behaviour checklist; Gittleman version of Conners' Parent Questionnaire; Children's Manifest Anxiety Scale and Children's Depression Inventory.		No (abstract only)
Fishkin et al (2000)	USA	Wechsler Preschool & Primary Scale of Intelligence-Revised.		No
Foster et al (2006)	UK	Neurological assessment – Gross motor function classification Developmental assessment – Bayley Index – psychomotor and mental scales	Health status and occipitofrontal head circumference	No
Fowler et al (2000)	USA	Bayley Scales; Cognitive and Motor Growth		
Frank E et al (1997)	USA	Cognitive functioning, e.g. visuomotor skills and IQ.		No (abstract only)
Gay et al (1995)	USA	Bayley Scales of Infant Development		No
Grover et al (2007)	India	The Child Behaviour Checklist		No
Havens J et al (1994)	USA	Psychiatric diagnosis interview and behaviour checklist		No (abstract only)
Hooper S et al (1993)	USA	Child Behaviour Checklist		46 male only
Hooper et al (1997)	USA	Neuropsychological measurement, e.g. motor, attention, language, visual processing, memory and IQ.		No (abstract only)
Knight et al (2000)	USA	Bayley scales of Infant development and a neurological examination.		24 male 21 female No difference
Kollar et al (2003)	Hungary	Neurological examinations	EEG	7 boys 2 girls
Levenson et al (1992)	USA	McCarthy Scales of Children's Abilities and Neurologic Examination for Children.		No significant differences in gender

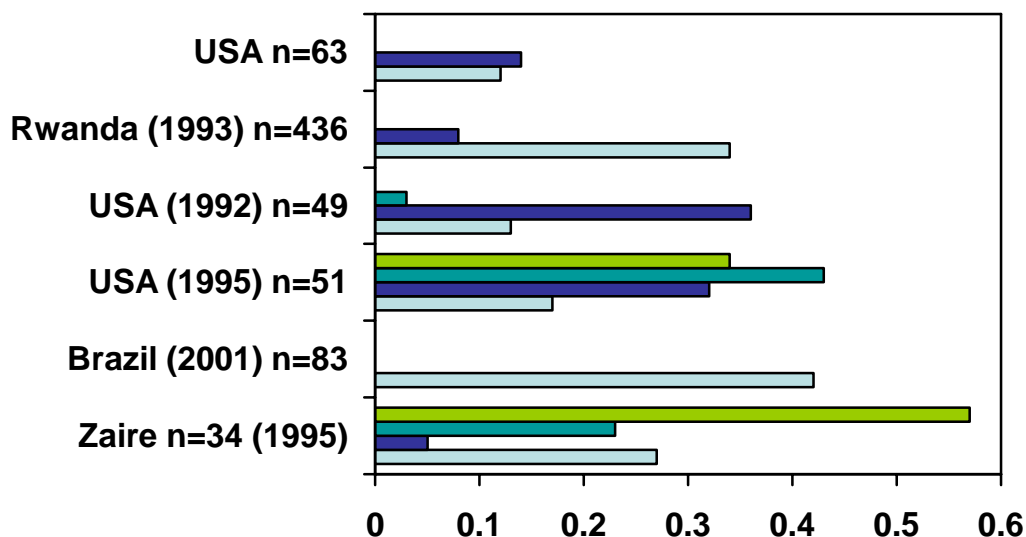
Lindsey et al (2006)	USA	Bayley Scales of Infant Development – 1 st and 2 nd edition		No
Llorente et al (2003)	USA	Bayley Scales of Infant Development, Neurological markers and mortality		85 male 72 females
Lobato et al (1995)	USA	Diagnosis of encephalopathy		50% each sex
Macmillan et al (2001)	USA	Bayley Scales of Infant Development		50% each sex
Martin et al (2006)	USA	Wechsler Intelligence Scales	CT brain scans CD4 cell counts	No
McKinney r & Robertson J (1993)	USA	Physical: weight-for-age and length-for-age.		No (abstract only)
Mellins et al (2003)	USA	Behavioural rating scale		50% each sex Males significantly higher hyperactivity, impulsivity and learning difficulty scores Females higher anxiety scores
Mialky et al (2001)	USA	School related issues		No (abstract only)
Msellati et al (1993)	Rwanda	Neurodevelopment examination, e.g. gross motor development, fine motor development, language acquisition & social contacts.		No
Ndugwe et al (1997)	Uganda	Neurological battery and social interactions.		
Nozyce et al (1994)	USA	Bayley Scales of Infant Development; Kent Scoring Adaptation		No (abstract only)
Nozyce et al (2005)	USA	Bayley Scales of Infant Development II	Wechsler Intelligence Scales Neuroimaging	No
Piazza et al (1995)	Italy	Griffiths Scales; Wisc-R Scale		No (abstract only)

Pilowsky et al (2001)	USA	Internalising & Externalising symptoms.		42 boys 31 girls
Pollack et al (1996)	USA	Cognitive motor development; growth.		No
Scafidi et al (1997)	USA	Brazelton Neonatal Behavioural Assessment Scale		No
Smith et al (2000)	USA	Neurological functioning		No
Smith et al (2006)	USA	McCarthy Scales of Children's Abilities		No
Tahan et al (2006)	Brazil	CAT/CLAMS DENVER I & II	CT scans	No
Tardieu et al (1995)	France	School achievement; cognitive abilities; fine motor & language skills; emotional adaptation.		No
Vanprapar et al (2005)	Thailand	Cognitive Adaptive Test/ Clinical Linguistic and Auditory Milestone Scale		No
Watkins et al (2000)	USA	Continuous Performance Test; Span of Apprehension – attention deficit measures		Male participants only
Whitt et al (1993)	USA	Neuropsychological functioning (motor, language, memory, attention, visual processing & problem solving).		No (abstract only)

Effect size

There are strong arguments against calculating overall effect sizes given the mixed measures used and the fact that some studies compared HIV positive with seroreverters while others compared both of these two with uninfected/unexposed control groups while yet another group compared HIV positive with uninfected/unexposed control groups only. Some groups had subanalysis components according to severity of disease and presence of drug levels in the infant which further compounded the comparability of studies. Figure 11 sets out effect sizes for studies where means and standard deviations were provided. For three group design studies, only data from HIV+ve compared to control uninfected groups are included.

Figure 11. Effect size (SD) for controlled studies on outcomes for HIV+ve and control children.



Effect sizes were calculated from data reported in 6 studies meeting criteria of reported means and standard deviation, presence of control group and standardised cognitive measure from studies from USA, (59,73,87) Rwanda (78), Brazil (57) and Zaire (56). For three group designs HIV+ve and uninfected control groups only are included.

Limitations of the studies

The studies clearly show detrimental effects on child development of HIV infection. The systematic overview also shows a number of methodological problems with the international body of work. Studies are US focused and very little can be generalized to African settings. Policy for African children based on findings from the USA may be inaccurately focused. Within the studies there are mixed control and comparison groups. Furthermore the overview includes studies from across the age span. Very few take account of gender despite the fact that gender is well studied in terms of developmental outcomes. This is more curious given that some studies do report the gender distribution, but fail to analyse their data according to gender. There is no control in the studies for fine tuned factors such as timing of infection (i.e. does it matter if infection is early in pregnancy, at delivery or through breast feeding or other means?)

The mixture of measures and the lack of standardized inventories and key concepts makes the literature difficult to navigate.

Lastly there is little understanding of the mechanism of effect. Thus interventions to ameliorate, reduce or remove such effects are unclear. The data would point out the gap. In order to examine the potential benefit of antiretroviral treatment on outcome, standardized measures need to be incorporated into treatment evaluation. The effect of HIV exposure for the group who are classified as seroreverters is difficult to understand. It may be that there is some residual virus effect, or it may be that a seroreverting child is a surrogate marker for parental infection, and this points to the effects on development of an ill or HIV affected mother/father or family members generally.

Future policy needs to urgently address the developmental needs of children infected and affected by HIV. Clear global indicators need to be agreed and incorporated into treatment and development studies to ensure that studies can be compared. The existing evidence base clearly indicates a detrimental effect of HIV on child development, and this needs to form an urgent agenda item.

Effect of Parental Depression and Illness on Child development

Current Policy

Very few policies include measurement, provision, monitoring and recording of mental health state.

Key Findings

The general literature cautions that parental depression and other mental health states is associated with child development outcomes. Adult studies show clearly that mental health states are associated with HIV infection.

Family Considerations

A family approach would ensure that wellbeing and ability to parent was addressed and provided for.

A wealth of evidence from developed countries indicates a negative influence of post-partum depression (PPD) on child development. In a series of papers based on a large controlled cohort study, Murray and colleagues (1992, 1993, 1996) found PPD was associated with poorer cognitive performance. For example, children of mothers with PPD were more likely to fail the object concept task at both 9 and 18 months old, and boys had poorer cognitive development in general at 18 months. Hay and Kumar (1995) also found that mother's PPD was associated with children's lower GCI scores at age 4. Longer term effects have also been identified: lower IQ at age 11 years is significantly associated with mother's PPD at age 3 months (Hay et al, 2001), independent of parent IQ, SES, later maternal mental health problems, behavioural problems and breastfeeding. Other studies have found no association between PPD and child cognitive development (e.g. Kurstjens & Wolke, 2001; Brennan et al, 2000), however, they MAY have not controlled for such a variety of confounding factors. Behavioural effects have also been demonstrated, although evidence is more equivocal than for cognitive outcomes. Some studies have found PPD to be associated with children's internalizing problems (Alpern & Lyons-Ruth, 1993), externalizing difficulties (Essex et al, 2001) and behavioural disturbance independent of SES, attachment status and parental conflict (Murray et al, 1999). Hay and colleagues (2003) found that mother's PPD increased the risk of violent behaviour in the child at age 11. However, others suggest only concurrent depression is related to behavioural problems (Phillips & O'Hara, 1991; Brennan et al, 2000). A review by Grace and colleagues (2003) identified a small but significant effect of PPD on cognitive development, and a smaller one on behavioural development. The authors suggest is most likely these effects are mediated by parenting and interaction difficulties associated with PPD (see also Lovejoy et al, 2000; Murray et al, 1993, 1996), and that they interact with SES, where adversity increases the risk of a poor outcome. This clearly has important implications for children in impoverished African families.

Paternal depression is, belatedly, also being studied (Ramchandani et al 2005, Sherr et al 2006, Elgar et al 2007), with consistent findings of association between paternal depression and child development. Clearly HIV affects both mothers and fathers and the findings are relevant in the HIV field.

Most research has concentrated on mental outcomes of PPD on the child, because the majority has taken place in developed countries where physical health is less of a

concern. However, some recent studies have highlighted a link between PPD and physical development in low-income countries. PPD has been significantly associated with low weight and length at age 6-8 weeks for a cohort babies in Goa, India (Patel et al, 2003). In addition, the case babies had worse mental development scores than controls, even after controlling for birth weight and maternal education. Rahman and colleagues (2004) found that both prenatal and postnatal maternal depression predicted poorer growth and a greater risk of problems in infants in rural Pakistan at 2, 6 and 12 months. Others have found an interactive effect between child malnutrition, low birth weight, low maternal IQ and PPD (Anoop et al, 2004). Tomlinson et al (2006) examined the relationship between PPD and weight in South Africa. The authors failed to find an association at either 2 months or 18 months, after adjusting for birth weight. However, they suggest that the large loss to follow up of 33% caused by the mobility of the community and the low prevalence of PPD at 18 months may have affected the power of their study. In a previous paper, the authors found PPD was associated with insensitive engagement with the infant (Cooper et al, 1999), supporting similar findings from developed countries that have led researchers to propose parent interaction style as a mediating variable between PPD and child mental development. It is possible that adverse developmental outcomes were present but not measured in this sample.

There is a paucity of research into PPD in Africa. Recent studies estimate the prevalence of PPD to be between 18.6% in Nigeria (Abiodun et al, 2006) and 34.7% in South Africa (Cooper et al, 1999). Risk factors for African women may be similar to Western risk factors, for example younger age and being primigravida (Abiodun et al, 2006), unplanned pregnancy and unemployment (Rochat et al, 2006) and poor emotional and practical support from a partner (Cooper et al, 1999). In addition, relationships between mothers and mother-in-laws and baby gender have been identified as risk factors (Abiodun et al, 2006). Future research may also focus on the relationship between spirituality/religiosity, PPD and HIV given the strong religious traditions in many African communities; high religiosity among low-income African American women was related to higher risk of PPD (Jesse et al, 2005), whereas high spirituality among Puerto Rican women with HIV/AIDS in New York City was associated with lower risk of depression (Simoni & Ortiz, 2003). Studies investigating specifically PPD in the context of HIV are particularly rare. One study found the prevalence of PPD among women being tested for HIV for the first time in South Africa was high, at 41% (Rochat et al, 2006).

These women did not know their serostatus when assessed for depression. The authors identified that PPD was associated with a perception that access to healthcare would be limited following a HIV diagnosis, and suggest that this may prevent HIV-positive women using critical healthcare services during and after pregnancy. Whilst 41% of this sample were subsequently diagnosed HIV positive, it was not the same 41% previously diagnosed with PPD, and there was no association between HIV and PPD (Rochat et al, 2006). This finding is supported by research in Zambia that found neither pre nor post-partum mental health was associated with HIV status or with post-partum physical health, although the latter two were significantly related. Research from elsewhere however does suggest that being HIV positive may increase the risk of post-partum psychological difficulties. Depressive symptoms and HIV-related worries were common amongst HIV positive new mothers in Bangkok, and HIV-related worry was associated with a HIV-infected baby and undisclosed HIV status (Bennetts et al, 1999). Unfortunately there was no control group to confirm if higher depression was associated with HIV status. Larrabee and colleagues (1996) report a lower perceived quality of life in HIV-positive women post-partum compared with HIV-negative women, indicated by reported decrease in cognitive and social function at 6 months post-partum. There were no studies found that investigated rates of PPD in mothers widowed by AIDS, and the effects of this on the orphaned children. However, given that a lack of support from a partner (Cooper et al, 1999) has been identified as a risk factor for PPD, it is certainly possible that the risk is increased, especially given the numerous other problems faced by these women.

Clearly, with the prevalence of both HIV and PPD running high in African countries, and the known child development outcomes of PPD, further research into the relationship between these factors is needed in the current African context. There may be complications in this research. There is some consensus that post-partum depression may not differ in any identifiable way from depression women experience at any other time (e.g. Najman et al, 2000; Whiffen, 1992) and this has been confirmed in Africa (Storkey, 2006). However, treating PPD as a separate disorder may be useful in relation to health consequences for both mothers and children. This may be especially true in HIV positive mothers given the health behaviours required at this time (e.g. not breastfeeding, antiretroviral therapy). Many women in Africa only discover their serostatus when routinely tested during pregnancy. They therefore may be more likely to

be depressed postnatally following their diagnosis due to shock, reduced social support and stigma stemming from the diagnosis, or because of complications with healthcare. It may be that onset of depression following HIV diagnosis, and its effects on the child, are qualitatively different to post-partum depression in women previously diagnosed with HIV, or those uninfected. It is also likely that factors involved with HIV, such as deaths in the family, will be related to mother's mental health and the child's development. Another issue to be investigated might be the mental health of lone fathers to newborn babies. In a situation where many mothers are dying from AIDS, could fathers be at risk for 'post-partum' depression, and how might this affect the child's development? Clearly there are many issues to be untangled before appropriate programs can be implemented to promote the healthy development of children in Africa.

4. Gender evidence in programme/evidence focus

Current Policy

International prevalence, treatment and statistics are gathered for children. No gender specific policies are in place.

Key Findings

WHO data, global data and roll out treatment data do not seem to systematically disaggregate information by the gender of the child. Not all studies examine gender in outcome. Many studies note gender, but do not analyse their findings according to gender (which would be easy to do given gender data appears to be collected). When gender data is analysed, there are distinctive gender effects on schooling, HIV transmission (in utero and via breast feeding), and psychosocial and cognitive outcomes.

Family Considerations

A family approach would ensure that the individual characteristics, roles and gender of all family members were studied. The data would recommend that Global statistics on children are routinely disaggregated by gender, and that studies examine findings according to gender. It appears that it is not only the gender of the child that is important, but gender issues related to the carer (such as gender of parent who has died, gender of caretakers).

4.1 Gender and children

Strengthening families relies on complete family focus – including all members and all genders. Our society is bisected by gender. Within families, as within societies, gender affects both the biological susceptibility to HIV/AIDS as well as the social susceptibility as gender roles, gender differences and gender responses intertwine with daily life. Much has been written about gender discrimination (Bhana et al 2006) and how, from an early age, roles and role differentiation may adversely affect children generally, and girls specifically. Clearly the family plays a key role in the construction of gender, gender roles, gender expectations and gender differences. Within this construction, there are a number of aspects of gender related issues that are highly relevant to the study of HIV/AIDS, programme provision and research questions. They relate to gender differences in provision (within families and within the social network), social and cultural constructs of gender which disadvantage or disempower sub groups, violence, sexual attitudes, gender selection and preferential treatment in terms of schooling, nutrition, attention and provision, female genital mutilation and marriage.

On the other hand there are gender issues associated with care, caring roles, and the imbalance of impact on a young child with disruption of care according to the gender of both the child and the caregiver.

Given these important aspects of gender, it is probably vital that research, policy and programme provision take gender into account from the earliest stages. This is done as a matter of course with the adult literature, yet is piecemeal within the children's literature. This section will summarise findings in relation to gender. The table sets out studies and clarifies gender measurement (child and parent) as well as findings. Overall the literature is difficult to navigate with clear answers given that there is:-

- A neglect of fathers and a focus on mothers in the pregnancy programmes.
- Often incomplete gender data in studies of early childhood. This is most notable for babies, where the term infant supplants male and female infants, and the literature is often not disaggregated by gender.

- Even when gender is recorded, the data is often not analysed according to gender and thus data for evidence based understanding (such as in transmission, infection, outcome) is not clarified by gender.
- There appears to be a lack of gender focus in programmatic provision for young children.

4.2 Findings on gender and HIV in children

Global Statistics

International Data on prevalence, treatment, HIV testing and need is disaggregated by gender for adults, and in some cases for adolescents. For both these groups clear differences in trends are visible, triggering gender related policy and strategy. For example the age distribution of infection in young adults varies by gender (young women have higher rates of infection than young men). However, the international statistics (WHO and UNAIDS) do not disaggregate any global HIV statistics for young children by gender. This is clearly a limitation, could easily be addressed and there is good empirical evidence to suggest that gender differences among young children are as important as gender differences in adolescents and adults. At the recent JLIA meeting in Boston (October 2007) Peter Piot, Director of UNAIDS, reported that there was no intention to disaggregate the children's data by gender. This is a short-sighted approach.

Risk of infection

Sex differences have been noted in disease progression in children (European Collaborative Study (ECS) 2003, ECS 2002). Two studies have demonstrated that girls were at elevated risk of infection in mother to child transmission (Gaabiano et al 1992, Temmerman et al 1995). Thorne et al (2004) studied 3231 mother child pairs (1684 boys (52%) and 1547 girls (47.9%). Of these, 10.6% (350 children – 48.6% boys and 51.4% girls) were infected. Associations between gender and mother to child transmission in multivariable regression (allowing for antiretroviral treatment, cesarean section and maternal CD4 cell count) girls were 1.5 times at greater risk of HIV infection relative to boys. When the data was examined according to mode of delivery (C Section or vaginal delivery) within C Section girls were twice as likely to be infected compared to boys.

Exclusive breast-feeding

Read et al (2003, cited in Thorne et al 2004), noted in a meta analysis of HIV postnatal transmission via breastfeeding that boys were at a significantly greater risk of HIV infection than girls. Feeding was also studied by Coovadia et al (2007) who monitored 1372 infants and found that of those who were HIV negative at six weeks, mixed breast and formula feeding was associated with increased HIV infection to the infant. In this study they reported on gender (49% Males, 49% females) and showed that gender played no part in transmission.

Treatment need

Treatment need, uptake, rollout, cotrimoxicol availability are all not recorded according to gender in global statistics. It would be crucial to know if there are any gender considerations in terms of treatment access and availability.

Adherence to treatment

Adherence is vital for efficacy in children (Simoni et al 2007), yet the majority of studies are not in resource poor settings, and cover a wide age range of children. In her review Simoni et al (2007) noted that gender was not a significant factor in treatment adherence in the few studies that examined gender as a variable.

Resistance

A systematic review (Arrive et al 2007) looked at all studies that examined nevirapine resistance in mothers and children. They identified 33 reports where “offspring” received nevirapine, of which 24 were excluded on methodological grounds. The 11 entered into a meta-analysis (covering 339 children) revealed that half the children who became infected despite NVP treatment developed resistance. No data on gender of the child was given. Yet in a developed country study (France), resistance defined as triple resistance (resistance to three classes of drugs) was seven times higher in boys than girls (Delalguere et al 2007). This dramatic finding would suggest an urgent need to examine resistance data by gender.

Schooling

Within the systematic review above, 15 studies on schooling and HIV children were identified with a control group. Of these 1 did not look at gender, 3 looked at the gender of parents only (not the child's gender), and 11 reported on child gender. Of these 11, 10 also gave parent gender.

Only 12 studies analysed the data by gender – be it child/adult or both. Six studies showed no gender differences on schooling outcome for the children. Five showed a female disadvantage on schooling in the presence of HIV in the family. Two studies showed a male disadvantage to school completion in the presence of HIV in the family. Clearly completion is not an issue if a child has already dropped out of school. Furthermore, 8 studies showed a differential affect on schooling according to the gender of the parent who had died of AIDS. The death of a mother was more commonly implicated in reduced school enrolment or dropout.

Nutrition

14 studies with control groups were identified looking at HIV issues for children according to nutrition issues. 11 provided child data (10 of these child and parent gender data). 1 did not provide gender data and 2 only provided parental gender data.

Of the 14, only 9 analyzed the data by gender (either child or parent or both). The majority of these (n=6) reported no gender effects on nutritional outcome measures for the child. Three studies that explored gender of parental death and its effect on child nutrition showed variation according to gender. They were mixed with two showing adverse effects associated with paternal loss, and one showing such effects associated with maternal death. Yet a number of studies also found no effect, depending on the control or comparison group used. It appears that nutrition generally is set against a backdrop of poverty and associated nutrition considerations.

Bereavement

15 controlled studies were identified where issues of HIV and bereavement among children were studied. Of these studies, 2 reported on the gender of parent only, one provided no gender data and 12 provided gender of child. 9 of those with child gender data, also provided parental gender data. Although all the controlled studies on children orphaned by HIV provided information on child gender, 5 did not provide analysis of the outcome data according to gender. In all, 13 studies analysed the data by gender (either child or parent). Bhargava et al (2005) showed a negative effect for females on emotional adjustment and social adjustment measures. Cluver et al (2006) found no gender differences. Dowdney et al (1999) reported male children had heightened negative effect on externalizing scores and total problem scores. Gregson et al (2005) noted that females were at increased risk of HIV infection, sexually transmitted infection symptoms and teenage pregnancy. Similarly Operario noted increased risk of HIV, commencement of sex and multiple partners in the preceding year for girls. Lee (2007) noted an increased risk of depression among males. However, Lester (2006) noted an increased risk of depression among females. Makame et al noted effects on internalizing problems for females. Rotherham Borus et al (2006) recorded that females were at increased risk of emotional distress, while males had heightened risk of substance abuse. Wolchik et al (2006) recorded female children with heightened negative effect on fear of abandonment, internalizing problems and self esteem.

Parental loss (Mother, Father or Both) was also analysed according to gender. Sengendo et al (1997) noted that maternal death was related to increased depression scores, while Gregson et al (2005), noted that maternal death was associated with poor reproductive health outcomes and secondary school interruption.

Mobility

Ford and Hosegood (2005) noted that female children were at an increased risk of residential mobility. In terms of parental gender, this study reports that there are no gender effects, but a generalized effect for orphans in terms of mobility.

Depression

The studies exclusively explore maternal postnatal depression. No study was found that examined paternal depression and its effect on child development in the HIV arena. This is a gap, given that the mental health effects of HIV diagnosis and illness are well documented in males.

Cognitive development

54 studies were examined according to gender variables on Cognitive outcomes. 21 studies provided data on gender, but only 6 (11%) analysed their data according to gender. All 6 of these had a control group. Five found no differences between boys and girls. One recorded that males scored significantly higher on measures of hyperactivity, impulsivity and learning difficulty scores. Females had higher anxiety scores. Five of these studies emanate from the USA and 1 from Brazil. Thus in terms of cognitive development there is no data for Africa where the vast majority of children are based. The dire gap of controlled studies exploring outcome variables for children according to gender needs to be urgently addressed..

Table 15 – Gender sub analysis on HIV and Children studies can be found in appendix 1.

5. A family approach - who should be studied?

Finally a family approach would suggest that data and perspectives are gathered from all key individuals within a family system. This means that an understanding of maternal issues should be matched with studies on paternal issues, grandparenting, siblings and extended family issues. The literature does not reflect this. Fathers are overlooked or neglected. Grandparent studies are few and far between. There is some, but relatively scant information on siblings – often gathered in the course of control groups in studies – but information in its own right. A family approach would underscore the importance of including these members in the research designs and the academic information and knowledge base.

Grandparents

Literature search generated 75 papers, of which 36 were relevant. 22 of these provided quantitative data, and 14 qualitative descriptions.

Search Words	Generated	Relevant	Quant	Qual	Explicitly refer to Grandparents aged over 50
“Grandmother HIV”	19	13	8	5	4
“Grandparent HIV”	12	6	3	3	1
“Older Caregiver HIV”	37	10	5	5	5
Extended Search	7	7	6	1	6
Total	75	36	22	14	16

Quantitative Outcomes	Qualitative Outcomes
<p>Many of the relevant quantitative studies were not specifically investigating grandparents, but looking at the changing patterns of child care in AIDS affected communities in general.</p> <p>It is difficult to estimate accurately numbers cared for by grandparents because studies are few and sample sizes are generally small. However, demographic data from 24 sub-Saharan countries show that 46% of adults over 60 years live with a grandchild, and 13.7% of households have a grandparent and grandchild but no adult parent. However the most common reason for this is that the parents are alive but living elsewhere. About 8% of older adults live with a grandchild who has at least one deceased parent. 1.7% older adults live with a double-orphaned grandchild.</p> <p>Households in South Africa with a woman over the age of 60 resident are twice as likely to have a fostered child living in the household and three times as likely to have an orphaned child in the household. In Uganda, 34% households had caregivers of AIDS orphans aged over 50, and 97.9% households headed by older people had on average 3 school-going orphaned children.</p>	<p>This is an understudied field.</p> <p>Grandparents, and particularly grandmothers, are taking on the role of parent to their grandchildren as their own adult children die of AIDS. Negative effects of this role exert on grandparents in several dimensions: economic, emotional, physical, and nutritional. Weak health infrastructure and poor resources already exacerbate these problems.</p> <p>For example, economic contributions of older and younger women to the household in terms of both productivity and childrearing are qualitatively and quantitatively different. Older women struggle to produce similar incomes to their adult children within the same time frames.</p> <p>Emotionally, older people may have to deal with resentment towards their adult children, bereavement, stigma, social isolation and the feeling of starting life over again. Older women report feeling overwhelmed with magnitude and multiplicity of tasks they have to perform.</p> <p>Assuming the role of younger adults may be detrimental to older women’s health. Physical health problems often reported in caregiving</p>

Care by grandparents is particularly true for double orphans: A large population study in Zimbabwe identified that 45.3% double orphans are cared for by grandparent, versus 12.9% of paternal orphans and 19.7% maternal orphans, and 8.7% non-orphans.

Maternal and double orphans in South Africa have higher likelihood of having their school fees paid for by a grandmother than paternal orphans - 36% / 37%. Only 37% of these grandmothers are aged under 60.

In Zimbabwe, 34% foster caregivers are aged over 60 vs. 4% of non-fostering caregivers. 15% were in their 70s or 80s.

53% fostering caregivers in Zimbabwe are grandmothers – twice as often maternal as paternal. 6% are grandfathers.

In the USA, 8% the caregiver was a grandparent: 47% were over 55, 25% were over 60 and 8% were over 70 years. Most were caring for more than one child.

Time spent by elderly parents on household chores rose following an adult death and participation in wage employment fell. Adult death primarily exerts a bad influence on health of elderly whilst an adult child is ill before their death. In Thailand, two thirds of adults with AIDS lived with a parent by the terminal stage. A parent, usually mother, acted as the main caregiver for about half, and for 70% a parent provided at least some care.

Total stress experience for both groups linked to grandchildren's perceived behavioural difficulty, and to limited instrumental support and emotional support for the part-timers. At least one chronic health problem reported in 18 people, two problems or more in 13 people. 15 had arthritis and 9 had hypertension.

Those who were sole caregivers had significantly more chronic health conditions, as did those looking after more than one child.

grandparents and stress is frequently reported. However, the relationship between health and stress in this instance is undocumented.

Poor health may be experienced prior to the death of the adult child, due to combined caregiving duties to grandchildren and an ill adult. Responsibility for day-to-day patient care falls primarily to elderly females, who report a higher rate of physical ailments than elderly males.

Grandfathers largely ignored in research

Children cared for by grandparents may be disadvantaged in several ways:

- Grandmothers less likely to be educated – poor feeding practices and inappropriate health seeking behaviour
- Grandparents reduced ability to earn money and produce food and have been robbed of their economic support mechanism (their children)
- They will die sooner than a healthy parent would, indeed their increased workload may precipitate this
- They are unable to learn traditional skills and practices from their grandparents as they are too busy trying to provide for the family
- Young girls missed school, sexually and physically abused, depressed. This maybe due to their lack of attention from the older women who are too busy.
- Orphans may be forced to drop out of school to help contribute financially.

Originally orphan care was the responsibility of the patrilineal kin, and paternal grandmothers have a powerful and multifaceted role within the extended family. However, grandmothers are often excluded from health education, their views ignored and looked upon disparagingly by hospital staff. Research has shown conversely that grandmothers are able to learn modern techniques and information to benefit younger women and that interventions should address this avenue.

One project reported in Uganda aims to equip grandparents who are caregivers of children affected by HIV/AIDS with skills in raising them and increase social networks.

6. Overall synthesis and discussion

HIV and AIDS have generated many national and international policies that have provided vehicles for prevention, care, response and reaction. There are some examples of creative thinking and provision that have benefited communities and children. The Global fund has revolutionized treatment for resource poor countries. The WHO 3x5 initiative catapulted inertia into action. Country National AIDS Councils have created policy think tanks and attempted to coordinate provision. However, piecemeal, add on, vertical and stand-alone policies and programme have created a disjointed and inadequate response to children affected by HIV to date. Although advances have been made, implementation is unacceptably hampered. It appears that the international and local efforts are now realigning their focus on children, but are sometimes at a loss as to how to proceed. Despite good will, there are entrenched approaches that may need a radical rethink. This overview has examined a number of existing strands of provision, policy, research and knowledge. It has highlighted the evidence base (or in most circumstances the lack of an evidence base). A number of issues emerge

A family approach which will serve children, will also serve the entire family well. The best HIV response to children is to help them avoid being infected in the first place. This means that the PMTCT and PMTCT+ programmes are vital and are a core element in the dialogue around children. Medicine may separate out “obstetrics” and “paediatrics”, but social science sees the family as a continuum. The roll out of treatment for prevention and care to both parents and infants is chronically slow and this does a disservice to children. The policies and programmes for such roll out are singular in approach. They focus on preventing HIV infection in the child and not at the robust health of the family. This approach is short-sighted.

If the family was seen as the unit of care, HIV testing policies would precede pregnancy as well. Family planning and termination clinics would be captured within this provision umbrella. HIV testing in pregnancy would be offered to both mother and father. When HIV is identified both infant prevention and parental treatment should be available. They are equally important.

Biomedical care treatment plans need to understand and incorporate mental health and emotional wellbeing as part of the integrated service if they are to provide adequately and appropriately for families. They need to understand the devastating emotional impact of HIV diagnosis. They need to exploit the HIV prevention opportunity for HIV negative and discordant couples. They need to provide early and accurate HIV status information on the infant to relieve anxiety and promote cohesion in the family. Strategies are ineffective if they are unaware of stigma, informed consent, gender interactions, power relationships, competencies and gaps.

For those infants who are infected with HIV, treatment should be available. This includes antiretroviral treatment, opportunistic infection prophylaxis, and good quality care. At a national level data needs to be gathered systematically for children as well as adults. Such data needs to be collected by gender to ensure that gender issues are understood. It is not possible to tailor provision in a gender sensitive way if the evidence base is not available.

HIV positive children represent the tip of the iceberg of HIV affected children. As all young children require protection and nurturing, HIV /AIDS serves to exacerbate the negative effects of poverty. Child development is best served with good quality family provision. When families are stretched support should be their right.

The evidence reviewed points to established effects on child development outcomes of HIV either directly or indirectly. Labelling of children as “AIDS Orphans” has been an unhelpful strategy. The focus on orphans and other vulnerable children needs to be balanced. Definition inaccuracy may hinder the understanding. From a family perspective a surviving parent is a cherished resource for a bereaved child. Orphan fears may result in a knee jerk return to institutions and stigma. The literature clearly points to the negative child development outcomes within institutions and would suggest that family based care, in its broadest sense, is the primary response.

A family-centred approach would also help to combat the problem of HIV/AIDS clustering in families, an issue supported by evidence showing that parental death is associated with HIV infection in adolescents, in addition to sexual risk behaviours and early pregnancy (Operario et al 2007; Gregson et al, 2005).

Family data is sorely lacking. Family definitions, like orphan definitions, need to be clear. Extended families, sibling ties, community kith and kin links and grandparents are all links within the competent family system. Evidence based understanding of their role, their needs and effective ways of reaching them is urgently required.

The evidence base for children is also sorely lacking. Good quality, evidence based policy can only emerge if sound evaluation, with sufficiently powered studies utilizing adequate methodologies and control groups are available. When such evidence is available, it is mostly Western data. It is complex to understand how culture and background factors interact and therefore it is difficult to generalize from some settings to others.

The evidence that does exist shows clearly:-

- Prevention of infant infection is possible
- Prevention of infant infection in the west has made dramatic advances. Prevention of infant infection in resource poor countries is inadequate
- Protection of maternal and paternal health to provide quality parenting for young children is inadequate
- Attention to emotional health in programmes and provision at the family level is lacking
- Treatment for children is inadequate, especially in relation to actual treatment provision for adults within the same setting.
- Monitoring of treatment in children in resource poor settings is inadequate and often does not incorporate psychosocial parameters.
- Barriers, such as child appropriate medications are now on the agenda. They are urgently needed.
- The family situation of young children experiencing bereavement is not clearly defined. Surviving parents are discounted when “Orphan” labels include children with a surviving parent.
- There are negative effects of parental death on child development outcomes.
- There are negative effects of multiple bereavement on child development outcomes.
- There are gender specific negative effects of bereavement (according to both the gender of the bereaved child and the gender of the deceased parent).
- HIV AIDS affects schooling, nutrition, mobility, bereavement, cognitive development and care.
- Resilience is not well studied or understood – yet the main response for young children to date has been lodged within families.
- Psychosocial wellbeing measures are difficult and complex. No agreed indicators exist that allow for cross comparisons of findings, or integration of psychosocial measures into broader biomedical studies.
- Cognitive effects of both those infected and those affected are recorded in the 54 studies to date.

- Focus should be broader than just the children with HIV infection. The use of seroreverting children in control/comparison groups also shows a level of affect.
- Parental physical state, as well as mental state has an important effect on early child development. HIV is known to be associated with an array of mental health burdens (anxiety, depression), social burdens (stigma, job loss, economic decline, isolation, rejection), relationship burdens (discordancy, relationship loss, barriers to formation of new relationships) and medical burdens (opportunistic infections, HIV disease, treatment side effects, and death). All these affect the family environment in which the child is reared.
- Quality care is good for child development. Family care is the preferred environment for children compared to institutionalized care.
- There is a paucity of data on fathers.
- Gender is known to play a role in development, yet it is inadequately studied and recorded in official statistics on young children.
- There seems to be a pronounced gender effect in HIV transmission (Girls are more likely to be infected in utero, boys are more likely to be infected post partum, boys are more likely to experience treatment resistance). The mechanisms are not understood.
- There is little accurate and reliable gender specific data on psychosocial outcomes. Girls are more at risk for sexual behavioural problems and schooling interruption.
- Gender data should be routinely collected on all interventions and trials.
- It is not sufficient to record gender, but results need to be analysed by gender.
- Policies that do not consider the family do a disservice to those they aim to help.

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