

WORKING PAPERS IN

Early Childhood Development

Young children and HIV/AIDS sub-series

34

HIV and young children:

*An annotated bibliography on
psychosocial perspectives*

Lorraine Sherr



About the paper

This paper is one of a dedicated 'Early Childhood and HIV/AIDS' sub-series of our long-standing 'Working Papers in ECD' series. The purpose of the sub-series is to generate work that responds to emerging needs, or that present information, experiences, ideas, and so on, to inform all those concerned with young children impacted by HIV/AIDS – including ourselves.

Papers will often be 'think pieces' deliberately produced quickly to reflect the fact that ideas, understandings and approaches are developing rapidly, and to share emerging lessons fast and efficiently.

Each is tightly focused and has a specific purpose. *HIV and young children: An annotated bibliography on psychosocial perspectives* is a companion to *Young children and HIV/AIDS: Mapping the field* (Bernard van Leer Working Paper 33), which offers a mapping of what studies show in this field at the moment. Largely drawn from a review of literature, and with a psychological slant, it also identifies gaps in knowledge and experience.

This annotated bibliography offers a practical guide to the content of the references which informed *Young children and HIV/AIDS: Mapping the field*. Its intention is to help readers who want to go deeper into the issues and topics raised to quickly find their way to the original sources.

As we present papers in this sub-series, we do so because we believe that they have something useful to offer. We do not claim they are necessarily exhaustive or balanced in their coverage, nor will we always agree with what they say. In the case of this paper, we believe that it will help those engaged

in young children and HIV/AIDS to readily access information, ideas and experiences to inform their understandings.

The author, Professor Lorraine Sherr, would like to acknowledge the team who assisted with all aspects of this annotated bibliography, with special mention of the diligence and input of Hannah Fenton.

All the references in this bibliography, which was completed in mid-2004, are accompanied by an abstract or brief description of the published articles or websites. Items are clustered according to a number of areas, which are listed in alphabetical order on the contents pages. Within each area, abstracts are organised alphabetically by first-author name. Key biomedical elements are briefly covered, and the psychosocial aspects of HIV and young children and their families are discussed in more detail.

A large number of reviews, position papers, policy guidance and practical papers exist on various aspects of children who are affected by HIV. A list of some of them is also included, together with the website addresses for the organisations which produced them.

Please note: The publications listed in the bibliography cannot be ordered through the Bernard van Leer Foundation. Original articles will be available from publishers. Abstracts for many articles are also available on the internet.

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By Lorraine Sherr

February 2005

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Acronyms

AIDS	<i>acquired immunodeficiency syndrome</i>
CNS	<i>central nervous system</i>
HAART	<i>highly active antiretroviral therapy</i>
HIV	<i>human immunodeficiency virus</i>
HIV-1	<i>human immunodeficiency virus type 1</i>
HIV-2	<i>human immunodeficiency virus type 2</i>
HIV-	<i>HIV negative</i>
HIV+	<i>HIV positive</i>
MTCT	<i>mother-to-child transmission</i>

Child psychology – general issues relevant to HIV

There is a comprehensive body of knowledge and understanding evolving in relation to HIV infection in children. However, many lessons have been learned from wider experience and parallel situations. These few studies give an overview of the areas of literature where general child development knowledge, studies and understanding can inform, underpin and direct programmes for children affected by HIV. Although the entire area of child development is potentially of consideration, a few themes are highlighted, such as adversities, family disruption and change, child development, emotional distress and challenge, conflict, parenting and stress

Relationship quality of aggressive children and their siblings: A multiinformant, multimeasure investigation

Aguilar B, O'Brien KM, August GJ, Aoun SL and Hektner JM

Journal of Abnorm Child Psychology 2001 December 29(6):479-89

This study examined sibling influence on the learning and enactment of aggressive behaviour. Although research on normative and aggressive children's sibling interactions has increased recently, a number of limitations in this literature are addressed in this study by (1) including both an aggressive and nonaggressive comparison group, (2) examining both positive and negative features of sibling relationships, (3) employing a multimethod/multiinformant approach to data collection and (4) utilizing an improved self-report method. It was found that aggressive children's sibling relationships were marked by higher levels of observed conflict and lower levels of self-reported positive features. When gender was examined, results showed that older brother/younger sister dyads were characterised by higher levels of negative features and lower levels of positive features.

Exposure to violence, coping resources, and psychological adjustment of South African children

Barbarin OA, Richter L and deWet T

Am J Orthopsychiatry 2001 Jan;71(1):16-25

This study examined the impact of violence on 625 6-year-old black children in South Africa. The authors noted that ambient community violence was related to a variety of psychosocial outcomes. They also noted that child resources, such as resilience, maternal levels of coping and family relationships mitigated the negative impacts in all the domains measured in this study.

Adversities in childhood: Siblings' experiences, and their relations to self-esteem

Beardsall L and Dunn J

Journal of Child Psychology and Psychiatry 1992 February 33(2):349-59

The prevalence and negative impact of life events and adversities over a three-year period on 80 children participating in a study of siblings was examined, together with perceived self-competence, temperament and their mothers' mood. The majority of life events with negative impact and adversities were not shared by siblings, but were negatively correlated with children's perceived self-competence, an association apparently not mediated by children's temperament nor by maternal mood.

Sibling relationship quality: Its causes and consequences

Brody GH

Annu Rev Psychol 1998 49:1-24

Current work on children's individual characteristics and family processes which contribute to variation in sibling relationship quality is reviewed. Findings from these studies are summarised in a heuristic model which specifies hypothesised links among family processes, intrapersonal characteristics, and variations in sibling relationship quality. It is suggested that sibling relationships comprised of a balance of both prosocial and conflicted interactions create experiences that are most likely to nurture children's social, cognitive, and psychosocial development.

Perceptions of sibling relationships during middle childhood and adolescence

Buhrmester D and Furman W

Child Development 1990 October 61(5):1387-98

In this study, children of four age groups were administered the Sibling Relationship Questionnaire. Relationships were rated as progressively more egalitarian across the four groups, with adolescents reporting less dominance and nurturance by their older siblings than younger participants. Adolescents also reported less companionship, intimacy, and affection with siblings than younger participants reported. The findings suggested that sibling relationships (1) become more egalitarian and less asymmetrical with age, (2) become less intense with age and (3) encompass experiences which are partially determined by the child's standing in the family constellation.

Sibling influences on childhood development

Dunn J

Journal of Child Psychology and Psychiatry 1988 March 29(2):119-27

The authors summarise the main points concerning sibling influence: (1) siblings play a causal role in the development of aggressive behaviour, (2) problems in the sibling relationship are indicative of other problems, (3) family factors are closely involved in the quality of sibling relationships, (4) studies of families under stress indicate heightened importance of these family factors and (5) it is likely that later-born siblings are influenced by first-born in socio-cognitive development. It has been shown that the major source of environmental influence on the development of individual differences is within-family rather than between-family differences in experience (Plomin R and Daniels D. (1987) Why are children in the same family so different from one another? *Behavioral and Brain Science* 10;1-60.)

Children's adjustment and prosocial behaviour in step-, single-parent, and non-stepfamily settings: Findings from a community study

Dunn J, Deater-Deckard K, Pickering K, O'Connor TG and Golding J

Journal of Child Psychology and Psychiatry 1998 November 39(8):1083-95

The adjustment and prosocial behaviour of 4-year-old children and their older siblings growing up in step-parent or single-parent families, or with two biological parents, was investigated within a community study, the Avon Longitudinal Study of Pregnancy and Childhood (ALSPAC). Differences in mothers' perception of

adjustment were found for children in different family settings, with higher levels of problems and lower prosocial scores reported for those in single- and step-parent families than those in non-step families.

Why are siblings so different? The significance of differences in sibling experiences within the family

Dunn J and Plomin R

Family Process 1991 September 30(3):271-83

The authors of this study investigated siblings who are 50% similar genetically and grow up within the same family, but differ markedly in personality and psychopathology. The findings imply within-family processes which lead to sibling differences – called non-shared environment – are crucial for understanding environmental influences on individual development

Adjustment in middle childhood and early adolescence: Links with earlier and contemporary sibling relationships

Dunn J, Slomkowski C, Beardsall L and Rende R

Journal of Child Psychology and Psychiatry 1994 March 35(3):491-504

The relation of individual differences in behaviour in middle childhood and early adolescence to children's concurrent sibling relationships and their mothers' mood in the preschool period was studied among 39 younger and 39 older siblings. It was found that differences in adjustment were related to contemporary sibling relationships and maternal mood, and to sibling and mother-child interaction in the preschool period, even when mothers' current mood was taken into account.

Child neglect: Developmental issues and outcomes

Hildyard KL and Wolfe DA

Child Abuse and Neglect 2002 June 26(6 – 7):679-95

This article highlights the manner in which child neglect, the most common form of maltreatment, affects children's development. The current review offers further support for the long-standing conclusion that child neglect poses a significant challenge to children's development and well-being.

Brief report: Empathy and psychological adjustment in siblings of children with cancer

Labay LE and Walco GA

Journal of Pediatric Psychology 2004 June 29(4):309-14

The objective of the study was to examine relationships between empathy, illness concepts, sibling relationship variables, and psychological adjustment among 29 siblings of children with cancer. It was concluded that (1) siblings did not exhibit increased rates of behaviour problems, but did display more social and academic difficulties and (2) empathy may play an important role in sibling adjustment following the diagnosis of cancer.

Parenting style and adolescent's reaction to conflict: Is there a relationship?

Miller J.M, DiIorio C and Dudley W

Journal of Adolescent Health 2002 December 31(6):463-8

The purpose of this study was to determine if the reactions of adolescents toward hypothetical situations

which can lead to conflict and violence varied by parenting style of their mothers. It was found that parenting style is associated with adolescents' reactions to hypothetical situations which can provoke conflict. This finding highlights the importance of considering parents and their approach to child-rearing as a factor in the adolescent's ability to react to conflict.

The development of a brief screening measure of emotional distress in children

Parker G, Yiming C, Tan S and Rutter M

Journal of Child Psychology and Psychiatry 2001 February 42(2):221-5

This study reports several studies developing a parent-rated measure of emotional distress for children in Singapore. Paternal scores correlated more strongly than maternal scores with clinician-generated distress score, while girls and boys received identical total scores.

Social and emotional adjustment of siblings of children with autism

Pilowsky T, Yirmiya N, Doppelt O, Gross-Tsur V and Shalev RS

Journal of Child Psychology and Psychiatry 2004 May 45(4):855-65

This study explores the social and emotional adjustment of 30 siblings of children with autism and their risk or resilience to effects of genetic liability. It was found that most siblings were well adjusted, which is in sharp contrast to the severe social and emotional disabilities characteristic of autism.

Poverty, underdevelopment and infant mental health

Richter LM

Journal of Paediatric Child Health 2003 May – June 39(4):243-8

The authors discuss the ways in which infants and children living in conditions of poverty and underdevelopment achieve social adjustment and productive competence. Protein-energy malnutrition, maternal depression, and institutional care of infants and small children are cited as illustrative of areas in which interventions, and their evaluation, are desperately needed in resource-poor countries. An argument is made for the critical importance of considering and addressing psychological factors in care givers and children in conditions of extreme material need. An example is provided of a simple intervention model based on sound developmental principles which can be implemented by trained non-professionals in conditions of poverty and underdevelopment.

Family systems theory, attachment theory, and culture

Rothbaum F, Rosen K, Ujiie T and Uchida N

Family Process 2002 Fall 41(3):328-50

The authors consider two areas in which the theories converge: (1) in family system theorists' description of an overly close, or 'enmeshed,' mother-child dyad, which attachment theorists conceptualise as the interaction of children's ambivalent attachment and mothers' preoccupied attachment; (2) in family system theorists' description of the 'pursuer-distance cycle' of marital conflict, which attachment theorists conceptualise as the interaction of preoccupied and dismissive partners. The study briefly reviews family-systems theory evidence, and more extensively review attachment theory evidence, pertaining to these points of convergence. It also reviews cross-cultural research, which leads us to conclude that the dynamics described in both theories reflect,

in part, Western ways of thinking and Western patterns of relatedness. While the authors believe that both theories will be greatly enriched by their integration, they caution against the application of either theory outside the cultures in which they were developed.

Institutional care: associations between overactivity and lack of selectivity in social relationships

Roy P, Rutter M and Pickles A

Journal of Child Psychology 2004 May 45(4):866-73

This research studied the behaviour, and in particular the over-activity of 19 primary-school-age children raised in institutional care. The research found just over one-third of institutional children to display patterns of over-activity.

Psychosocial adversity and child psychopathology

Rutter ML

British Journal of Psychiatry 1999 June 174:480-93

The authors re-evaluate this issue in the light of developments over the past half-century. The findings are used to consider the challenges still to be met as we enter the next century. It is argued that it is necessary to put aside the absurd brain–mind dualisms of the past.

Are there biological programming effects for psychological development? Findings from a study of Romanian adoptees

Rutter M and O'Connor TG

Developmental Psychology 2004 January 40(1):81-94

This study examines the factors responsible for psychological development at an early age. The study compares Romanian children from deprived institutions with UK-born children placed into adoptive families before the age of six months. The pattern of findings suggests some form of early biological programming or neural damage stemming from institutional deprivation.

Early life family disadvantages and major depression in adulthood

Sadowski H, Ugarte B, Kolvin I, Kaplan C and Barnes J

British Journal of Psychiatry 1999 February 174:112-20

The authors explored evidence that exposure to social and family disadvantages in childhood are a risk factor for adult depression. It was found that multiple family disadvantages, such as marital instability and overcrowding in childhood, substantially increase the risk of suffering a major depressive disorder in adulthood.

Do high-threat life events really provoke the onset of psychiatric disorder in children?

Sandberg S, Rutter M, Pickles A, McGuinness D and Angold A

Child Psychology and Psychiatry 2001 May 42(4):523-32

Meeting some important methodological challenges overlooked in the past research, this study set out to examine whether the onset of psychiatric disorder in 99 children aged 8-16 was more likely to occur shortly after a severe event as compared with other times. The study offers only quite limited support to the notion of

negative life events provoking onset of psychiatric disorder in children and young people. The possible reasons for this are discussed, together with important conceptual and methodological issues to problems of defining onset, and the choice of appropriate designs for data analysis.

Grandchildren of survivors: Can negative effects of prolonged exposure to excessive stress be observed two generations later?

Sigal JJ, DiNicola VF and Buonvino M

Canadian Journal of Psychiatry 1988 April 33(3):207-12

The study aims to determine whether negative psychological repercussions on children of parents who experienced extreme, prolonged stress might continue into the third generation. The authors examined the presenting complaints of patients in a child psychiatry clinic who could be reliably identified as: (1) children whose parents were native born but who had at least one grandparent who was a survivor of the Nazi persecution (Index 1) and (2) other children who had at least one parent and one grandparent who was a survivor (Index 2). It was found that Index-2 children manifested more difficulties related to school performance

Some determinants of individual differences in the behaviour of children of parentally deprived parents

Sigal JJ, Meislova J, Beltempo J and Silver D

Canadian Journal of Psychiatry 1988 February 33(1):51-6

Parents who had been placed in an orphanage as children rated the behaviour of all their children who were between the ages of 6 and 18 on a children's behaviour survey instrument. A significant number of relationships were found between parental background variables and higher reported levels of conflict with siblings and with parents, dependent-unassertive behaviour, and undemandingness in the children. These events most frequently related to individual differences in the third generation in the area of undercontrol of aggression directed toward parents and siblings.

Maternal preoccupation and parenting as predictors of emotional and behavioural problems in children of women with breast cancer

Sigal J.J, Perry J.C, Robbins J.M, Gagne M.A and Nassif E

J Clin Oncol. 2003 Mar 15;21(6):1155-60

The purpose of the study was to test the hypothesis that differences between sicker and not-so-sick women in their preoccupation with their illness and parenting behaviour can explain why some investigators find that children of breast-cancer patients fare better than controls, and other investigators find the reverse. Less preoccupation with their illness and less poor parenting behaviour by sicker mothers may explain why their children seem to fare better than those of not-so-sick mothers.

Do children cope better than adults with potentially traumatic stress? A 40-year follow-up of Holocaust survivors

Sigal JJ and Weinfeld M

Psychiatry 2001 Spring 64(1):69-80

This study discusses reports which suggest that child survivors of the Nazi persecution are functioning well

as adults. Child-survivor parents did not differ from native-born parents on these measures 40 years later, whereas, consistent with the empirical findings of others, survivors who were adolescents or young adults at the end of the war manifested more paranoid and depressive/masochistic symptoms than native-born parents. To explain this possible greater long-term resilience among those who were child survivors, reference is made to later caretakers, endowment, cognitive and social development, and psychodynamics.

Stability of coping style 33 years after prolonged exposure to extreme stress

Sigal JJ, Weinfeld M and Eaton WW

Acta Psychiatrica Scandinavica 1985 June 71(6):559-66

Responses, attitudes and perceptions were examined in the two groups for the persistence of confronting coping styles 33 years after World War II, in a study of randomly selected community sample of Jews. Taken as a whole, but not individually, responses to the questionnaire items suggested that the traits did persist. The results highlight the importance of distinguishing individual differences in coping style when studying the long-term effects of prolonged, stressful experiences.

Predictors of antisocial personality. Continuities from childhood to adult life

Simonoff E, Elander J, Holmshaw J, Pickles A, Murray R and Rutter M

British Journal of Psychiatry 2004 February 184:118-27

This study explores the independent and joint effects of childhood characteristics on the persistence of antisocial behaviour into adult life. It was found that childhood disruptive behaviour has powerful long-term effects on adult antisocial outcomes, which continue into middle adulthood. The importance of number of symptoms, the presence of disruptive disorder, and intermediate experiences highlight three areas where interventions might be targeted.

Influences of marital conflict on child adjustment: Review of theory and research

Zimet DM and Jacob T

Clinical Child and Family Psychology 2001 December 4(4):319-35

This review summarises the literature on the relationship between marital conflict and child maladjustment with an emphasis on variables that qualify, explain the association, or both. Mediating models include exposure theories (Modeling, Cognitive-Contextual effects: appraisal of threat and blame, and Emotional Insecurity) and changes in the parent-child relationship (Spillover). Variables that moderate or qualify the relationship include children's cognitions and behaviours, contextual factors, and demographic differences. A model is presented summarizing these mechanisms.

Cognitive and developmental factors

As children grow, they develop physically and mentally. This section explores a number of studies which elaborate on the effects of HIV on such development pathways.

Cognitive and motor development in infants at risk for human immunodeficiency virus

Aylward EH, Butz AM, Hutton N, Joyner ML and Vogelhut JW

American Journal of Dis Child 1992 February 146(2):218-22

The study evaluates the natural course of cognitive and motor development among infants infected with human immunodeficiency virus from birth. The Bayley Scales of Infant Development were administered to 96 infants between 5.5 and 24 months of age. Significant group differences were found on the Mental Development Index and Psychomotor Development Index, with the seropositive infants scoring significantly lower than the seronegative or seroreverter infants.

The neuropathology of HIV-infected African children in Abidjan, Cote d'Ivoire

Bell JE, Lowrie S, Koffi K, Honde M, Andoh J, De Cock KM and Lucas SB

Journal Neuropathol Exp Neurol 1997 June 56(6):686-92

In an autopsy study of HIV-infected children in Abidjan, Cote d'Ivoire, the neuropathology of 76 HIV-1- and 2 HIV-2-positive children were compared with that of 77 frequency-matched HIV-negative children, in whom the systemic pathology was also known. The HIV-negative children showed a high background level of neuropathological abnormalities, including non-specific inflammatory infiltrates, micromineralisation, and bacterial and lymphocytic meningitis. In the HIV-positive children, HIV encephalitis was found in 6%, cytomegalovirus in 3%, toxoplasmosis in 4% and measles encephalitis in one 1%. The low prevalence of HIV encephalitis may reflect comparatively early death in HIV infection in Africa as compared with our experience in Europe and the US.

HIV-1 infection and AIDS

Belman AL

Neurol Clin 2002 November 20(4):983-1011

Since the initial descriptions of AIDS in the late 1970s, much has been learned about the biology of HIV-1 and the cells it infects. Much has also been learned about mother-to-infant viral transmission and the natural history of HIV-1 infection. The long-term effects of prenatal exposure to antiretroviral agents are not yet known and continue to be studied. Just exactly how HAART therapy may affect early signs of pediatric HIV-1/AIDS-associated CNS disease, should they develop, is unclear. As new anti-retroviral agents are developed and new combination drug regimens are instituted, the potential for neurologic complications, toxicities, and adverse drug interactions (e.g., with antiepileptic drugs (AEDS)) exists and needs to be identified and monitored.

Neurologic status of human immunodeficiency virus 1-infected infants and their controls: A prospective study from birth to 2 years

Belman AL, Muenz LR, Marcus JC, Goedert JJ, Landesman S, Rubinstein A, Goodwin S, Durako S and Willoughby A

Pediatrics 1996 December 98(6 Part 1):1109-18

The study determines the timing, extent, severity, and persistence of neurologic abnormalities in children with perinatally acquired HIV-1 infection compared with similar uninfected children of HIV-1-infected women and control children. Exposure to HIV-1 without infection seems to have no negative impact on neurologic function in children in the first 2 years of life. Among children with perinatally acquired HIV-1 infection, the most severe and pervasive neurologic problems occur in those children who have early serious HIV-1 clinical disease. Most children without serious AIDS-defining clinical conditions in the first 2 years of life are also free from serious neurologic problems during that period.

Neuropsychological evaluation of neurologically asymptomatic HIV-infected children

Bisiacchi PS, Suppiej A and Laverda A

Brain Cognition 2000 June-August 43(1-3):49-52

Forty-two children born to HIV-positive mothers underwent evaluation using a range of neuropsychological tests. Executive function impairments were present in all infected children, whereas memory and visuo-praxic deficits were evident only in those with full-blown AIDS. Language abilities and overall intelligence were spared. Performance of seroreverters was in the normal range. These findings suggest that even in neurologically asymptomatic children, neuropsychological evaluation can identify early impairment of specific cognitive functions.

Cognitive and motor development in children with vertically transmitted HIV infection

Blanchette N, Smith ML, Fernandes-Penney A, King S and Read S

Brain Cognition 2001 June - July 46(1-2):50-53

This study was designed to examine mental and motor development in 25 infants with vertically transmitted HIV infection. On the mental scale (MDI), the HIV-infected infants obtained significantly lower scores than did the uninfected infants. On the performance scale (PDI), the HIV-infected infants obtained significantly lower standard scores than the uninfected infants. CT-scan abnormalities were associated with developmental delays, particularly for motor development.

Cognitive development in school-age children with vertically transmitted HIV infection

Blanchette N, Smith ML, King S, Fernandes-Penney A and Read S

Development and Neuropsychology 2002 21(3):223-41

The authors examined a broad range of neuropsychological functioning in 14 school-age children with vertically transmitted HIV infection and a control group made up of siblings of children with HIV infection. Results revealed that school-age children with vertically transmitted HIV infection show many areas of cognitive function within the normal range. Despite normal cognitive development, subtle motor impairments were documented in children with vertically transmitted HIV infection.

Cognitive and motor development in children with vertically transmitted HIV infection

Blanchette N, Smith ML, Fernandes-Penney A, King S and Read S

Brain Cognition 2001 June - July 46(1-2):50-3

This study was designed to examine mental and motor development in infants with vertically transmitted HIV infection. Early neurodevelopment was examined in 25 young children with HIV infection acquired through

vertical transmission. Compared with 25 children born to HIV-positive mothers but not infected with the virus, and after controlling for developmental risk factors, the HIV-infected group showed impairments in mental and motor development. The results point to the importance of early abnormalities in myelination and of subcortical lesions of cognitive and motor development.

A preliminary evaluation of the cognitive and motor effects of pediatric HIV infection in Zairian children

Boivin MJ, Green SD, Davies AG, Giordani B, Mokili JK and Cutting WA

Health Psychology 1995 January 14(1):13-21

This paper reports results from a direct comparison of differences in cognitive and motor skills development between HIV-1-seropositive and HIV-1-seronegative children born to infected African mothers. The authors conclude that HIV infection affects CNS structures mediating motor and spatial memory development, even in seemingly asymptomatic children. Moreover, maternal HIV infection compromises the labor-intensive provision of care in the African milieu and undermines global cognitive development in even uninfected children.

Correlation between computed tomographic brain scan abnormalities and neuropsychological function in children with symptomatic human immunodeficiency virus disease

Brouwers P, DeCarli C, Civitello L, Moss H, Wolters P and Pizzo P

Arch Neurol 1995 January 52(1):39-44

This study evaluates the clinical significance of computed tomographic brain-scan abnormalities observed in 87 previously untreated children with symptomatic human immunodeficiency virus disease. Computed tomographic brain scan abnormalities, even when mild, were of clinical significance, suggesting that human immunodeficiency virus-associated CNS compromise is a continuous process and that scans may be helpful at baseline in defining patients at risk and for monitoring them during therapy.

Neurobehavioral manifestations of symptomatic HIV-1 disease in children: Can nutritional factors play a role?

Brouwers P, Decarli C, Heyes MP, Moss HA, Wolters PL, Tudor-Williams G, Civitello LA and Pizzo PA

Journal of Nutrition 1996 October 126(10 Supplement):2651S – 2662S

The study explores CNS abnormalities of infants and children infected with HIV-1. These results seem to suggest that general supportive and medical care as well as nutritional factors may only play a limited role in the neurocognitive improvements after antiretroviral therapy with continuous infusion ZVD. The sample size was, however, small and the nutritional measure rather global; thus these findings have to be considered as very preliminary.

Developmental milestones of vertically HIV infected and seroreverters children: Follow up of 83 children

Bruck I, Tahan T.T, Cruz CR, Martins LT, Antoniuk SA, Rodrigues M, Souza SM and Bruyn LR

Arq Neuropsiquiatr 2001 September 59(3-B):691-5

The aim of the study was to detect neurological abnormalities in 43 HIV-infected children. It was concluded that in HIV-infected children, a neurodevelopment delay occurs early in the disease, which can be detected by screening tests.

The neuropathology of pediatric acquired immunodeficiency syndrome

Burns DK

Journal of Child Neurology 1992 Oct 7(4):332-46

The authors considered neuropathologic studies, based primarily on the autopsy, as providing valuable insights into the spectrum and pathogenesis of acquired immunodeficiency syndrome-associated neurologic disorders, including primary HIV encephalopathy and as the spectrum of infectious, neoplastic and cerebrovascular diseases that may complicate the course of acquired immunodeficiency syndrome. Progressive encephalopathy represents the single most common neurologic disorder in pediatric acquired immunodeficiency syndrome and appears to be caused in most cases by direct infection in brain parenchyma by HIV. CNS lymphoma and cerebrovascular disease continue to account for most focal CNS lesions in the pediatric population. In contrast to adults with AIDS, opportunistic CNS infections remain relatively uncommon in the pediatric population.

Early neurodevelopmental growth in children with vertically transmitted human immunodeficiency virus infection

Chase C, Vibbert M, Pelton SI, Coulter DL and Cabral H

Arch Pediatric and Adolescent Medicine 1995 August 149(8):850-5

The objective of this study was to examine mental and motor development in children with vertically transmitted HIV infection in the first 30 months of life. Early and persistent delay in motor development and deceleration in mental development in late infancy distinguishes many children who are HIV infected from exposed but uninfected children, but there is significant variability in early neurodevelopmental outcome among children with HIV infection

Early cognitive and motor development among infants born to women infected with human immunodeficiency virus

Chase C, Ware J, Hittelman J, Blasini I, Smith R, Llorente A, Anisfeld E, Diaz C, Fowler MG, Moye J and Kaligh L

Pediatrics 2000 August 106(2): e25

The study examined the frequency, timing and factors associated with abnormal cognitive and motor development during the first 30 months of life in infants born to women infected with HIV-1. A significant proportion of infants with HIV-1 infection show early and marked cognitive and motor delays or declines which may be important early indicators of HIV disease progression. These abnormalities are independent of other risk factors for developmental delay.

Neuropsychological functioning in human immunodeficiency virus type 1 seropositive children infected through neonatal blood transfusion

Cohen SE, Mundy T, Karassik B, Lieb L, Ludwig DD and Ward J

Pediatrics 1991 July 88(1):58-68

The neuropsychological development of 15 HIV-1 seropositive children infected through neonatal blood transfusion was compared with that of a control group of 33 HIV-1 seronegative children who had also received blood transfusions as neonates. The results indicated that the two serostatus groups did not differ in overall intelligence, even as long as 8 years after HIV-1 infection. Significant group differences, though slight, were found on school achievement and on tasks that require motor speed, visual scanning, and cognitive flexibility.

Functional brain imaging in HIV-1-infected children born to seropositive mothers

Depas G, Chiron C, Tardieu M, Nuttin C, Blanche S, Raynaud C and Syrota A

Journal of Nucl Med 1995 December 36(12):2169-74

The aim of this work was to study cerebral function in 8 vertically infected children with HIV-1. Functional cerebral abnormalities seem to precede clinical symptoms in HIV-1 infection of the brain in children.

Neurodevelopmental outcomes of Ugandan infants with human immunodeficiency virus type 1 infection

Drotar D, Olness K, Wiznitzer M, Guay L, Marum L, Svilar G, Hom D, Fagan J.F, Ndugwa C and Kiziri-Mayengo R

Pediatrics 1997 July 100(1): e5

The neurodevelopmental outcomes of HIV-1-infected Ugandan infants of nondrug-using mothers were studied. It was concluded that HIV infection results in more frequent and earlier abnormalities in infants' neurologic status and motor development which are not attributable to other biological and environmental risk factors. More frequent mental developmental abnormalities were evident at several ages. However, information-processing abilities, such as recognition memory, may be spared from HIV-related deficits.

Antiretroviral therapy, fat redistribution and hyperlipidaemia in HIV-infected children in Europe

European Paediatric Lipodystrophy Group

AIDS 18:1443-1451, 2004

In a European study, over a quarter of HIV-positive children on treatment have lipodystrophy. An assessment of body shape change in 477 HIV+ European children and adolescents found that fat redistribution and lipodystrophy is significant. The investigators expressed particular concern as the problem may worsen with time with an association between lipodystrophy and increasing age, and longer duration of HAART.

Cognitive functioning in school-age children with human immunodeficiency virus

Frank EG, Foley GM and Kuchuk A

Percept Mot Skills 1997 August 85(1):267-72

This study focused on 27 HIV+ children aged 6–17 and attending public schools. Cognitive functioning and the relation between this domain of functioning and stage of disease, drug therapy, mode of transmission, and caretaker were examined. No relationships were found between IQs and drug treatment or caretakers, but the caretakers' effect on visuomotor skills highlights the influence of environmental factors on functioning.

The effects of HIV on cognitive and motor development in children born to HIV-seropositive women with no reported drug use: Birth to 24 months

Gay CL, Armstrong FD, Cohen D, Lai S, Hardy MD, Swales TP, Morrow CJ and Scott GB

Pediatrics 1995 December 96(6):1078-82

This study documents delays in the mental and motor functioning of infants perinatally infected with HIV while controlling for confounding effects of prenatal drug exposure, ethnicity, socioeconomic status, and maternal separation and death. Over the first 24 months of life, the mean rate of development of HIV-infected infants is significantly slower than that of noninfected infants born to seropositive mothers. This occurs even when the effects are not confounded with those of prenatal drug exposure.

Hemophilia growth and development study. Design, methods, and entry data

Hilgartner MW, Donfield SM, Willoughby A, Contant CF Jr, Evatt BL, Gomperts ED, Hoots WK, Jason J, Loveland KA and McKinlay SM et al.

American Journal of Pediatr Hematol Oncol 1993 May 15(2):208-18

The study design, research questions, and baseline data are presented from a multicenter longitudinal epidemiologic investigation of the impact of HIV infection on three areas of functioning in children and adolescents with hemophilia: physical growth and sexual maturation, immune function, and neurological and neuropsychological functioning. Entry data for this study reveal a greater likelihood for HIV+ children and adolescents with moderate to severe hemophilia to have abnormal growth, and to exhibit antibody levels not indicative of prior exposure to disease or vaccination, which could be attributed to HIV infection. Lowered neuropsychological test performance in both groups may be attributable to the deleterious effects of chronic illness.

HIV-infected children with hemophilia: One- and two-year follow-up of neuropsychological functioning

Hooper SR, Whitt JK, Tennison MB, Burchinal M, Gold SH and Hall CD

Pediatric AIDS HIV Infection 1997 April 8(2):91-7

This report describes the absence of neuropsychologic change observed over a 2-year period for 25 HIV+ children and adolescents with hemophilia. Mixed models analyses did not indicate that the HIV+ group performed more poorly than the HIV- group on any of the neuropsychological domains, nor did they show different patterns of change over time on these variables for the HIV+ group. Consistent with emergent findings, it continues to be premature to attribute subtle neuropsychologic deficits in seropositive children with hemophilia directly to the CNS effects of HIV infection.

Cognitive assessment of human immunodeficiency virus-exposed children

Levenson RL Jr, Mellins CA, Zawadzki R, Kairam R and Stein Z

American Journal of Dis Child 1992 December 146(12):1479-83

This study determines (1) the level of impairment in cognitive and motor functioning in HIV-exposed and HIV-infected preschool and school-age children; (2) cognitive strengths and weaknesses that characterise HIV-infected children; and (3) potential contributions of serostatus, neurologic impairment, and prenatal drug-exposure to cognitive functioning. Cognitive deficits were detected in HIV-infected and seroreverted children. The presence of neurologic dysfunction in HIV-infected children markedly intensified these deficits.

Early neurodevelopmental markers predictive of mortality in infants infected with HIV-1

Llorente A, Brouwers P, Charurat M, Magder L, Malee K, Mellins C, Ware J, Hittleman J, Mofenson L, Velez-Borras J and Adeniyi-Jones S

Developments in Medicine and Child Neurology 2003 February 45(2):76-84

Infected HIV-1 positive infants underwent assessment to determine whether early neurodevelopmental markers are useful predictors of mortality in those infants who survive to at least 4 months of age. Analyses revealed increased mortality associated with baseline CD4+ < 29%, gestational age less than 37 weeks, smaller head circumference, advanced HIV and higher plasma viral load.

Encephalopathy in children with perinatally acquired human immunodeficiency virus infection. Pediatric Spectrum of Disease Clinical Consortium

Lobato MN, Caldwell MB, Ng P and Oxtoby MJ

J Pediatr. 1995 May 126(5 Pt 1):710-5

This article aims to define the incidence, characteristics and survival of children with perinatally acquired HIV infection and encephalopathy. It was concluded that HIV encephalopathy in children with perinatally acquired AIDS is a common condition and is associated with severe morbidity evidenced by frequent hospitalisations, severe immunodeficiency and short survival.

HIV-associated immune dysfunction and delayed pubertal development in a cohort of young hemophiliacs. Hemophilia growth and development study

Mahoney EM, Donfield SM, Howard C, Kaufman F and Gertner JM

Journal of Acquire Immune Deficiency Syndrome 1999 August 1;21(4):333-7

As part of the Hemophilia Growth and Development Study (HGDS), this study investigated the relationship between HIV-associated immune dysfunction and delayed pubertal development in a cohort of 333 boys and adolescents with moderate or severe hemophilia who were between the ages of 6 and 19. The analysis revealed significant delays in pubertal development associated with increasing levels of immune dysfunction. The results emphasise the importance of following pubertal development in HIV-infected adolescent boys since delays in maturation may reflect underlying disease progression.

Effect of human immunodeficiency virus infection on the growth of young children. Duke Pediatric AIDS Clinical Trials Unit

McKinney RE Jr and Robertson JW

Journal of Pediatr 1993 October 123(4):579-82

The authors retrospectively analyzed the growth of 170 children less than 25 1/2 months of age who were referred for evaluation of HIV antibody status. By the age of 4 months, the 62 HIV-infected children were significantly smaller than the 108 uninfected children in both weight-for-age and length-for-age measurements; linear growth and weight gain were proportionally decreased.

Polymerase chain reaction testing for early detection of HIV infection in children

Midani S and Rathore MH

South Med Journal 1997 March 90(3):294-5

To evaluate the usefulness of PCR testing in the early diagnosis of perinatally acquired HIV infection, the authors reviewed records of 122 children having follow-up in the Northeast Florida Pediatric AIDS Program. In 24 of 27 (85%), results were positive by the time the children reached 4 months of age. The data suggest that the PCR test is a useful tool for early diagnosis of vertically transmitted HIV infection.

Maternal and infant factors associated with failure to thrive in children with vertically transmitted human immunodeficiency virus-1 infection: the prospective, P2C2 human immunodeficiency virus multicenter study

Miller TL, Easley KA, Zhang W, Orav EJ, Bier DM, Luder E, Ting A, Shearer WT, Vargas JH and Lipshultz, S

Pediatrics 2001 December 108(6):1287-96

This study aimed to explore the problems associated with growth and nutrition among HIV-1 positive children. It was found that clinical and laboratory factors associated with failure to thrive (FTT) among HIV-1 infected children include history of pneumonia, maternal illicit drug use during pregnancy, lower infant CD4+ T-cell count, exposure to antiretroviral therapy by 3 months of age and HIV-1 RNA viral load.

Persistence of human papillomavirus infection in HIV-infected and -uninfected adolescent girls: Risk factors and differences, by phylogenetic type

Moscicki AB, Ellenberg JH, Farhat S and Xu J

Journal of Infectious Diseases 2004 July 1;190(1):37-45

The objective of this study was to examine the rates of and risk factors for persistence of HPV types among HIV-infected and -uninfected adolescent girls. Persistence of high-risk HPV types was strongly linked with the development of invasive cancer, which underscores the importance of prevention of HPV infection in this group.

Neurodevelopmental testing of children born to human immunodeficiency virus type 1 seropositive and seronegative mothers: A prospective cohort study in Kigali, Rwanda

Msellati P, Lepage P, Hitimana D.G, Van Goethem C, Van de Perre P and Dabis F

Pediatrics 1993 December 92(6):843-8

The results of developmental testing of 218 children born to HIV-seropositive mothers and infected or uninfected themselves were compared with those of 218 children born to HIV-seronegative mothers in an ongoing cohort study in Kigali, Rwanda. It was found that HIV-1-infected children are more frequently developmentally delayed than uninfected children during the first 2 years of life in this African population and that this developmental delay is related to the AIDS stage of pediatric HIV infection.

Effect of perinatally acquired human immunodeficiency virus infection on neurodevelopment in children during the first two years of life

Nozyce M, Hittelman J, Muenz L, Durako S.J, Fischer ML and Willoughby A

Pediatrics 1994 December 94(6 Part 1):883-91

The study aimed to determine the timing, extent and magnitude of neurodevelopmental problems in children with perinatal HIV infection compared to similar uninfected children of HIV-infected women and controls. Children with serious HIV symptomatology appear to be at very high risk for serious developmental impairments; HIV-infected children not highly symptomatic have relatively normal neurodevelopment; and uninfected children of HIV-infected mothers do not appear to be adversely affected by the mother's HIV infection.

Neuropsychological development of children born to HIV-positive mothers

Piazza F, Astori MG, Maccabruni A, Caselli D, Bossi G and Lanzi G

Pediatric Med Chir 1995 July-August 17(4):331-3

One hundred and thirty-eight children born to HIV infected mothers (58 HIV infected and 80 seroreverted uninfected) underwent an evaluation of neurological assessment and psychological assessment every three months. Development deficit and psychological problems were discovered both in asymptomatic infected and in non-infected children, without difference of percentage between the two groups.

Human immunodeficiency virus rebound after suppression to <400 copies/mL during initial highly active antiretroviral therapy regimens, according to prior nucleoside experience and duration of suppression. Royal Free Centre for HIV Medicine; Goethe Universitat Clinic Cohort

Phillips AN, Staszewski S, Lampe F, Youle MS, Klauke S, Bickel M, Sabin CA, Doerr HW, Johnson M., Loveday C and Miller V

Journal of Infectious Diseases 2002 Oct 15 186(8):1086-91. Epub 2002 September 30

This study evaluated 1433 HIV-infected patients starting HAART, 409 (28%) of whom had prior nucleoside experience and achieved an HIV load of <400 copies/mL by 24 weeks of therapy. Even patients who had experienced <2 months of nucleoside therapy before beginning HAART had an increased risk of virus rebound. It appears that only a small period of pre-HAART nucleoside therapy is sufficient to confer a disadvantage, in terms of risk of virus rebound, that persists for several years.

Neurodevelopment, growth, and viral load in HIV-infected infants

Pollack H, Kuchuk A, Cowan L, Hacimamutoglu S, Glasberg H, David R, Krasinski K, Borkowsky W and Oberfeld S

Brain and Behaviour Immunology 1996 September 10(3):298-312

The relation of HIV-1 infection to infant growth and neurodevelopment was studied in a cohort of 65 infants born to women at risk for HIV infection. No differences were observed at birth between infected infants and uninfected infants of HIV-infected women, and infants of uninfected women with similar socioeconomic background and exposure to drugs.

Central brain atrophy in childhood AIDS encephalopathy

Scarmato V, Frank Y, Rozenstein A, Lu D, Hyman R, Bakshi S, Pahwa S and Pavlakis S

AIDS 1996 September 10(11):1227-31

The authors determine differential patterns of brain atrophy in 25 pediatric AIDS encephalopathy. It was concluded children with AIDS encephalopathy demonstrate a specific pattern of brain atrophy distinct from other etiologies: a central atrophy, primarily affecting the subcortical white matter or the basal ganglia regions.

Timing of perinatal human immunodeficiency virus type 1 infection and rate of neurodevelopment

Smith R, Malee K, Charurat M, Magder L, Mellins C, Macmillan C, Hittleman J, Lasky T, Llorente A and Moye J

Pediatric Infectious Disease Journal 2000 September 19(9):862-71

The authors aim to identify HIV-1-infected children who are at greatest risk for disease-related morbidities is critical for optimal therapeutic as well as preventive care. Several factors have been implicated in HIV-1 disease onset and severity, including maternal and infant host characteristics, viral phenotype and timing of HIV-1 infection, with the conclusion being that early HIV-1 infection increases a child's risk for poor neurodevelopmental functioning within the first 30 months of life.

Morbidity among human immunodeficiency virus-1-infected and -uninfected African children

Taha TE, Graham SM, Kumwenda NI, Broadhead RL, Hoover DR, Markakis D, van der Hoeven L, Liomba GN, Chipangwi JD and Miotti PG

Pediatrics 2000 December 106(6): e77

The authors determine patterns of morbidity and associated factors in late infancy and early childhood among HIV-808 infected and -uninfected African children. The frequency of diseases was high, and progression from asymptomatic or symptomatic HIV disease to death was rapid. Management strategies that effectively reduce morbidity for HIV-infected children are needed.

Cognitive decline with immunologic and virologic stability in four children with human immunodeficiency virus disease

Tamula MA, Wolters PL, Walsek C, Zeichner S and Civitello L

Pediatrics 2003 Sep; 112(3 Pt 1):679-84.

In a study of 107 children with HIV infection receiving treatment, 4 children were found to have good physical outcome, but showed cognitive decline. The authors caution that some of the treatments may not affect the CNS and emphasise the need to look at cognitive outcomes regularly.

HIV-1-related encephalopathy in infants compared with children and adults. French pediatric HIV infection study and the SEROCO group

Tardieu M, Le Chenadec J, Persoz A, Meyer L, Blanche S and Mayaux M

Neurology. 2000 Mar 14;54(5):1089-95.

The objective of this study was to characterise the specificities of HIV-1-related encephalopathy in children. It was concluded that early encephalopathy in infants has a different pathophysiologic mechanism than that occurring in children, which in turn shows similarities with that observed in adults. Early encephalopathy is probably related to the occurrence of pathologic events during late fetal life.

Cognitive assessment of school-age children infected with maternally transmitted human immunodeficiency virus type 1

Tardieu M, Mayaux M.J, Seibel N, Funck-Brentano I, Straub E, Teglas J.P and Blanche S

Journal of Pediatrics 1995 March 126(3):375-9

Thirty-three children born before 1985 and vertically infected with HIV-1 were followed in a single center and were studied and tested for school achievement. It was concluded that children whose HIV-1 infection is maternally acquired have better cognitive abilities and school achievement than was initially thought, and that the percentage of circulating CD4+ lymphocytes during the first years of life appears to be predictive of future school adaptation or cognitive abilities

Neurodevelopment in pediatric HIV infection. The use of CAT/CLAMS: Clinical Adaptive Test/Clinical Linguistic and Auditory Milestone Scale

Wachtel RC, Tepper VJ, Houck D, McGrath CJ and Thompson C

Clinical Pediatrics (Phila) 1994 July 33(7):416-20

As part of the neurodevelopmental examination of children, the Clinical Adaptive Test/Clinical Linguistic and Auditory Milestone Scale (CAT/CLAMS) was investigated as a tool for pediatricians to monitor the development of children at risk for HIV infection. The CAT/CLAMS was found to detect neurodevelopmental differences between HIV-infected and uninfected children at 12 and 18 months of age. These findings suggest that the CAT/CLAMS should be considered as a part of the neurodevelopmental examination of children at risk for pediatric neuro-AIDS.

Neuropsychologic functioning of human immunodeficiency virus-infected children with hemophilia

Whitt JK, Hooper SR, Tennison MB, Robertson WT, Gold SH, Burchinal M, Wells R, McMillan C, Whaley RA, Combest J et al.

Journal of Pediatrics 1993 January 122(1); 52-9

Examinations of 63 children and adolescents with hemophilia were conducted by examiners unaware of HIV status. They measured six domains of neuropsychologic functioning (motor, language, memory, attention, visual processing, and problem solving) and suggested it premature to attribute early, subtle neuropsychologic deficits in seropositive children with hemophilia to the CNS effects of HIV infection.

Death

HIV and AIDS constitute a life-threatening disease. This section provides an insight into the statistical, emotional and long-term issues surrounding infant/child HIV infection and death.

HIV impact on mother and child mortality in rural Tanzania.

Ng'weshemi J, Urassa M, Isingo R, Mwaluko G, Ngalula J, Boerma T, Marston M, Zaba B.

J Acquir Immune Defic Syndr. 2003 Jul 1;33(3):393-404

This study in Tanzania notes that child mortality rose from 137 for every 1000 in 1992 to 147 in 1999. A large study with information on mothers and babies was available, together with survival and HIV status. 584 deaths of children were recorded. The workers were able to show that infant mortality was 158 per 1000 when mothers had HIV and 79 for uninfected mothers. They also recorded deaths of mothers (51 had died, 14 who were HIV+). They then noted that infant mortality was more than 5 times higher for those whose mothers had died with HIV than those with a surviving mother. A series of models are used to set a specific rate of impact of HIV on child survival for future calculations.

Maternal HIV-1 and HIV-2 infection and child survival in The Gambia

Ota MO, O'Donovan D, Alabi AS, Milligan P, Yamuah LK, N'Gom PT, Harding E, Ariyoshi K, Wilkins A and Whittle HC

AIDS 2000 March 10;14(4):453-9

The authors compared the survival of children born to HIV-1 or HIV-2 seropositive mothers with that of children born to HIV-seronegative mothers and evaluated risk factors for mortality. More children born to HIV-1-infected mothers died in comparison with those born to HIV-2-infected mothers or to mothers from the control group. This effect was due to excess death in HIV-1-infected infants, which was associated with a high viral load in the affected mother and child.

Clinical manifestations and biological markers in the natural history of HIV-1 infection in vertically infected children. Longitudinal study

Resino S, Bellon JM, Jimenez JL, Gurbindo D, Munoz-Fernandez MA

An Esp Pediatr. 2000 Feb;52(2):138-47

This Spanish study looked at 43 HIV+ infants whose mothers had not received antiretroviral treatment, to study clinical symptoms and how they related to longer term outcome. They found that viral load $> 5 \log_{10}$ and type of virus were predictive markers of progression to death. Furthermore, the presence of progressive encephalopathy and cardiopathy were also markers of progression death.

Mortality in HIV-1-seropositive women, their spouses and their newly born children during 36 months of follow-up in Kinshasa, Zaire

Ryder RW, Nsuami M, Nsa W, Kamenga M, Badi N, Utshudi M and Heyward WL

AIDS 1994 May 8(5):667-72

The objective of this study was to calculate 3-year mortality rates in HIV-1-seropositive and HIV-1-seronegative

mothers, their newborn children and the fathers of these children. It was found that families in Kinshasa, Zaire, in which the mother was HIV-1-seropositive, experienced a 5- to 10-fold higher maternal, paternal and early childhood mortality rate than families in which the mother was HIV-1-seronegative.

Survival of HIV-1 and HIV-2 perinatally infected children in The Gambia

Schim van der Loeff MF, Hansmann A, Awasana AA, Ota MO, O'Donovan D, Sarge-Njie R, Ariyoshi K, Milligan P and Whittle H

AIDS 2003 November 7;17(16):2389-2394

This study re-visited children who were part of a large MTCT study in The Gambia during 1993-1997 in order to compare the long-term survival of children perinatally infected with HIV-2 with that of seronegative and of HIV-1 infected children. Children with perinatally acquired HIV-2 infection have a higher mortality than children of seronegative mothers.

Mortality in the first 2 years among infants born to human immunodeficiency virus-infected women in Harare, Zimbabwe

Zijenah L, Mbizvo M.T, Kasule J, Nathoo K, Munjoma M, Mahomed K, Maldonado Y, Madzime S and Katzenstein D

Journal of Infectious Diseases 1998 July 178(1):109 -13

Transmission of HIV and mortality was studied among 367 infants of infected women in Zimbabwe. Among 27 infected infants tested at birth, 70%, 19%, and 11% were apparently infected via in utero, intrapartum or early postpartum and late postpartum transmission, respectively. The majority of HIV-infected infants who died in the first 2 years of life were likely to have acquired in utero infection.

Disclosure

It is well documented that unlike many other terminal illnesses, HIV/AIDS has emerged as a stigma-bound condition. This particularly affects disclosure to the child of their own HIV status or the fact of HIV in the family. This section summarises studies which explore levels of disclosure, methodology for disclosure and barriers to disclosure for young children.

Patterns of disclosure and perceptions of the human immunodeficiency virus in infected elementary school-age children

Funk-Brentano I, Costagliola D, Seibel N, Straub E, Tardieu M and Blanche S

Arch Pediatric and Adolescent Medicine 1997 October 151(10):978-85

This study aimed to investigate the patterns of disclosure and perceptions of HIV status in a group of HIV-infected elementary-school-age children. The children were exposed to various disclosure patterns regarding their HIV infection or disease, and most children reported stressful experiences due to HIV, regardless of the disclosure patterns.

Home-based treatment for children and families affected by HIV and AIDS. Dealing with stigma, secrecy, disclosure, and loss

Gewirtz A and Gossart-Walker S

Child Adolesc Psychiatr Clin N Am. 2000 Apr;9(2):313-30

This paper describes the struggles faced by children in the presence of HIV. The authors list the assaults on child development, such as caregiving disruption, loss, abandonment and mental health needs. They describe the need and content for home based services and support integrated services for continuity of care.

The specificity of maternal disclosure of HIV/AIDS in relation to children's adjustment

Kirshenbaum SB and Nevid JS

AIDS Education Prevention 2002 February 14(1):1-16

Disclosure experience of 58 HIV-seropositive women was examined as a multi-faceted process comprising eight variables: level, seriousness, breadth, frequency, source, secrecy, age at first disclosure and time since disclosure. The majority of children were told that their mothers had HIV/AIDS and were given additional information about mothers' health, including prognosis of potential death. Most were disclosed to by their mothers and were not asked to keep disclosures secret. For most discussion regarding mother's health was infrequent. Children, on average, were first disclosed information at age 7 and had been aware of information for 3 years. Disclosure characteristics were related to demographics of mothers and children.

Disclosure of the diagnosis of HIV/AIDS to children born of HIV-infected mothers

Lee CL and Johann-Liang R

AIDS Patient Care STDS 1999 January 13(1):41-5

This study examines the issue of disclosure of diagnosis, which becomes a more significant part of comprehensive medical care as HIV treatments render this a more chronic approach. The importance of

disclosure relates directly to medication adherence, treatment compliance, sexual exploration, fears associated with premature death, and the child's developing autonomy. Disclosure of HIV disease to an infected child poses complex issues, such as transmissibility, maternal guilt, more than one family member with the virus, and the potential for social stigma and isolation. Continuous communication and negotiation among the members of the team, which includes the parents and caregivers, are vital to the gradual process leading to complete disclosure. In this study of 73 children, 41% had full disclosure and 19% partial disclosure.

Disclosure, stress, and psychological adjustment among mothers affected by HIV

Murphy LM, Koranyi K, Crim L and Whited S

AIDS Patient CARE STDS 1999 February 13(2):111-8

This study examined patterns of disclosure and psychological adjustment among mothers infected or affected by HIV. Analyses suggested that perceived stress accounted for a significant 43% of the variance in psychological adjustment.

Disclosing the diagnosis of pediatric HIV infection: mothers' views.

Nehring WM, Lashley FR, Malm K

J Soc Pediatr Nurs. 2000 Jan-Mar;5(1):5-14

This small study was set up to understand disclosure of HIV status of the child. The authors conducted interviews with both foster and biological mothers and identified three themes around disclosure. People disclosed to assist in generating support, were concerned about who should know and were challenged by the way in which to disclose to children.

When children tell their friends they have AIDS: Possible consequences for psychological well-being and disease progression

Sherman BF, Bonanno GA, Wiener LS, Battles and HB

Psychosomatic Medicine 2000 March - April 62(2):238-47

The study examines the physiological and psychological consequences of children's self-disclosure of their HIV/AIDS status to friends. The results were consistent with previous studies showing the positive health consequences of self-disclosure in adults, and suggest potentially important implications for professional and familial care givers of HIV/AIDS individuals.

Disclosure of diagnosis and planning for the future in HIV-affected families in Europe

Thorne C, Newell ML and Peckham CS

Child Care and Health Development 2000 January 26(1):29-40

This study examined information relating to disclosure of infection status in families affected by HIV and the existence of plans for the future social care of children with infected parents. Disclosure of both the child's and the parent's infection status was rare and found to be associated with child's age in both cases. Infected children living with their parents were less likely to know their diagnosis than those living in alternative care. Infected parents also face difficult decisions regarding the issue of who will care for their children when they are unable to. Increasing numbers of vertically infected children are reaching adolescence as a result of improvements in the management of paediatric HIV infection.

Educational development

Child development in the presence of HIV infection needs careful consideration. Development challenges occur for children with HIV, uninfected children but with HIV in their family and those living in a social system where HIV is prevalent. This section explores some of the educational factors which have been studied in relation to young children and HIV.

Pediatric HIV infection: A neuropsychological and educational challenge

Armstrong FD, Seidel JF and Swales TP

Journal of Learning Disability 1993 February 26(2):92-103

The authors considered pediatric AIDS and HIV infection as the primary infectious cause of perinatally acquired developmental disabilities in the USA. HIV encephalopathy and a variety of opportunistic infections, neoplasms, and vascular changes associated with pediatric HIV infection create a high probability of neuropsychological impairment among preschool and school-age children infected perinatally. Although the use of antiretrovirals may moderate some of the functional difficulties faced by these children, specific neuropathological and neuropsychological deficits are likely to remain. Treatments that prevent the CNS effects of HIV have yet to be identified.

HIV-related stress at school and at home in Zambia

Baggaley R, Sulwe J, Chilala M and Mashambe C

AIDS Anal Africa 1997 June 7(3):14-5

This study interviewed 19 randomly sampled schoolteachers from Lusaka to learn how the HIV epidemic affects their professional and personal lives. Each teacher had students who had lost both parents to AIDS, many teachers had several orphans in their class, and student absenteeism to care for sick adults and younger siblings at home interferes with the ongoing in-school learning process. Outside of the classroom, many teachers were troubled by the loss of relatives, friends, and colleagues due to AIDS, and concerned that they and/or their children may become infected or are already infected with HIV.

Early language development in children exposed to or infected with human immunodeficiency virus

Coplan J, Contello K.A, Cunningham C.K, Weiner LB, Dye TD, Roberge L, Wojtowycz MA and Kirkwood K

Pediatrics 1998 July 102(1): e8

The study aimed to compare language development in infants and young children with HIV infection to language development in children who had been exposed to HIV but were uninfected, and (among subjects with HIV infection) to compare language development with cognitive and neurologic status. Language deterioration occurs commonly in infants and young children with HIV infection, is seen frequently in the absence of abnormalities on neurologic examination or CNS imaging, and may precede evidence of deterioration in global cognitive ability.

Speech and language functioning in paediatric HIV disease

Hodson A, Mok J and Dean E

International Journal of Language and Communication Disorders 2001 36 (Supplement):173-8

This study was the first to compare selected aspects of speech motor control, expressive language and receptive language functioning in individual HIV-infected children. Results suggested clinically stable HIV-infected children can develop linguistic impairment. Such impairment is in danger of going unnoticed without assessment. Thorough and regular assessment of the linguistic functioning of long-term survivors of paediatric HIV disease is essential if optimal speech and language therapy management strategies are to be devised.

Attention in HIV-infected children: Results from the hemophilia growth and development study

Watkins JM, Cool VA, Usner D, Stehbens JA, Nichols S, Loveland KA, Bordeaux JD, Donfield S, Asarnow RF and Nuechterlein KH

Journal of International Neuropsychology and Society 2000 May 6(4):443-54

Attentional functioning was examined in three groups of 7 to 19-year-old male participants with hemophilia. The longer the HIV+ children were required to sustain attention to the Continual Performance Test (CPT), the more they responded to the incorrect stimulus. This effect decreased as age increased. Attention span was found to be associated with a history of hemorrhaging, but not sensitive to HIV status or degree of immune suppression in HIV+ children, suggesting morbidity related to hemophilia.

Differential receptive and expressive language functioning of children with symptomatic HIV disease and relation to CT scan brain abnormalities

Wolters PL, Brouwers P, Moss HA and Pizzo PA

Pediatrics 1995 January 95(1):112-9

This study investigated the effect of HIV on the receptive and expressive language of 36 children and the relationship between CT-scan brain abnormalities and language functioning. It was found that pediatric HIV disease is associated with differential receptive and expressive language functioning in which expressive language is significantly more impaired than receptive language. The sibling data and CT-scan correlations suggest that the observed language impairments are associated with the direct effects of HIV-related CNS disease.

Interventions – Antiretroviral treatment, feeding and mode of delivery

This section provides a brief overview of studies exploring, in detail, the various interventions currently under study to avert infant infection. The strategies relate to three approaches:

- *antiretroviral treatment (to the mother, the infant or both);*
- *mode of delivery (vaginal, cesarean section and allied procedures such as episiotomy, forceps, vaginal washing);*
- *mode of feeding given that HIV can enter breast milk and can potentially be transmitted by breast feeding (from both mother to baby and baby to mother).*

The effects on infants of potent antiretroviral therapy during pregnancy: A report from Spain

Bellon Cano JM, Sanchez-Ramon S, Ciria L, Leon JA, Gurbindo D, Fortuny C, Bertran JM, Ruiz Contreras J, Ramos JT, Asensi O, Mur A, Resino R, Munoz-Fernandez MA

Med Sci Monit. 2004 May;10(5):CR179-84. Epub 2004 Apr 28.

This study examined the effect of antiretroviral therapy given to the mother on infant outcomes in 11 centres in Spain. Given that there are a variety of treatment combinations, the workers divided them into two categories: those with a protease inhibitor (PI) and those without. They concluded that treatment was well tolerated, that no children were born HIV+, and that the two infant deaths were in very premature babies. A small level of anemia was noted in the children, but this was not reported as life threatening.

Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. Pediatric AIDS Clinical Trials Group Protocol 076 Study Group

Connor EM, Sperling RS, Gelber R, Kiselev P, Scott G, O'Sullivan MJ, VanDyke R, Bey M, Shearer W and Jacobson RL, et al

New England Journal of Medicine 1994 November 3;331(18):1173-80

The authors conducted a randomised, double-blind, placebo-controlled trial of the efficacy and safety of zidovudine in reducing the risk of maternal-infant HIV transmission. In pregnant women with mildly symptomatic HIV disease and no prior treatment with antiretroviral drugs during the pregnancy, a regimen consisting of zidovudine given *ante partum* and *intra partum* to the mother and to the newborn for six weeks reduced the risk of maternal-infant HIV transmission by approximately two-thirds.

Late postnatal transmission of HIV-1 in breast-fed children: an individual patient data meta-analysis

Coutsoudis A, Dabis F, Fawzi W, Gaillard P, Haverkamp G, Harris DR, Jackson JB, Leroy V, Meda N, Msellati P, Newell ML, Nsuati R, Read JS, Wiktor S; Breastfeeding and HIV International Transmission Study Group.

J Infect Dis. 2004 Jun 15;189(12):2154-66. Epub 2004 May 26

In this study the authors conducted a patient analysis of transmission of HIV through breastfeeding to estimate the contribution of later postnatal transmission of HIV to the overall risk of MTCT. Data was used from 4085 children from 9 trials (breast-fed babies (who were not twins) and for whom HIV-1 testing was performed) with results available for study. Male infants and children of mothers with low CD4 cell counts were at greater risk of infection through breastfeeding, suggesting that substantial efforts will be needed to identify mothers

with advanced HIV disease who would benefit from antiretroviral treatment. The findings strongly support strategies being pursued by programmes such as MTCT-Plus, which seek to provide short-course antiretroviral treatment around the time of delivery and also treatment for mothers with advanced HIV disease, both to reduce the risk of mother to child transmission and to improve the chances that the baby will be raised by its birth mother.

Antiretroviral therapy, fat redistribution and hyperlipidaemia in HIV-infected children in Europe

European Paediatric Lipodystrophy Group

AIDS. 2004 Jul 2;18(10):1443-51

Body-fat redistribution is a side effect of HIV treatments in adults. This study examined the side effect in children across Europe over a 2-3 months with 477 children aged 3 years or more. Twenty-six percent of children showed a prevalence of body-fat redistribution.

Somatic growth and clinical manifestation in formula fed infants born to HIV-infected mothers during the first year of life

Gulgolgarn V, Ketsararat V, Niyomthai R, Junsiriyotin K, Thungjang S, Leelaporn W, Tovanabutra S, Nelson K, Khamboonrueng C and Robb M

Journal of the Medical Association Thailand 1999 November 1982 82(11):1094-9

This was a comparative study of the growth and clinical manifestation between infected and uninfected HIV infants both of whom were fed with a limited quantity of powder milk from birth until one year of age. In conclusion for the infants born to HIV- infected mothers, monitoring signs and symptoms including their weight and height from birth till 9-12 months old, is predictive of the infectious status of most infected infants. The administration and management of infant formula in a limited quantity to HIV infected mothers in upper northern provinces of Thailand is possible without causing abnormal infant growth.

Prenatal and postpartum zidovudine adherence among pregnant women with HIV: results of a MEMS substudy from the Perinatal Guidelines Evaluation Project

Ickovics JR, Wilson TE, Royce RA, Minkoff HL, Fernandez MI, Fox-Tierney R and Koenig LJ; Perinatal Guidelines Evaluation Group.

J Acquir Immune Defic Syndr. 2002 Jul 1;30(3):311-5

This study explores the rates of adherence to antiretroviral treatment for pregnant HIV-positive women in the USA. They found that extremely low adherence - 50% adherent 3 weeks prior to delivery and 34.1% adherent at 3 weeks post delivery. The authors raise the importance of monitoring and supporting adherence to maximise benefit.

The incidence of complications after caesarean section in 156 HIV-positive women

Semprini AE, Castagna C, Ravizza M, Fiore S, Savasi V, Muggiasca M.L, Grossi E, Guerra B, Tibaldi C, Scaravelli G, et al

AIDS 1995 August 9(8):913-17

The study investigates the risks of post-operative complications in 156 HIV-positive mothers who undergo a caesarean section (CS) because the delivery cannot be safely accomplished by the vaginal route, or to protect the infant from viral infection. The results indicated that HIV-positive mothers are at an increased risk of post-operative complications when delivered by CS. The risk of post-operative complications is higher in HIV-infected women who are severely immunodepressed

Natural history

This section briefly summarises studies which explore the natural history of HIV in the young child.

The early natural history of vertically transmitted HIV-1 infection in African children from Durban, South Africa

Bobat R, Moodley D, Coutsooudis A, Coovadia H and Gouws E

Ann Trop Paediatric 1998 September 18(3):187-96

The study examined 48 children with vertically transmitted HIV-1 infection, and 93 uninfected infants were followed up at regular intervals from birth for a mean of 26 months. Mortality in infected infants was 35.4%, and 76% of deaths occurred within the 1st year. About two-thirds of HIV-infected infants survived into early childhood. In South African children with vertically acquired HIV-1 infection, the onset of disease is early and deterioration to AIDS and death are rapid.

Neurologic aspects of HIV infection in infants and children: therapeutic approaches and outcome

Civitello L

Curr Neurol Neurosci Rep. 2003 Mar;3(2):120-8

This paper provides an up-to-date overview of the consequences of HIV infection on the CNS and the progress made as a result of early diagnosis and new treatments. Various interventions to treat and prevent neuropathogenesis are reviewed.

Natural history of vertically acquired human immunodeficiency virus-1 infection

European Collaborative Study

Pediatrics 1994 December ;94(6 Pt 1):815-9

The objective of this study was to describe the natural history of vertically acquired HIV infection. The progression of disease in this cohort of vertically infected children was not as fast as previously suggested, even though treatment was not widespread. Although infected children have a high risk of developing some manifestation of HIV infection early in life, serious HIV-related symptoms became less frequent with increasing age.

Paediatric HIV infection

Lwin R, Melvin D.

J Child Psychol Psychiatry 2001 May;42(4):427-38

This overview paper gives a historical perspective on HIV in children. The authors note how medical treatment has altered the course of the HIV epidemic in children. They also note the psychological literature where HIV has been monitored in terms of its effect on child development, social and cultural attitudes and family function. Issues that have emerged include disclosure, long-term management, and family/societal functioning.

A four-year cohort study of HIV seropositive Ethiopian infants and children: Clinical course and disease patterns

Muhe L

Ethiopian Medical Journal 1997 April 35(2):103-115

This study followed 62 HIV positive infants who were admitted to the Missionaries of Charity Orphanage in Addis Ababa for a total period of 4 years. The level of mother-to-child HIV transmission was 29-47%. Among the clinical signs presented, generalised lymphadenopathy, hepatomegaly, splenomegaly, wasting, stunting and delayed motor development were more often found in the definitely HIV-positive children. Upper-respiratory-tract infections, acute diarrhea, pneumonia, pyogenic skin infections, sepsis and candidal infections were the most commonly seen illnesses.

Child survival in relation to mother's HIV infection and survival: Evidence from a Ugandan cohort study

Nakiyingi JS, Bracher M, Whitworth JA, Ruberantwari A, Busingye J, Mbulaiteye SM and Zaba B

AIDS 2003 August 15;17(12):1827-34

This study analyses the contribution of maternal survival and HIV status to child (under 5 years) mortality in a cohort of 10,000 rural people in south-west Uganda. Maternal survival and HIV status were found to be strong predictors of child survival. The higher mortality in HIV-infected women compounds mortality risks for their children, regardless of children's HIV status. Programmes aimed at the welfare of children should take into account the independent effect of mothers' HIV and vital status.

Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis

Newell ML, Coovadia H, Cortina-Borja M, Rollins N, Gaillard P, Dabis F; Ghent International AIDS Society (IAS) Working Group on HIV Infection in Women and Children.

Lancet 2004 Oct 2;364(9441):1236-43

This overview collated information from 7 trials which monitored mothers and babies during intervention treatment initiatives and looked at follow up information to study mortality in African children born to a mother with HIV. Children could become infected early (established by PCR test by 4 weeks) or later (established by an initial negative test at 4 weeks, but a subsequent positive test). Using statistical methods, the workers examined the effects of mother's health, whether or not the baby had HIV, how the baby was fed, whether it was early or late HIV infection for the baby for 3,468 children. 378 (11%) had died. The authors claim that by 1 year, an estimated 35.2% infected and 4.9% uninfected children will have died; by 2 years 52.5% and 7.6%, respectively, will have died. Factors linked to the death of the baby included the mortality of the mother, the immune state of the child, and whether the baby had HIV infection or not. Feeding did not have an effect, but timing of infection did where children who were infected later had lower mortality.

Child mortality and HIV infection in Africa: A review

Newell ML, Brahmbhatt H and Ghys PD

AIDS 2004 Jun;18 Suppl 2:S27-34

This study examined child survival in the era of HIV. The authors note that there are several mechanisms accounting for child survival. They note that highest mortality is for HIV-positive children born to HIV-positive mothers. Studies need to establish whether the child has HIV or not, but clearly the impact of HIV on long-term survival is important to study, hand in hand with HIV-infected and HIV-uninfected children.

Survival of HIV-1 and HIV-2 perinatally infected children in The Gambia

Schim van der Loeff ME, Hansmann A, Awasana AA, Ota MO, O'Donovan D, Sarge-Njie R, Ariyoshi K, Milligan P and Whittle H

AIDS 2003 November 7;17(16):2389-94

The authors revisited children who were part of a large MTCT study in the Gambia (conducted during 1993–97), in order to compare the long-term survival of children perinatally infected with HIV-2 with that of seronegative and of HIV-1-infected children. The findings show children with perinatally acquired HIV-2 infection have a higher mortality than children of seronegative mothers.

Natural history of human immunodeficiency virus type 1 infection in children: A five-year prospective study in Rwanda

Spira R, Lepage P, Msellati P, van de Perre P, Leroy V, Simonon A, Karita E and Dabis F

Pediatrics 1999 November 104(5): e56

The study compared morbidity and mortality of HIV-1-infected and HIV-1-uninfected children and to identify predictors of AIDS and death among HIV-1-infected children in a developing country. In Africa, HIV-1-infected children develop disease manifestations early in life. Specific clinical findings are predictive of HIV-1 disease, AIDS stage, and death. Bimodal expression of HIV-1 pediatric disease is encountered in Africa, as in industrialised countries, but prognosis is poorer.

Nutrition

Infant feeding and child nutrition are important concomitants of psychosocial development in young children with HIV.

Breast milk and HIV-1: vector of transmission or vehicle of protection?

Kourtis AP, Butera S, Ibegbu C, Beled L and Duerr A

Lancet Infect Dis. 2003 Dec;3(12):786-93

The authors provide an overview on the dilemmas facing breastfeeding mothers in the light of potential HIV transmission. They note that although 40% of infant infections are probably accounted for by breastfeeding, most breastfed infants are actually not infected. The authors explore the balance between protection and exposure and raise the complex issues of breastfeeding and HIV transmission.

Evolution of nutritional status of infants infected with the human immunodeficiency virus

Leandro-Merhi VA, Vilela MM, Silva MN, Lopez FA and Barros Filho A

Sao Paulo Medical Journal 2000 September 7;118(5):148-53

The objective of this research was to study the nutritional status of infants infected with HIV. It was found the growth of infected infants was observed to be severely affected in comparison with that of seroreversed infants in the same age groups. Although clinical manifestations may take time to appear, the onset of growth changes begin soon after birth.

Orphanhood

Maternal or paternal HIV infection, when left untreated, may result in premature parental death. The growing challenge of orphanhood (single or double) emerges as a key development and provision issue worldwide. This section provides an overview of a number of studies examining orphanhood and the variety of implications on young children, society, development and the future.

AIDS causes sharp rise in number of Brazilian orphans

AIDS Weekly Plus 1996 October 28:13-4

The survey, sponsored by UNICEF, estimates that 10,600 Brazilian children younger than 14 years have already lost their mothers to AIDS, 34,600 have mothers with AIDS, and 137,800 have mothers infected with HIV. Of these 183,000 children, 8% are infected with HIV. Further estimates are that the number of children orphaned by AIDS could more than double by the year 2000 and that support for each orphan could cost Brazil up to \$16,000 annually. Preventive measures would only cost between \$400 and \$1000 annually per child. Preventive measures should include better access to HIV testing and treatment and programs directed at low-income families, custody plans for orphans and legal measures to support families affected by AIDS.

Finding solutions to the nutritional dilemmas in Africa for child health: HIV/AIDS orphans, poverty and hunger

Atinmo T and Oyewole D

Asia Pac J Clin Nutr. 2004;13(Suppl):S6.

This article explores the intertwined linkages between poverty and hunger and how they affect child survival. The article explores a number of production-capacity needs and explores nutritional and food requirements for future planning, especially regarding HIV/AIDS and its ramifications.

The experience of family foster care in Malawi: A preliminary investigation

Bandawe CR and Louw J

Child Welfare 1997 Jul-Aug;76(4):535-47

24 Foster parents were studied to give a detailed insight into fostering in Malawi.

Dimensions of the emerging orphan crisis in sub-Saharan Africa

Bicego G, Rutstein S and Johnson K

Soc Sci Med. 2003 Mar;56(6):1235-47.

This paper looks at trends in orphans and parallel trends in HIV mortality to confirm the probable causal pathway between HIV and the growing orphan numbers across 17 countries in sub-Saharan Africa. The authors then examine a variety of outcomes for orphans compared to those with surviving parents and conclude that parental loss is associated with lowered chances of being in the correct school year for age. Such educational disadvantage has widespread results.

Proposed initiatives for healthy children orphaned by AIDS

Cameron T

J Health Soc Policy 2000;11(4):15-39

This overview examines the changing demands of children orphaned to HIV, and the abilities of child welfare systems to respond appropriately. An overview of services in 8 major cities is provided and sets the basis for future initiatives.

Kenya: AIDS-law sensitization results in schooling for orphans*Can HIV AIDS Policy Law Rev.* 2004 Apr;9(1):33-4

This report points to a legal case in Kenya which allowed for admission of HIV-positive children into government schools. In the past such children were refused entry. The long-term effects of education deprivation would clearly violate the rights of the child.

The long-term impact of HIV and orphanhood on the mortality and physical well-being of children in rural Malawi

Crampin AC, Floyd S, Glynn JR, Madise N, Nyondo A, Khondowe MM, Njoka CL, Kanyongoloka H, Ngwira B, Zaba B and Fine PE

AIDS 2003 February 14;17(3):389-97

The objective was to assess the influence of maternal HIV status and orphanhood on child mortality and physical well-being. It was concluded that mortality in children under 5 years is much higher in children born to HIV-positive mothers than in those born to HIV-negative mothers. With 10% of pregnant women HIV positive, it was estimated that approximately 18% of under-5 deaths in this population are attributable to HIV, most of which is attributable to vertical transmission of HIV.

Strategies for providing care and support to children orphaned by AIDS

Drew RS, Makufa C and Foster G

AIDS Care 1998 Apr;10 Suppl 1:S9-15.

This study examines the balancing needs of a community with growing numbers of orphans, and it cautions that a simple reactive system may miss the most needy, especially when the care burden is falling on the very old and the very young. The paper then describes a programme where home visits and costs are provided. The components of such a programme are set out, in terms of visits, frequency, record keeping, activities, monitoring and outreach scope. Gaps in political and social provision are seen as impediments to rolling out and upscaling programmes.

Caring for the people living with HIV/AIDS and AIDS orphans in Osun State: a rapid survey report

Folayan MO, Fakande I and Ogunbodede EO

Niger J Med. 2001 Oct-Dec;10(4):177-81

This study examines a number of opinions from different perspectives to understand the role of NGOs in HIV control. Focus group discussion revealed the priority concern relating to orphans and education.

Orphan prevalence and extended family care in a peri-urban community in Zimbabwe

Foster G, Shakespeare R, Chinemana F, Jackson H, Gregson S, Marange C and Mashumba S

AIDS Care 1995;7(1):3-17

This study, carried out in 1992, surveys 570 households in Zimbabwe to reveal orphan prevalence: 13% had one parent dead and 5% had lost both parents. Socioeconomic bandings affected orphan distribution. Parental deaths had increased towards the time of the survey. Care was satisfactory in extended families under difficult circumstances. Communities were adapting by involving maternal kin as well as the traditional route of paternal kin. The worrying emergence of households headed by young brothers or sisters was noted and seen as a sign of the system under stress. Community rupture should be prevented by supportive inputs at the community level.

Supporting children in need through a community-based orphan visiting programme

Foster G, Makufa C, Drew R, Kambeu S and Saurombe K

AIDS Care 1996 Aug;8(4):389-403

There is an urgent need for programmes to support the growing number of orphans in countries severely affected by AIDS. Most orphans are being cared for by extended families under difficult circumstances. Few descriptions of community-based orphan-support programmes exist. The authors describe one such programme established in Zimbabwe in 1993. Twenty-five volunteers identified 300 orphan households. During one year, volunteers made 1725 home visits and 123 households received an average of \$11 in material support or school fees. In 292 orphan households there were 702 orphans, which is 14.7% of the children under 15 years in the area. The rate of parental deaths was increasing, with 3.5% of households in the area having a parental death in 1994. Forty-five per cent of caregivers were grandparents, and 33% of caregivers were over 60 years. Three per cent of orphans was cared for by adolescent siblings. The poorest orphan households were those in receipt of school fees with out-of-school children or with an older sibling as caregiver. Community members initiated activities to help orphans. The programme described is targeted, effective and replicable. Community-based organisations such as local churches and women's groups can be mobilised to administer programmes which provide support to the poorest orphan households.

Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe

Foster G, Makufa C, Drew R, Mashumba S and Kambeu S

AIDS Care 1997 Aug;9(4):391-405

This report gives perceptions of orphans, caretakers and community workers in Zimbabwe which emerge from focus group discussions. The authors identify concerns from orphans who feel different, under stress, stigmatised, exploited, neglected and compromised in their schooling. Exploitation was present as was care. Partnerships can be used to strengthen community resources and tendencies such as 'property grabbing' should be halted. Adaptive changes are set out.

AIDS and the orphan crisis in Zimbabwe

Foster G

AIDS Anal Afr. 1996 June 6(3):12-3

The study discusses the growing number of AIDS-infected young adults who die, causing sibling- and grandmother-headed households to become increasingly common in developing countries. It was found that many children prefer to stay together as a family unit despite the inevitable hardship and obstacles they will encounter to survival. These families are weak, but surviving. The AIDS pandemic will likely cause a 10-fold rise in the number of maternal orphans. In Zimbabwe alone, 40% of children may have lost their parents within a decade.

Comparison of household-survey estimates with projections of mortality and orphan numbers in sub-Saharan Africa in the era of HIV/AIDS

Grassly N, Lewis J, Mahy M, Walker N and Timaeus I

Popul Stud (Camb). 2004;58(2):207-217

This study looks in depth into the basis of some of the United Nations models which provide estimates of orphan numbers and questions the validity of these estimates by examining information from household surveys. Underreporting of orphanhood and adult disease reporting leads the authors to conclude that the fraction of orphans attributable to AIDS is greater than estimated before. The United Nations publishes estimates of HIV.

The orphan problem: experience of a sub-Saharan Africa rural population in the AIDS epidemic

Kamali A, Seeley J.A, Nunn AJ, Kengeya-Kayondo JF, Ruberantwari A and Mulder DW

AIDS Care 1996 October 8(5):509-15

An assessment of the prevalence of orphans and the magnitude of their problems and the extent to which HIV-1 is contributing to this was conducted in a rural population in South-West Uganda with an HIV-1 seroprevalence of 8% among adults. Slightly over 10% of the children under 15 years of age were reported to have lost one or both parents. Generally, orphans are living with their surviving parent or other relatives, but the study also note that some children with both parents alive lived with relatives as part of the extended family system. HIV-1 seroprevalence rates were higher among orphans than among non-orphans and were up to 6 times higher in the 0-4 year age group. The HIV-1 epidemic has substantially increased the number of orphans in this community, a finding which is probably typical of many other sub-Saharan African countries. It appears that these orphans were generally well looked after within the community. This coping capacity may, however, become overstretched if the epidemic evolves further.

Estimated number of children left motherless by AIDS in the United States, 1978-1998

Lee LM and Fleming PL

Journal of Acquired Immune Deficiency Syndrome 2003 October 1;34(2):231-6

To estimate the number and characteristics of maternal AIDS orphans in the USA, demographic techniques were applied to data from several sources. From the national HIV/AIDS surveillance system, reporting delays were adjusted for the number of deaths among women aged 15-44 diagnosed with AIDS through 1998 and reported as deceased by December 1999. After increasing each year, the annual number of orphaned children younger than 21 years peaked in 1995. Due to declines in AIDS deaths, the annual number of children orphaned by AIDS has declined. Nevertheless, each year thousands of youth are orphaned.

Orphans of the HIV epidemic: unmet needs in six US cities

Levine C

AIDS Care 1995;7 Suppl 1:S57-62.

This paper sets out the needs of orphans in the USA and the types of services that are utilised, required and ought to be available.

Health and nutritional status of orphans <6 years old cared for by relatives in western Kenya

Lindblade KA, Odhiambo F, Rosen DH and DeCock KM

Tropical Medicine and International Health 2003 January 8(1):67-72

The authors used data from a population-based study in rural western Kenya to compare basic health and nutritional indicators between non-orphaned children <6 years old and children who lost either or both of their parents. While there was no difference between orphans and non-orphans regarding most of the key health indicators (prevalence of fever and malaria parasitaemia, history of illness), W/H Z-scores in orphans were almost 0.3 standard deviations lower than those of non-orphans. This association was more pronounced among paternal orphans and those who had lost a parent more than 1 year ago. These results suggest that the health status of surviving orphans living in their community is similar to that of the non-orphan population.

Fosterage patterns in the age of AIDS: continuity and change

Madhavan S

Soc Sci Med. 2004 Apr;58(7):1443-54

This paper proposes that the extended family system is no longer able to cope with the burden of orphans. The authors discuss care issues, notably continuity of care and changes in care that affect young children.

Psychological well-being of orphans in Dar El Salaam, Tanzania

Makame V, Ani C and Grantham-McGregor S

Acta Paediatr 2002 9(4):459-65

This study compared 41 orphans whose fathers and/or mothers had died from AIDS, and were living in the poor suburbs of Dar Es Salaam, Tanzania, with 41 matched non-orphans from the same neighbourhoods. The orphans not only had unmet basic needs, but also had markedly increased internalizing problems, thus their long-term mental health would be in jeopardy. There is an urgent need to expand and improve current intervention programmes not only to meet the basic needs, but also to include psychosocial support, counselling services for the orphans, and training for their carers and teachers.

The social situation of motherless children in rural and urban areas of Guinea-Bissau

Masmas TN, Jensen H, da Silva D, Hoj L, Sandstrom A, Aaby P

Soc Sci Med. 2004 Sep;59(6):1231-9.

This study provides a description of the social conditions of children who are orphaned to HIV/AIDS in Guinea-Bissau. Comparisons between rural (n=128) and urban children (n=192) who were motherless were made with 808 control children. The authors concluded that traditional extended family system was capable of handling motherless children. Although they were not disadvantaged on some outcomes, they did move more frequently and lived in smaller families. The long-term stresses of HIV/AIDS on the traditional system needs to be monitored.

Survival among motherless children in rural and urban areas in Guinea-Bissau

Masmas TN, Jensen H, da Silva D, Hoj L, Sandstrom A, Aaby P

Acta Paediatr. 2004 Jan;93(1):99-105.

This piece describes survival patterns of motherless children in Guinea Bissau. The study of 128 rural children, 192 urban children and 807 who were not motherless and acted as comparisons revealed a higher mortality in motherless children. This was concentrated in deaths in the under-2-year group. The authors conclude that premature weaning may contribute to explaining this.

Mass orphanhood in the era of HIV/AIDS

Matshalaga NR and Powell G

BMJ. 2002 Jan 26;324(7331):185-6

This paper discusses the limitations of narrow approaches which explore antiretroviral drug treatment and ignore poverty and social problems in African populations. They warn of the need for ongoing sustainable solutions to HIV in Africa and highlight the overall importance of economic security, investment and growth to confront AIDS and equip children to face the future.

Response for all AIDS affected children, not AIDS orphans alone

Morgan S

AIDS Anal Afr. 2000 Apr-May;10(6):3

Children who live in families where HIV is present but who are not HIV positive themselves, also have needs. The ripple effect on children generally should be noted as resources are targeted and used. This study explores the situation in South Africa, with particular note on the sexual abuse challenges and the need for advocacy for children and HIV generally.

Changing patterns of orphan care due to the HIV epidemic in western Kenya

Nyambedha EO, Wandibba S and Aagaard-Hansen J

Social Science Med 2003 July 57(2):301-11

The paper describes a rural community in western Kenya in which one out of three children below 18 years of age had lost at least one biological parent – and one out of nine had lost both. The main problems these children faced were lack of school fees, food and access to medical care. The high number of orphans has overwhelmed the traditional mechanisms for orphan care, which were based on patrilineal kinship ties. Thus, 28% of the orphans were looked after by culturally ‘inappropriate’ categories such as matrilineal kin or strangers. Furthermore, many of the caretakers were themselves not capable due to ill health or old age. Factors such as poverty, negative attitudes, and traditional funeral customs made the orphans’ situation even worse. The authors conclude that though community-based interventions are urgently needed as the most appropriate way to address the issue, the complex, local reality in which cultural factors, kinship ties, and poverty are interwoven needs to be taken into consideration if sustainable solutions are to be found.

Policy implications of the inadequate support systems for orphans in western Kenya

Nyambedha EO, Wandibba S, Aagaard-Hansen J

Health Policy 2001 Oct;58(1):83-96.

This paper describes support for HIV orphans in western Kenya. School fees were a problem for many, followed by shortages of food, medical care and clothing. The long-term consequences are discussed.

Custody plans among parents living with human immunodeficiency virus infection

Rotheram-Borus MJ, Lester P, Wang PW, Shen Q

Arch Pediatr Adolesc Med. 2004 Apr;158(4):327-32

This US study explores custody plans for 296 parents of 708 children over a five-year period. With time, the number of parents who had made custody plans increased from 23 to 52%. Most provide custody arrangements with family members. Many change plans over time. Nearly half (44.8%) had died leaving no custody plans. The study highlights the importance of custody planning and explores factors which are associated with lack of such plans.

Widows' and orphans' property disputes: the impact of AIDS in Rakai District, Uganda

Roys C

Dev Pract. 1995 Nov;5(4):346-51

This study explores some of the property rights and disputes which arise on parental death and will affect the welfare of offspring in the future. The author cautions against the glib use of the concept of women empowerment, and promotes the need for economic independence and rights.

Children orphaned by AIDS: A global perspective

Shetty AK and Powell G

Seminars in Pediatric Infectious Disease 2003 January 14(1):25-31

This study discussed the international orphan crisis caused by HIV/AIDS. Sub-Saharan Africa is the most severely affected, accounting for more than 80% of those orphaned as a result of AIDS. Combining local and international responses to deliver protection and services to all orphans and vulnerable children is critical. Saving the lives of parents through access to antiretroviral therapies in resource-poor countries in conjunction with bold support for alleviation of poverty and education must be an integral part of the global response to the orphan crisis in sub-Saharan Africa.

AIDS and orphans: legal and ethical issues

Siamwiza R

SAfAIDS News. 1998 Mar;6(1):15-6.

This paper examines rights surrounding AIDS and orphans in Zambia. The differences between civil and customary law are examined and the rights of adoptive kin are explored. This includes property rights, rights to know the health of the child and for the child to know the health of the foster parents.

Zambia's AIDS orphans will change the structure of society

Webb D

AIDS Anal Afr. 1996 Jun;6(3):10-1

This study notes that 10–15% of the rural population and 25–30% of the urban population are HIV positive. With this high level of infection rates, mortality increases and will continue to do so, increasing the numbers

of orphans. A 1993 survey noted that 42% of the households cared for an HIV-related orphan. By 1995, data showed that 53.9% of orphans have lost a father, and 18% their mother. Double orphanhood continues to increase. The paper explores living standards of orphans and how they and the society cope with the situation.

The impact of HIV/AIDS on child survival and development in Kenya

Wekesa E

AIDS Anal Afr. 2000 Jan;10(4):12-4

This paper describes the widespread effect of HIV on child development and child survival. Well being worsens in a spiral of economic and social effects including poverty, sex work, poor environmental sanitation, lack of access to clean water. The author points out how more and more children will become vulnerable.

The real challenges: The orphan generation and employment creation

Whiteside A

AIDS Anal Afr 2000 January 10(4):14-5

This study considers that one million children under the age of 15 are projected to lose their mothers by 2005 due to AIDS. These orphans are less likely to receive adequate parenting, education, and nutrition; others will seek to survive on the streets and thus will be more likely to face sexual abuse and exploitation. The long-term impact of HIV/AIDS on both the children and society will be severe. The orphans that AIDS is creating pose serious social, economic, political, and developmental challenges for South Africa. There are two options left for the government: (1) dramatically increasing welfare grants and staffing of welfare departments in order to care for the orphans; (2) find new imaginative measures of meeting the challenge. In addition, provision of employment for its population is another challenge the region is facing. Having the required resources and infrastructure, a potential intervention for South Africa would be training and employing a new cadre of workers to care for AIDS orphans.

Parental and family effects – mothers/fathers and grandparents

HIV is said to be a disease of families. This section gives an overview of literature exploring a variety of perspectives, including parental and family effects in general, families, mothers, fathers and grandparents

Research on families and pediatric human immunodeficiency virus disease: A review and needed directions

Cohen FL

Journal of Development Behaviour Pediatric 1994 June 15(3): S34-42

The authors evaluate the long-lasting effects of pediatric HIV disease within families. There is little in the research literature about normal family functioning under these conditions. Many older studies of childhood illness were based on negative assumptions and did not address concepts such as resiliency. Family theories, approaches, and common themes are briefly discussed. The few studies addressing families and pediatric HIV disease are reviewed and recommendations are made for future research directions.

Effects of home environment, socioeconomic status, and health status on cognitive functioning in children with HIV-1 infection

Coscia JM, Christensen BK, Henry RR, Wallston K, Radcliffe J and Rutstein R

Journal of Pediatric Psychology 2001 September 26(6):321-9

The objective of this article was to investigate the effects of the home environment, socioeconomic status (SES) and health status on cognitive functioning in a sample of 43 children with HIV-1 infection in a cross-sectional study. The home environment is associated with cognitive functioning among children with HIV-1 infection. Moreover, interventions aimed at enhancing the quality of the home environment may have a positive impact on these children's cognitive development.

Child-rearing practices of primary caregivers of HIV-infected children: An integrative review of the literature

Klunklin P and Harrigan RC

Journal of Pediatric Nursing 2002 August 17(4):289-96

The purpose of this article is to describe what is known about the child-rearing practices of primary caregivers of HIV-infected children. Themes that emerged were: caregiver, child and interactions or child-rearing practices. These findings affirm the parent-child interaction model generated by Kathryn E. Barnard and support this framework as a tool for investigating the relationships between these children and their caregivers.

Who are the primary caretakers of children born to HIV-infected mothers? Results from a multistate surveillance project

Schable B, Diaz T, Chu S.Y, Caldwell MB, Conti L, Alston OM, Sorvillo F, Checko PJ, Hermann P and Davidson AJ et al

Pediatrics 1995 Apr;95(4):511-5

This study determines the primary caretakers of children born to women with HIV infection. Mothers with HIV, often alone, are the primary caretakers of their children. Increased provisions for child care assistance and planning for future permanent placement of orphaned children are urgently needed.

Families

The child in the family—responding to AIDS and HIV

Melvin D, Sherr L

AIDS Care 1993;5(1):35-42

This study examines the psychosocial needs of children with AIDS and HIV infection based on a cohort of 18 infected children. Fifteen of the children live with their mothers, nine of whom are single mothers. For 14 children the mother is HIV+ and for a further eight the father is also HIV+. Many children have siblings (10), but only one of these is infected. Close family and grandparents are rarely involved in care and only one child, the oldest, is aware of parental and personal HIV status. Where children attend school or preschool centres, none have been informed of the child's HIV infection. Cultural issues are prevalent, especially marked when English is not the first language (n = 10), which renders obstacles for counselling and developmental appraisal. Children in this group are hospitalised more frequently than the parents. Child and parental hospitalisation is problematic. Three case situations arising in this group are described in some detail to highlight the nature of the emotional challenges facing carers and service providers.

Challenges of parenting for families living with HIV/AIDS

Antle BJ, Wells LM, Goldie RS, DeMatteo D and King SM

Social Work 2001 April 46(2):159-69

This article reviews relevant literature and reports on the parenting needs which emerged in a Canadian study which examined the experiences of 105 mothers and fathers living with HIV/AIDS, with the majority of the children not being HIV positive. In the study, parenting was found to be a source of joy and an additional challenge in an already complicated life. Important new themes were family life as precious time, focused parenting, the different effects of HIV/AIDS, the parenting preparation needs of fathers and the efforts to parent affected and infected children differently.

“At my age I should be sitting under that tree”: The impact of AIDS on Tanzanian lakeshore communities

Appleton J

Gender Development 2000 July 8(2):19-27

This article gives an outsider's analysis of the ways in which AIDS was changing livelihoods in poor fishing and farming communities. On the lakeshore and islands, adults were falling ill and were dying. This loss of men and women in their prime was causing major economic and social stresses for the single parents, grandparents and orphans whom the authors met. They showed resilience and adaptability in the face of this threat to their already precarious livelihoods. The article ends by suggesting ways in which development policy makers and practitioners should support livelihoods in the era of AIDS.

Psychological adjustment in caregivers of school-age children infected with HIV: Stress, coping, and family factors

Bachanas PJ, Kullgren KA, Schwartz KS, McDaniel JS, Smith J and Nesheim S

Journal of Pediatric Psychology 2001 September 26(6):331-42

This study aims to assess for significant differences in psychological functioning between caregivers of HIV-infected children and caregivers of healthy children, and to examine the utility of applying a stress and coping model to caregivers of children with HIV disease. High rates of psychological distress were observed in caregivers of children with HIV disease; however, similarly high rates of psychological adjustment problems were found in caregivers of healthy children. Caregivers who reported high levels of daily stress and emotion-focused coping styles tended to report more psychological distress.

The impact of HIV on family size preference in Zambia

Baylies C

Reprod Health Matters 2000 May; 8(15):77-86

This paper examines the impact HIV has on decision making among families about family size. HIV risk and conception were often not linked. Yet in some cases concerns about possible HIV infection had affected decisions for reduced numbers of children. Although limits on family size were considered in the light of burdens, fuelled at times by HIV and HIV/orphan considerations, many expressed a view of limited personal control, which may affect the extent to which they perceive or act upon fertility rights and decision making.

Social care of children born to HIV-infected mothers in Europe European Collaborative Study

Thorne C, Newell M.L and Peckham C

AIDS Care 1998 February 10(1):7-16

This article describes the family circumstances and social care of 1,123 children born to HIV-infected women enrolled in the European Collaborative Study and followed prospectively from birth. Whether or not a child was infected did not influence the likelihood of living in alternative care. Maternal injecting drug use, single parenthood and health status were the major reasons necessitating alternative care, with the type of alternative care varied according to maternal characteristics, child's age and geographic location.

Stresses on grandparents and other relatives caring for children affected by HIV/AIDS

Linsk NL and Mason S

Health Soc Work 2004 May; 29(2):127-36

This study sets out the complex emotional and behavioural issues stressing HIV-affected kin caregivers. The core issues related to child behaviour, HIV-linked concerns, adolescent issues, sexual abuse, emotional difficulties.

Impact of the HIV epidemic on population and household structure: the dynamics and evidence to date

Heuveline P

AIDS 2004 Jun;18 Suppl 2:S45-53

This review paper utilises demographic theory to explore changes over time of the impact of HIV on households. They note some male:female ratio changes. Orphans and widows are increasing in the most HIV-affected countries. Notably the number of double orphans are increasing, but overall they continue to live with a family member, most often grandparents, if there is no surviving parent.

Impact of HIV on families of HIV-infected women who have recently given birth, Bangkok, Thailand

Manopaiboon C, Shaffer N, Clark L, Bhadrakom C, Siriwasin W, Chearskul S, Suteewan W, Kaewkungwal J, Bennetts A and Mastro TD

Journal of Acquired Immune Deficiency Syndrome Human Retroviral 1998 May 1;18(1):54-63

The objective of this study was to assess changes in the family situation of 129 HIV-infected women who have recently given birth. Within 2 years after childbirth, substantial change within the families of HIV-infected women was evident. These were manifest by partner illness or death, family separation, reduced family income, shifting responsibilities for child care, and signs of depression and isolation.

Families affected by pediatric acquired immunodeficiency syndrome: Sources of stress and coping

Mellins CA and Ehrhardt AA

Journal of Development Behaviour Pediatrics 1994 Jun; 15(3):S54-60

This study explores stress and coping among inner-city, ethnically diverse families with HIV-infected children. Compared with uninfected caregivers, HIV-infected parents reported more isolation and fewer financial and support resources. All children were particularly vulnerable to separations and loss, with uninfected siblings reporting anger and burden from caregiving tasks. Although some families had coping resources, many families might benefit from family-focused mental health services, particularly those that reduce isolation, promote family functioning and provide respite care.

Psychological distress in family members living with human immunodeficiency virus/acquired immune deficiency syndrome

McShane RE, Bumbalo JA and Patsdaughter CA

Arch Psychiatr Nurs 1994 February 8(1):53-61

This article describes the psychological distress experienced by 133 family members living with HIV/AIDS. The physical and psychological health of individual family members was assessed by the 53-item Brief Symptom Inventory. Parents, siblings, and people living with AIDS (PWAs) reported higher levels of overall distress and scored higher on symptom dimensions and clinically discrete symptoms than normative comparison groups. Implications of these findings for research, clinical practice, and health and social service policy are identified and discussed.

Families affected by HIV: Parents' and children's characteristics and disclosure to the children

Nostlinger C, Jonckheer T, de Belder E, van Wijngaerden E, Wylock C, Pelgrom J and Colebunders R

AIDS Care 2004 Jul;16(5):641-8

This study examines the situation of children born to HIV positive parents in Belgium. 628 patients were included, and it was found that 27% had children under 18 years. 68% of all children were HIV negative. Only 10% of the children were aware of their parent's HIV disease. The authors looked at the complex issues intertwined between HIV, disclosure, migration and illness.

The role of families in adolescent HIV prevention: A review

Perrino T, Gonzalez-Soldevilla A, Pantin H and Szapocznik J

Clinical Child and Family Psychology 2000 June 3(2):81-96

This article reviews empirical research on the role of families in HIV prevention, discusses current intervention efforts that involve families and ecosystems, and addresses prospects and implications for future research and interventions. As the most proximal and fundamental social system influencing child development, families provide many of the factors that protect adolescents from engaging in sexual risk behaviours. Among these are positive family relations, effective communication about sexuality and safer sexual behaviours, enhancement and support of academic functioning, and monitoring of peer activities

The economic burden of illness for households in developing countries: A review of studies focusing on malaria, tuberculosis, and human immunodeficiency virus/acquired immunodeficiency syndrome

Russell S

Am J Trop Med Hyg. 2004 Aug;71(2 Suppl):147-55

This review paper examines economic costs on families of HIV in resource-poor settings. They concluded that the costs for were catastrophic for households, consuming more than a tenth of income, and rarely occurring as a single illness.

The extended family and support for people with AIDS in a rural population in south west Uganda: A safety net with holes?

Seeley J, Kajura E, Bachengana C, Okongo M, Wagner U and Mulder D

AIDS Care 1993; 5(1):117-22

This paper examines the assumption that the extended family in Africa provides a safety net for individuals in times of need. Using data on the care of people with AIDS in a rural population in South-West Uganda, it was found that there was evidence of limited care. Various reasons were given for this by the carers, including lack of food and money for medications and the carer's other family extended responsibilities. The findings suggest that there is a need to question the assumption that the extended family, in the culture under study, is able to provide adequate support for AIDS patients.

Fathers

Assisted reproduction techniques for HIV serodiscordant couples: 18 months of experience

Ohl J, Partisani M, Wittemer C, Schmitt MP, Cranz C, Stoll-Keller F, Rongieres C, Bettahar-Lebugle K, Lang JM and Nisand I

Hum Reprod. 2003 Jun;18(6):1244-9

This study examines the use of artificial insemination techniques in couples where one partner has *HIV* and the other is HIV negative. Assisted reproduction provides HIV+ men with a safe alternative to conception, but techniques for women were less effective.

The right to love: the desire for parenthood among men living with HIV

Paiva V, Filipe EV, Santos N, Lima TN and Segurado A

Reprod Health Matters 2003 Nov;11(22):91-100

In Brazil, 250 men with HIV were studied to explore fathering roles: 80% of men reported a current sexual

partner and many (43%) wanted a child. Information and health care support were lacking. This data was in contrast to similar findings for HIV+ women who had greater levels of information and support, despite a lower rate of sexual partners and subsequently fewer reporting a desire for children.

Father-child contact in inner-city African American families with maternal HIV infection

Pelton J, Forehand R, Morse E, Morse PS and Stock M

AIDS Care 2001 August 13(4):475-80

This study examines father-child contact in inner-city African American families with maternal HIV infection. Participants were 246 African American women, 40% of whom are infected with HIV, and one of their non-infected children. Children from non-infected families were more likely to have fathers who are alive and who are living in the home. In addition, regardless of whether or not the father lived in the home, these children had more frequent father contact than did children from families with maternal HIV infection.

Fatherhood and HIV positive heterosexual men

Sherr L and Barry N

HIV Medicine 2004 5, 258-63

Systematic questionnaire data was gathered from 32 HIV positive men attending an HIV clinic in London. Heterosexual men were rarely given medical advice on reproduction (only 9.4%). Few felt fully informed (21.9%), while many (46.9%) felt uninformed and 28.1% needed more information. Over half would value fertility/fathering consultations, up-to-date information and quick referral to fertility clinics. 43.8% have considered having children and 37.5% had a child prior to HIV diagnosis. HIV status affects views on fathering, and the advent of new treatments changed views in over half. 41% believed they would experience discrimination if they conceived a baby and a quarter would withhold their HIV status when attending antenatal clinics. The majority (81%) believed that a child gave meaning to life and something to live for – only 3.1% felt a child would be a burden. Most men overestimated potential vertical transmission and would value time to discuss fathering and fatherhood. Fatherhood should not be shunned as an issue for all HIV positive men.

Service needs of male caretakers of HIV-infected and affected children: Policy and practice implications

Strug DL and Burr C

Social Work and Healthcare 2003 38(2):73-92

This paper discusses the service needs of male carers (MCs) at Ryan White CARE Act Title IV programs, the challenges providers at these programs face in serving MCs and the strategies they have found effective in working with MCs. Providers report that MCs have specific service needs including the need for emotional support.

Brief report: Fathering a child living with HIV/AIDS: Psychosocial adjustment and parenting stress

Wiener LS, Vasquez MJ and Battles HB

Journal of Pediatric Psychology September 26(6):353-8

The study examines the psychosocial stressors experienced by fathers of children diagnosed with HIV/AIDS. The elevated levels of parenting stress and psychological distress in fathers of children living with HIV suggest the need for additional psychological intervention in this population.

Mothers

Maternal mental health and parenting in poverty

Beeber LS and Miles MS

Annu Rev Nurs Res. 2003;21:303-31

This review examines research, conducted by nurses, on maternal mental health, mothering and child outcomes in the context of rearing children in poverty, focusing on mothers who were either prisoners, homeless or HIV positive. While nurse scientists have made progress in conducting research with mothers rearing children in poverty, there is an urgent need for more developmentally sensitive research aimed at strengthening maternal mental health and assisting mothers to be more effective parents in the midst of the challenges of poverty and welfare reform. By doing so, nursing interventions can improve the child's developmental outcomes.

HIV-positive and AIDS-infected women: challenges and difficulties of mothering

Faithfull J

Am J Orthopsychiatry 1997 Jan;67(1):144-51

This qualitative study reports on the experiences of 12 mothers bringing up their children. Three core themes surrounding their experience related to problems with disclosure, grave fears of infecting children through casual contact, and the effects of grief.

Double binds and the reproductive and mothering experiences of HIV-positive women

Ingram D and Hutchinson SA

Qual Health Res. 2000 Jan;10(1):117-32

Twenty HIV-positive mothers provided in-depth views of the experience of mothering in the presence of HIV. Double-bind problems emerged as a key experience affecting these women.

Defensive mothering in HIV-positive mothers

Ingram D and Hutchinson SA

Qual Health Res. 1999 Mar;9(2):243-58

This study of 18 HIV-positive mothers examined mothering styles. They describe defensive mothering used as a basic social psychological process to respond to both their HIV diagnosis and the stigma of HIV. This defensive reaction in some way provided protection for the children. The tasks involved in the core thinking of these mothers related to HIV prevention. Preparation of their children for a time when they were left without a mother, and self protection.

Mothers living with HIV/AIDS: Mental, physical, and family functioning

Murphy DA, Marelich WD, Dello Stritto ME, Swendeman D and Witkin A

AIDS Care 2002 October 14(5):663-44

In this study the psychological condition of mothers living with HIV, their home life, and how these women function as caretakers with a chronic illness were explored. White mothers were less likely to be severely ill than

all other race/ethnic groups, the level of depression among this sample being associated with poorer cohesion in the family, and with poorer family sociability. Depression was also associated with the mothers being less able to perform tasks that they typically do; children of more depressed mothers had increased responsibilities for household tasks.

Grandparents

Relative caregiving. An effective option for permanency

Adnopoz JA

Child Adolescent Psychiatry Clin N Am 2000 April 9(2):359-73 vii

This article provides a historical overview of child caregiving, describes the complex needs of HIV/AIDS-affected children and their relative caregivers, usually grandparents, and suggests that with necessary supports, placement with relatives can be a thoughtful, realistic option for permanency.

The experience of being a grandmother who is the primary caregiver for her HIV-positive grandchild

Caliandro G and Hughes C

Nursing Research 1998 March-April 47(2):107-13

This study identifies the lived experience of 10 African American and Latino grandmothers as the primary caregivers for their grandchildren who are HIV-infected or have AIDS, and to identify the similarities and differences between the two groups. It was found that although there were differences related to family structure and cultural backgrounds, the grandmothers were more alike than different.

The prevalence of grandmothers as primary caregivers in a poor pediatric population

Joslin D and Brouard A

Journal of Community Health 1995 October 20(5):383-401

This study is the first in the USA to determine the prevalence of older surrogate parents among HIV-positive families registered at pediatric clinics. The young ages of the children suggest that many grandparents may continue to be caregivers as they reach their sixties, seventies and even eighties. Given the stresses associated with caregiving in late life and the greater risk of poor health among low-income African-American and Hispanic elderly, older surrogate parents from these communities are a potentially high health-risk population whose own needs may go unrecognised and unattended. Coordination between health and social services for the elderly and for children are needed to promote effective programs for these families.

Self-reported physical health among older surrogate parents to children orphaned and affected by HIV disease

Joslin D and Harrison R

AIDS Care 2002 October 14(5):619-24

An exploratory study found older relatives, largely grandparents, have become the surrogate parents to children and adolescents orphaned by parental death from HIV/AIDS and to those whose infected parents are too ill to serve as their primary caregivers. Largely invisible to research, programme and policy initiatives, these older

surrogate parents face compounded stress and the risk of neglected and compromised health. Fifty-five per cent rated their own health as 'fair' or 'poor' and 70% reported having insufficient time to attend to their own health. Supportive services are needed to address the health needs of these 'hidden patients'.

“Retirement lost” – The new role of the elderly as caretakers for orphans in Western Kenya

Nyambedha EO, Wandibba S and Aagaard-Hansen J

Cross Cult Gerontol. 2003 Mar 18(1):33-52

A study on the new role of the elderly as caretakers of orphans was conducted in a rural part of Kenya, applying a combination of qualitative and quantitative methods. One out of three children had lost at least one biological parent and one of nine had lost both. Most orphans were cared for by relatives, and about one out of five caretakers was 55 years of age or above. These elderly caretakers faced major difficulties in caring for the orphans in terms of schooling, food and medical care. There is a major difference between the present hardships of these caretakers and the traditional position of the elderly in the past. This dramatic deterioration in the situation of the elderly should be seen in the context of the rampant HIV/AIDS epidemic, population growth, changing socio-cultural values, and unfavourable macroeconomic trends.

Parentless children

HIV infection may be the root cause of parentless children, but this brief summary of studies provides insights into the more general literature and learning on the subject.

Longitudinal change in parenting associated with developmental delay and catch-up

Croft C, O'Connor T.G, Keaveney L, Groothues C and Rutter M

Journal of Child Psychology and Psychiatry 2001 July 42(5):649-59

The current study examined the predictors of parent-child relationship quality and developmental change in a sample of 158 children adopted into the UK following severe early privation, and in a comparison sample of nondeprived, within-country adoptees. Results indicated that adoptive parent-child relationship quality was related to duration of deprivation and that cognitive/developmental delay mediated this association. Longitudinal analyses revealed that positive change in parent-child relationship quality was most marked among children who exhibited cognitive catch-up between assessments. The direction of effects appeared to be primarily child to parent.

Child-parent attachment following early institutional deprivation

O'Connor TG, Marvin RS, Rutter M, Olrick JT and Britner PA

Dev Psychopathol 2003 Winter 15(1):19-38

Child-parent attachment quality with an adoptive caregiver at the age of 4 was examined in a sample of 111 children adopted into the UK following early severe deprivation in Romania and a comparison group of 52 nondeprived within-UK adoptees. Findings indicated that, compared with nondeprived adoptees, children who experienced early severe deprivation were less likely to be securely attached and more likely to show atypical patterns of attachment behaviour; ordinary forms of insecure attachment were not associated with deprivation. Within the sample of deprived adoptees, there was a dose-response association between duration of deprivation and disturbances in attachment behaviour. In addition, a minority of children who experienced severe early deprivation were classified as avoidant, secure, or dependent using conventional classification strategies, despite also exhibiting atypical patterns of attachment behaviours, and this was also more likely among children exposed to prolonged deprivation.

Some determinants of individual differences in the behaviour of children of parentally deprived parents

Sigal J.J, Meislova J, Beltempo J and Silver D

Canadian Journal of Psychiatry 1988 February 33(1):51-6

This study allowed parents who had been placed in an orphanage as children to rate the behaviour of all their children who were between the ages of 6 and 18 years on a children's behaviour survey instrument. A significant number of relationships were found between parental background variables and higher reported levels of conflict with siblings and with parents, dependent-unassertive behaviour, and undemandingness in the children. The results suggest that repercussion of events in the lives of the first and second generation which are usually pathogenic may be seen in the third generation, even when the second generation may not be grossly adversely affected. These events most frequently related to individual differences in the third generation in the area of undercontrol of aggression directed toward parents and siblings.

Unwanted infants: Psychological and physical consequences of inadequate orphanage care 50 years later

Sigal JJ, Perry JC, Rossignol M and Ouimet MC

American Journal of Orthopsychiatry 2003 January 73(1):3-12

The authors' study of the effects in middle-aged adults of institutionalisation at birth or early childhood is rare. The results show that members of a randomly selected, middle-aged group of orphans, most of whom were institutionalised at birth, were significantly more psychosocially dysfunctional and had significantly more chronic illnesses that could be stress related than a randomly selected, matched community sample.

Infant growth in the context of: A comparative study

Stein A, Murray L, Cooper P and Fairburn CG

Psychol Med 1996 May 26(3):569-74

The aim of the study was to examine whether there is a specific relationship between maternal eating disorders and maternal depression. The infants of mothers with eating disorders were compared with infants of mothers with post-natal depression and a large comparison group. The study also aimed to explore possible mechanisms for growth disturbance. It was found that the infants of mothers with eating disorders were smaller, both in terms of weight for length and weight for age, than either comparison group infants or infants of mothers with post-natal depression. There was little evidence, however, that mothers with eating disorders preferred smaller children or were dissatisfied with their children's shape or that they misperceived their children's size. On the contrary, the mothers seemed highly sensitive to their children's shape and, compared with the other two groups, were more likely to judge their children's size accurately. None of these maternal measures significantly predicted the child's growth. The mechanism whereby growth disturbance arises in the context of eating disorders does not appear to be by means of a direct extension of the maternal psychopathology to the infant.

The orphans of Eritrea: Are orphanages part of the problem or part of the solution?

Wolff PH and Fesseha G

American Journal of Psychiatry 1998 October 155(10):1319-24

This study compares the mental health and cognitive development of 9- to 12-year-old Eritrean war orphans living in two orphanages which differed qualitatively in patterns of staff interaction and styles of child-care management. When orphanages are the only means of survival for war orphans, a group setting where the staff share in the responsibilities of child management, are sensitive to the individuality of the children and establish stable personal ties with the children, serves the emotional needs and psychological development of the orphans more effectively than a group setting that attempts to create a secure environment through an authoritative style of management with explicit rules and well-defined schedules.

Physical development

These studies report on insights into physical development and HIV. It is difficult to draw the line between purely physical parameters and psychosocial aspects of development.

Growth in early childhood in a cohort of children born to HIV-1-infected women from Durban, South Africa

Bobat R, Coovadia H, Moodley D, Coutsooudis A and Gouws E

Ann Trop Paediatric 2001 September 21(3):203-10

This study describes growth in a cohort of black South-African children born to HIV-1-infected women in Durban. Infected children born to HIV-positive women have early and sustained stunting and are malnourished but not wasted. Children with rapidly progressive disease have both stunting and wasting and are more severely affected. Early nutritional intervention might help prevent early progression or death in HIV-infected children, particularly in developing countries without access to anti-retroviral therapy in state hospitals.

Delayed onset of pubertal development in children and adolescents with perinatally acquired HIV infection

Buchacz K, Rogol AD, Lindsey JC, Wilson CM, Hughes MD, Seage GR, Oleske JM and Rogers AS

Journal Of Acquired Immune Deficiency Syndrome 2003 May 1;33(1):56-65

The authors examine whether greater severity of HIV infection is associated with delayed initiation of pubertal development among perinatally HIV-infected children, and to compare sexual maturation of perinatally HIV-infected children with children in the general US population, using the National Health and Nutrition Examination Survey III. Immunosuppression was associated with delayed pubertal onset in perinatally HIV-infected children.

Survival, disease manifestations, and early predictors of disease progression among children with perinatal human immunodeficiency virus infection in Thailand

Chearskul S, Chotpitayasunondh T, Simonds RJ, Wanprapar N, Waranawat N, Punpanich W, Chokeyhaibulkit K, Mock PA, Neeypun K, Jetsawang B, Teeraratkul A, Supapol W, Mastro TD and Shaffer N

Pediatrics 2002 August 110(2 Part 1): e25

The authors describe survival and signs of HIV infection in perinatally infected children in Thailand. Among HIV-infected Thai children, survival times are longer than among children in many African countries, but shorter than among children in the USA and Europe. Signs of HIV develop early in most children.

Health and nutritional status of orphans <6 years old cared for by relatives in western Kenya

Lindblade KA, Odhiambo F, Rosen DH and DeCock KM

Trop Med Int Health 2003 Jan;8(1):67-72.

This study in rural Kenya looks at health and nutritional indicators in orphaned (single and double) and non-orphaned children below the age of 6. 1190 children were followed up after one year in 60 villages. 7.9% of the children had lost one or both their parents (6.4% had lost their father, 0.8% had lost their mother and 0.7% had

lost both parents). There were no differences in outcomes for orphans and non-orphans on some key health measures in the short term, but longer term-data was needed to note subtle changes on child health.

Head growth and neurodevelopment of infants born to HIV-1-infected drug-using women

Macmillan C, Magder L.S, Brouwers P, Chase C, Hittelman J, Lasky T, Malee K, Mellins CA and Velez-Borras J
Neurology 2001 October 23;57(8):1402-11

The objective of the study was to describe neurodevelopment and head growth in HIV-1-infected and exposed uninfected infants with and without in utero exposure to opiates and cocaine. It was found that HIV-1 infection and in utero opiate and cocaine exposure decrease birth head circumference and slow neurodevelopment at 4 months. At 24 months of age, however, only HIV-1 infection is associated with decreased neurodevelopment and head circumference. There may be some postnatal recovery from the effects of in utero hard drug exposure.

Puberty in perinatal HIV-1 infection: A multicentre longitudinal study of 212 children

Martino M, Tovo PA, Galli L, Gabiano C, Chiarelli F, Zappa M, Gattinara GC, Bassetti D, Giacomet V, Chiappini E, Duse M, Garetto S and Caselli D
AIDS 2001 August 17;15(12):1527-34

The study aimed to define age at entry into Tanner stages in children with perinatal HIV-1 infection. Perinatal HIV-1 infection interferes with sexual maturation. The mechanisms by which this occurs should be elucidated and intervention strategies designed. Intervention could save much psychological distress, since associated linear growth failure can exacerbate adolescents' feelings of being different and unwell.

Growth, morbidity, and mortality in a cohort of institutionalized HIV-1-infected African children

Nathan LM, Nerlander LM, Dixon JR, Ripley RM, Barnabas R, Wholeben BE, Musoke R, Palakudy T, D'Agostino A and Chakraborty R
Journal of Acquired Immune Deficiency Syndrome 2003 October 1;34(2):237-41

The study characterises patterns of morbidity and mortality among HIV-1-infected children residing at an orphanage in Nairobi. The optimal form of care for HIV-infected children in resource-poor settings may be the development of similar homes. Absence of tuberculosis disease in long-standing residents may have contributed to improved survival. Stunting in the absence of wasting implied that growth was compromised by opportunistic infections and other cofactors.

Height, weight and growth in children born to mothers with HIV-1 infection in Europe

Newell ML, Borja MC and Peckham C
Pediatrics 2003 January 111(1): e52-60

The objective of this study was to describe the height and weight growth patterns in 184 infected and 1403 uninfected children who are born to HIV-infected mothers. It was found that neither height nor weight was associated significantly with the main effects of HIV infection status at birth, but differences between infected and uninfected children increased with age.

Brief report: HIV-exposed newborns show inferior orienting and abnormal reflexes on the Brazelton Scale

Scafidi F and Field T

Journal of Pediatric Psychology 1997 February 22(1):105-12

The authors assessed 48 infants of HIV-positive and HIV-negative mothers on the Brazelton Neonatal Behavioral Assessment Scale. Infants exposed to HIV-positive mothers were disadvantaged from birth, because their mothers had obstetric complications and the infants had orienting problems and abnormal reflexes on the Brazelton Newborn Scale. These problems may be early precursors of the later visual-spatial delays and hypertonicity noted in these infants.

Psychological and behavioural development

These studies summarise the array of psychological and behavioural aspects of child development in the presence of HIV.

Predictors of psychological adjustment in school-age children infected with HIV

Bachanas PJ, Kullgren KA, Schwartz KS, Lanier B, McDaniel JS, Smith J and Nesheim S

Journal of Pediatric Psychology 2001 September 26(6):343-52

This study assesses for significant differences in psychological functioning between HIV-infected children and a demographically matched healthy control group and to examine the utility of applying a stress and coping model to children with HIV disease. Approximately 25% of children with HIV exhibited clinically significant emotional or behavioural problems; however, even higher rates of psychological adjustment problems were found in healthy children. Children with HIV disease who have not been told their diagnosis and children who endorse more emotion-focused coping strategies tend to exhibit more psychological adjustment problems.

Risk and resilience in the cognitive functioning of children born to HIV-1-infected mothers: A preliminary report

Coscia JM, Christensen BK and Henry RR

Pediatric AIDS HIV Infection 1997 April 8(2):108-13

This study explored the age-dependent differential impact of such risk factors on the cognitive functioning of 82 children exposed in utero to HIV-1. These findings support a risk and resilience model of development. That is, in the context of biologic risk factors, aspects of the child's environment may either facilitate or hinder cognitive development.

Behavioral and psychological disorders in uninfected children aged 6 to 11 years born to human immunodeficiency virus-seropositive mothers

Esposito S, Musetti L, Musetti MC, Tornaghi R, Corbella S, Massironi E, Marchisio P, Guareschi A and Principi N

Journal of Development and Behaviour of Pediatrics 1999 December 20(6):411-7

This study investigates the behavioural and psychological differences between 39 uninfected children born to HIV-seropositive mothers. The uninfected children revealed significantly more problems of social adjustment and attention and more externalizing symptoms than did the control children. Difficulties in verbal recall included aspects of depressive and anxious feelings; on the narrative task measure, uninfected children showed poorer skill in free verbal recall than did control children, and they simplified episodes with mixed emotions.

Brief report: Relationship between HIV infection and WPPSI-R performance in preschool-age children

Fishkin PE, Armstrong FD, Routh DK, Harris L, Thompson W, Miloslavich K, Levy JD, Johnson A, Morrow C, Bandstra ES, Mason CA and Scott G

Journal of Pediatric Psychology 2000 July - August 25(5):347-51

The study determines the neurodevelopmental effects of perinatally acquired HIV infection on children of preschool age. It was concluded that gross cognitive deficits are not evident among preschool children infected with HIV relative to matched controls.

Psychological aspects of HIV infection in children

Forsyth BW

Child and Adolescent Psychiatry Clinic North America 2003 July 12(3):423-37

This study examines the increasing number of children and adolescents personally affected by the epidemic. The psychological effects on these children are significant and relate not only to a parent's degree of illness and the threat of death, but also to the association of the disease with substance abuse and the pervasive effects of the stigma that surround it. To intervene optimally on behalf of these children, programs must be multidisciplinary and take a holistic approach to address specific social and psychological issues and ensure stability in a child's care giving.

The psychological effects of parental human immunodeficiency virus infection on uninfected children

Forsyth BW, Damour L, Nagler S and Adnopoz J

Arch Pediatr Adolesc Med. 1996 October 150(10):1015-20

The mental health of 26 children of mothers infected with HIV was assessed. This study, focusing specifically on uninfected children in families affected by HIV, demonstrates some of the psychological ramifications of the disease. Attention needs to focus on ameliorating these adverse effects on the children of the AIDS epidemic.

Psychiatric hospitalizations among children and youths with human immunodeficiency virus infection

Gaughan DM, Hughes MD, Oleske JM, Malee K, Gore CA, Nachman S: Clinical Trials Group

Pediatrics 2004 June 113(6): e544-51

The Pediatric AIDS Clinical Trials Group (PACTG) 219C is a study designed to examine long-term outcomes among HIV-infected children and HIV-uninfected infants born to HIV-infected women. Children with HIV/AIDS are at increased risk for psychiatric hospitalisations during childhood and early adolescence, compared with the general pediatric population. Knowledge of HIV seropositivity status and recent significant life events were significantly associated with increased risks of admission in this population.

Psychiatric morbidity in school-age children with congenital human immunodeficiency virus infection: A pilot study

Havens JF, Whitaker AH, Feldman JF and Ehrhardt AA

Journal of Development Behaviour Pediatric 1994 June 15(3): S18-25

This study examined the relationship between HIV infection and psychiatric morbidity within the context of prenatal drug exposure. Twenty-six HIV-infected, 14 seroreverted, and 20 control (non-HIV-exposed) children were studied. There was some suggestion that the HIV-infected children were experiencing higher levels of subjective distress than did either the nonexposed or seroreverted children. The possible relevance of drug exposure to the behavioural outcomes observed here is discussed, as well as the importance of using age-appropriate materials to elicit subjective distress in HIV-infected school-age children.

Behavioral adaptation to human immunodeficiency virus-seropositive status in children and adolescents with hemophilia

Hooper SR, Whitt JK, Tennison M, Burchinal M, Gold S and Hall C

American Journal Dis Child 1993 May 147(5):541-5

This study examines the behavioural adaptation to HIV-seropositive status, as defined by parental report, in children and adolescents with haemophilia. The current findings failed to confirm any clear evidence of behavioural problems in an asymptomatic group of HIV-seropositive children and adolescents with haemophilia.

Brief report: Effects of pediatric HIV infection on mental and psychomotor development

Knight WG, Mellins CA, Levenson RL Jr, Arpadi SM and Kairam R

Journal of Pediatric Psychology 2000 December 25(8):583-7

The investigators examine the effect of HIV status on infants' mental and psychomotor functioning, controlling for confounding factors such as prenatal drug exposure and birth conditions. The data suggests that CNS involvement is a critical pathway by which HIV affects infants' neurodevelopment.

Longitudinal correlates of depressive symptoms among urban African American children: Extension of findings across 3 years

Maikranz JM, Steele RG and Forehand R

Journal of Clinical Child and Adolescent Psychology 2003 December 32(4):606-12

The study examines the association between childhood self-reported depressive symptoms and two areas of child psychosocial functioning: social and cognitive competence. The analyses indicated that Children's Depression Inventory (CDI) scores at the initial assessment predicted changes in mother-reported social competence from the initial assessment to the latter assessment. The study also examined the impact of an additional stressor, maternal HIV infection, on this same relation. The analyses indicated that maternal HIV infection did not moderate the relation between childhood self-reported depressive symptoms and later competence.

Effects of pediatric HIV infection and prenatal drug exposure on mental and psychomotor development

Mellins CA, Levenson RL Jr, Zawadzki R, Kairam R and Weston M

Journal of Pediatric Psychology 1994 October 19(5):617-27

The study examines the effects of HIV infection and prenatal drug exposure on infant neurodevelopmental functioning. Children who were both HIV-infected and prenatally drug exposed performed significantly lower on both the mental and psychomotor scales of the Bayley. Drug exposure and neurological dysfunction were associated with mental development, whereas neurological dysfunction, drug exposure and HIV status were associated with psychomotor development.

High rates of behavioral problems in perinatally HIV-infected children are not linked to HIV disease

Mellins CA, Smith R, O'Driscoll P, Magder LS, Brouwers P, Chase C, Blasini I, Hittleman J, Llorente A and Matzen E

Pediatrics 2003 February 111(2):384-93

The authors examine the unique and combined influences of HIV, prenatal drug exposure and environmental factors on behaviour in 307 children who were perinatally exposed to HIV. This study suggests that although a high prevalence of behavioural problems does exist among HIV-infected children, neither HIV infection nor prenatal drug exposure is the underlying cause. Rather, other biological and environmental factors are likely contributors toward poor behavioural outcomes.

HIV infection in London children – Psychosocial complexity and emotional burden

Melvin D and Sherr L

Child Care Health Dev. 1995 Nov;21(6):405-12.

This paper provides an overview of a group of children with HIV attending a specialist child HIV clinic in London. The range of bereavement, disclosure, separation, illness and psychological needs are described.

School-age children with perinatally acquired HIV infection: Medical and psychosocial issues in a Philadelphia cohort

Mialky E, Vagnoni J and Rutstein R

AIDS Patient Care STDS 2001 November 15(11):575-9

This study was designed to explore some of the medical, educational and psychosocial aspects of perinatally acquired HIV among 85 older children. More than half required some special services while in school, and as the perinatally acquired HIV-infected population ages, health care providers must be cognisant of the range of issues, both medical and social, confronting these children.

A preliminary study of factors associated with psychological adjustment and disease course in school-age children infected with the human immunodeficiency virus

Moss H, Bose S, Wolters P and Brouwers P

Journal of Development and Behaviour of Pediatrics 1998 February 19(1):18-25

This study examines factors associated with psychological adjustment in a sample of 24 school-age children infected with HIV. Measures of depression, anxiety, and self-concept were administered to the children, and measures of behavioural problems, social functioning, and negative life events were administered to the parents. Generally, psychological adjustment seemed stable, though a decrease in positive social self-concept over time was observed. Negative life events were significantly associated with greater adverse psychological and behavioural outcomes.

Impairment of expressive behavior in pediatric HIV-infected patients with evidence of CNS disease

Moss HA, Wolters PL, Brouwers P, Hendricks ML and Pizzo PA

Journal of Pediatric Psychology 1996 June 21(3):379-400

Rated observations of videotapes were made of 16 variables representing five behavioural domains (task orientation, positive social-emotional, motor skills, expressive speech and activity) on a sample of 83 HIV-infected children. Comparisons were made on the rated behaviours between children classified as either encephalopathic or nonencephalopathic. The nonencephalopathic infants exhibited higher activity levels and were superior in motor and verbal skills and showed more social and emotional responsiveness than did the encephalopathic group. The older nonencephalopathic children functioned in a more adaptive and appropriate manner than did the encephalopathic children in all domains of behaviour.

Psychiatric diagnoses in adolescents seropositive for the human immunodeficiency virus

Pao M, Lyon M, D'Angelo LJ, Schuman WB, Tipnis T and Mrazek DA

Arch Pediatr Adolesc Med 2000 March 154(3):240-4

This study provides a descriptive analysis of the prevalence of past and current psychiatric disorders in 34 adolescents positive for HIV. The majority of subjects in this sample had had a previous psychiatric diagnosis, and almost half had a current affective disorder. Psychiatric disorders, especially affective disorders, may be a risk factor for high-risk sexual behaviours and substance use that increases the risk for HIV infection in adolescent populations.

The relationship of maternal and child HIV infection to security of attachment among Ugandan infants

Peterson NJ, Drotar D, Olness K, Guay L and Kiziri-Mayengo R

Child Psychiatry and Human Development 2001 Fall 32(1):3-17

This study examines the relationship of maternal and child HIV infection to the security of attachment of Ugandan infants. No differences were found in the security of attachment of infants of HIV-positive versus HIV-negative mothers. Infants of HIV-positive mothers with AIDS were less securely attached than infants of mothers without AIDS.

Children of injection drug users: Impact of parental HIV status, AIDS, and depression

Pilowsky DJ, Knowlton AR, Latkin CA, Hoover DR, Chung SE and Celentano DD

Journal of Urban Health 2001 June 78(2):327-39

The study investigates the association between parental factors (including infection with HIV, AIDS diagnosis, parental medical illness, and depression) and children's behavioural and emotional problems among children of injection drug users (IDUs). IDUs were recruited through community outreach. The clinical implications are that children of IDUs are known to be at high risk for psychiatric symptoms and disorders; this data suggests that children of depressed and/or medically ill IDU parents may be at even higher risk of symptoms of depression and anxiety symptoms than children of IDUs who do not suffer from these conditions.

Poverty, underdevelopment and infant mental health

Richter LM

J Paediatr Child Health 2003 May-Jun;39(4):243-8

This paper notes how work on infant development and its application to subsequent development is rarely applied in areas of poverty. The combined effects of poverty and AIDS may have long-term consequences. The paper provides strong argument for examining and addressing psychological factors in care providers and children facing poverty life circumstances. A call is made for straightforward interventions based on sound developmental principles.

The psychological effect of orphanhood: a study of orphans in Rakai district

Sengendo J and Nambi J

Health Transit Rev. 1997;7 Suppl:105-24.

193 Ugandan children were examined to monitor psychological effects of orphanhood. The authors set out the range of powerful cumulative negative effects of parental death. They describe three periods of recall: parents alive and well; parents sick; after parents died. Anger and depression were common moods. Differences were seen for children living with widowed fathers who had more negative moods than those living with widowed mothers. The ability of teachers to pick out such emotional states and respond appropriately should be enhanced.

Pregnancy and vertical transmission

HIV can infect a baby during pregnancy, delivery and breast feeding. A number of interventions have been studied to reduce the frequency of such transmission. The following references provide a very brief overview of some of the studies, the complexity of issues and the current state of intervention. Clearly, the issues relate to HIV in the family, pregnancy in the presence of parental HIV and the future physical, mental and social welfare of the new baby.

The situation is complicated by an inexact science, by inequity of access and by the complexities of multiple HIV infection within a family.

Neonatal predictors of infection status and early death among 332 infants at risk of HIV-1 infection monitored prospectively from birth

Abrams EJ, Matheson PB, Thomas PA, Thea DM, Krasinski K, Lambert G, Shaffer N, Bamji M, Hutson D and Grimm K et al

Pediatrics 1995 September 96(3 Pt 1):451-8

This early study of nearly 10 years ago is an example of the early studies showing effects of HIV and vertical transmission. The study examines differences in newborn outcome measures for 84 HIV-1-infected and 248 HIV-1-exposed but uninfected infants. Infants born to women with AIDS are at higher risk for HIV-1 infection than are infants born to HIV-1-infected women with AIDS not yet diagnosed. Women receiving zidovudine appear less likely to transmit HIV-1 to their infants. Significantly higher rates of prematurity and intrauterine growth retardation were found among HIV-1-infected infants than among those in the uninfected, HIV-1-exposed control group.

Antiretroviral therapy in the pregnant woman

Augenbraun M and Minkoff HL

Obstetrics and Gynecology Clin North America 1997 December 24(4):833-54

This article profiles each of the antiretroviral agents currently available, with a focus on issues relevant to the pregnant patient. Strategies for treating the non-pregnant patient and considerations for the use of these strategies in pregnancy also are discussed. Additional information about prophylaxis for common opportunistic infections is included.

Relation of the course of HIV infection in children to the severity of the disease in their mothers at delivery

Blanche S, Mayaux MJ, Rouzioux C, Teglas JP, Firtion G, Monpoux F, Ciraru-Vigneron N, Meier F, Tricoire J and Courpotin C et al.

New England Journal of Medicine 1994 February 3;330(5):308-12

The authors studied the clinical and biologic characteristics of the mothers of infants infected with HIV-1 in the French Prospective Multicenter Cohort. In infants whose HIV infection is maternally acquired, the rate of disease progression varies directly with the severity of the disease in the mother at the time of delivery.

Morbidity and mortality in European children vertically infected by HIV-1. The French Pediatric HIV Infection Study Group and European Collaborative Study

Blanche S, Newell ML, Mayaux MJ, Dunn DT, Teglas JP, Rouzioux C and Peckham C

Journal of Acquired Immune Deficiency Syndrome Human Retroviral 14(5):442-50

Based on 392 infected children enrolled in two European prospective studies of infants born to HIV-infected women, HIV disease progression in the first 6 years of life is described. Most children had developed minor or moderately severe illness in the first 4 years of life, although it was usually transient in nature, with the early, severe form of HIV disease affecting approximately 20% of infants.

Safety of late in utero exposure to zidovudine in infants born to human immunodeficiency virus-infected mothers: Bangkok

Chotpitayasunondh T, Vanprapar N, Simonds RJ, Chokephaibulkit K, Waranawat N, Mock P, Stat MA, Chuachoowong R, Young N, Mastro TD and Shaffer N

Pediatrics 2001 January 107(1): e5

This study explores the effects of giving a short-course of zidovudine (ZDV) in the late antenatal period in order to reduce HIV transmission. It was found that no significant adverse events were associated with short-course ZDV during 18 months of follow-up in this population.

HIV prevalence in pregnant women in an ethnically diverse population in the UK:1998–2002

Cortina-Borja M, Cliffe S, Tookey P, Williams D, Cubitt WD and Peckham C

AIDS 2004 Feb 20;18(3):535-40

This UK study looks at factors associated with HIV infection by studying all the dried spots routinely collected for baby screening and studied anonymously. 491,213 samples were gathered during 1998-2002, and 1,029 were HIV positive. For most, place of birth of mothers was known and it was found for the HIV-positive group: 80.5% of mothers were born in sub-Saharan Africa compared to 11.1% in the UK. If both parents were UK born, the risk of HIV in the sample was 0.016%. The risk of HIV in those from or linked to endemic countries is ongoing.

Prevalence and incidence of vertically acquired HIV infection in the United States

Davis SF, Byers RH Jr, Lindegren ML, Caldwell MB, Karon JM and Gwinn M

JAMA 1995 September 27;274(12):952-5

The objective of this study was to estimate HIV-1 prevalence among childbearing women, HIV incidence in infants, and the number of children living with HIV infection and AIDS as a result of MTCT. Approximately 6530 HIV-infected women gave birth in the USA in 1993, and, based on a 25% vertical transmission rate, an estimated 1630 of their infants were HIV infected. These results provide a basis for estimating medical and other resource needs for HIV-infected women and their children and for measuring the impact of interventions to reduce vertical transmission of HIV.

Selective transmission of multidrug resistant HIV to a newborn related to poor maternal adherence

Desai N and Mathur M

Sex Transm Infect. 2003 Oct;79(5):419-21

This study examined pregnant mothers with HIV, their adherence to antiretroviral treatment, and drug-resistant HIV. The authors found that lowered adherence in mothers was associated with resistant virus strains in the infant, which could jeopardise the baby's treatment options in the future.

Exposure to antiretroviral therapy in utero or early life: The health of uninfected children born to HIV-infected women

European Collaborative Study

Journal of Acquired Immune Deficiency Syndrome 2003 April 1;32(4):380-7

This study analyzed data relating to uninfected children enrolled in the European Collaborative Study and investigated the association between ART exposure, perinatal problems and major adverse health events later in life. There was no evidence of an association with clinical manifestations suggestive of mitochondrial abnormalities. The absence of serious adverse events in this large cohort of uninfected children exposed to prophylactic ART in the short to medium term is reassuring.

Mother-to-child transmission of HIV infection

European Collaborative Study

Lancet 1988 November 5;2(8619):1039-43

The study followed 271 children born to HIV-infected mothers in eight European centres. By June 1988, 45% had been followed for over 1 year: 10 had developed AIDS or AIDS-related complex, all by the age of 9 months, of whom 5 had died. Of 100 children followed for more than 15 months, 19 had persistent antibody, and 5 were antibody-negative but presumed to be infected because of virus isolation or antigen detection; these 5 children were clinically and immunologically normal. The estimated vertical transmission rate was 24%.

Higher rates of post-partum complications in HIV-infected than in uninfected women irrespective of mode of delivery

Fiore S, Newell ML, Thorne C; European HIV in Obstetrics Group

AIDS 2004 Apr 9;18(6):933-8.

This study was set up to examine any side effects of caesarean section deliveries for pregnant women with HIV in 13 European centres from 1992 to 2002, comparing HIV infected women and a control group of women not infected with HIV. The authors found that 29.2% of HIV women had complications, compared to 19.4% for the uninfected women. In general, HIV positive women were at increased risk of post delivery complications and should know about their risks when they make their decisions.

Preventing mother-to-child transmission of HIV in developing countries: recent developments and ethical implications

Hankins C

Reprod Health Matters 2000 May;8(15):87-92.

This paper examines the ethical issues surrounding universal uptake of nevirapine during labour for all mothers without the need to test for HIV as a possible HIV control intervention.

Perinatal transmission of HIV-I in Zambia

Hira SK, Kamanga J, Bhat GJ, Mwale C, Tembo G, Luo N and Perine PL

British Medical Journal 1989 November 18;299(6710):1250-2

The objective of this study was to determine the occurrence of vertical transmission of HIV-1 from women positive for the virus and the prognosis for their babies. It was found that vertical transmission from infected

mothers to their babies is high in Zambia, and prognosis is poor for the babies. Perinatal transmission and paediatric AIDS must be reduced, possibly by screening young women and counselling those positive for HIV-1 against future pregnancy.

A model of mother-child coping and adjustment to HIV

Hough ES, Brumitt G, Templin T, Saltz E and Mood D

Social Science Medical 2003 February 56(3):643-55

The paper reports the results of research designed to examine the pathways by which a mother's HIV-positive status affects the psychosocial adjustment of her uninfected school-age child. The principal predictor variables of the model are family sociodemographic characteristics, social support available to mother and child, HIV-related symptom distress in the mother, coping strategies of both mother and child, emotional distress of the mother and quality of the parent-child relationship.

Prenatal and postpartum zidovudine adherence among pregnant women with HIV: results of a MEMS substudy from the Perinatal Guidelines Evaluation Project

Ickovics JR, Wilson TE, Royce RA, Minkoff HL, Fernandez MI, Fox-Tierney R and Koenig LJ; Perinatal Guidelines Evaluation Group

J Acquir Immune Defic Syndr. 2002 Jul 1;30(3):311-5.

This study explored the rates of adherence to antiretroviral treatment for pregnant HIV-positive women in the USA. They found extremely low adherence – 50% adherent 3 weeks prior to delivery and 34.1% adherent at 3 weeks post delivery. The authors raise the importance of monitoring and supporting adherence to maximise benefit.

Risk of early febrile seizure with perinatal exposure to nucleoside analogues

Landreau-Mascaro A, Barret B, Mayaux MJ, Tardieu M and Blanche S

Lancet 2002 February 16;359(9306):538-4

The frequency of seizures was studied in a prospective cohort of 4426 uninfected French children born to HIV-1-infected mothers. The risk of first febrile seizure was higher for children perinatally exposed to antiretrovirals than for those not exposed. A similar trend was noted for other non-neonatal seizures but not for neonatal seizures

Pregnancy rates and predictors of conception, miscarriage and abortion in US women with HIV

Massad LS, Springer G, Jacobson L, Watts H, Anastos K, Korn A, Cejtin H, Stek A, Young M, Schmidt J and Minkoff H

AIDS 2004 Jan 23;18(2):281-6.

This study explores the effect of new treatments (HAART) on pregnancy rates in the USA across six centres. Women with HIV were found to be less likely to conceive than at-risk women who were uninfected, but pregnancy outcomes were similar. For HIV-positive women, 36% resulted in a live birth, 2% in a still birth, 36% had an abortion, while 24% miscarried. 5% had an ectopic pregnancy. Abortion became less common after the introduction of HAART.

The relationship of pregnancy to human immunodeficiency virus disease progression

Minkoff H, Hershow R, Watts DH, Frederick M, Cheng I, Tuomala R, Pitt J, Zorrilla CD, Hammill H, Adeniyi-Jones SK and Thompson B

American Journal of Obstetrics and Gynecology 2003 Aug;189(2):552-9

This study was undertaken to determine the effect of pregnancy on progression of HIV among 953 women. Women with repeat pregnancies were less likely to be on antiretroviral therapy and had a higher CD4% count immediately after their first delivery, and it was concluded that repeat pregnancies do not have significant effects on the course of HIV.

Human immunodeficiency virus infection in pregnancy

Minkoff H

Obstetrics and Gynecology 2003 April 101(4):797-810

This study discusses the access to therapies which clinicians can now offer to infected women in order to produce children who will be HIV uninfected. In caring for HIV-infected pregnant women and prescribing these medications, obstetricians must always bear in mind their dual responsibilities, providing optimal care to the mother and reducing the likelihood of MTCT of HIV. To accomplish those goals, the physician must first monitor the patient's immunological and virological status, including resistance testing. The results of those tests will guide the clinician in choosing when to initiate therapy and in deciding whether to use regimens directed solely at transmission interruption or those that will simultaneously treat the mother's infection. However, if a woman is not pregnant, then the initiation of therapy can be delayed because long-term adherence with medications can be difficult, side effects are not uncommon, and prognosis is not adversely affected so long as the CD4 count and the viral load remain in a reasonable range. None of the advantages cited above can be achieved, unless all women have their HIV status determined as early in pregnancy as possible.

Advances in the prevention of vertical transmission of human immunodeficiency virus

Mofenson LM

Semin Pediatr Infect Dis. 2003 Oct;14(4):295-308

This review paper gives an overview of infant HIV. The main way in which young children become infected with HIV is through transmission before, during or after birth. Where treatments are readily available, the rate of such infection is less than 2%. In countries where multiple interventions are not readily available, interventions are trailed and effective but implementation is not universal. This paper gives a comprehensive up-to-date review of intervention studies.

Diagnosis of perinatal human immunodeficiency virus infection by polymerase chain reaction and p24 antigen detection after immune complex dissociation in an urban community hospital

Nesheim S, Lee F, Kalish ML, Ou CY, Sawyer M, Clark S, Meadows L, Grimes V, Simonds RJ and Nahmias A
Journal of Infectious Diseases 1997 June 175(6):1333-6

This study compared the results of polymerase chain reaction (PCR) and p24 antigen detection after immune complex dissociation (p24-ICD) with antibody results after 18 months of age for HIV diagnosis in 345 prospectively followed, perinatally exposed infants. It was found that HIV status can be determined by PCR by age 6 months in most HIV-exposed infants. p24-ICD should not be used alone, because of its lower sensitivity, but may be useful in areas without advanced laboratory support.

Prevention of mother-to-child transmission of HIV: Challenges for the current decade

Newell ML

Bulletin World Health Organisation 2001 79(12):1138-44

The authors investigate the achievability of the targets set out by the United Nations Special Assembly on HIV/AIDS for a reduction of 20% and 50% for the numbers of children newly infected with HIV by 2005 and 2010 respectively. Antiretroviral monotherapy during pregnancy, delivery and the neonatal period can reduce the rate of MTCT of HIV-1 by two-thirds in non-breastfeeding populations. Shorter and simpler regimens of monotherapy have been associated with a reduction of 50% in such transmission among non-breastfeeding populations and of up to 40% in breastfeeding populations. Delivery by elective caesarean section is associated with a halving of the risk of MTCT. However, breastfeeding poses a substantial additional risk of acquisition of HIV, and, if prolonged, it more than doubles the overall rate of transmission. Rates below 2% are being reported from settings where combination therapy is applied during pregnancy and delivery, delivery is by elective caesarean section and breastfeeding does not take place.

Social and clinical characteristics of a group of mothers infected with HIV in Valencia Influence of parenteral drug addiction

Sanz Aliaga SA, Sabater Pons A, Alfonso Sanchez JL, Carbajal de Lara JA and Sancho Izquierdo E

2000 December 14(6):429-34

This observational study involved 220 HIV infected women who had recently given birth to children with high risk for infection. The authors evaluate the main social and clinical characteristics of a group of seropositive mothers and analyse their potential relationship with intravenous consumption of drugs. It was found that many of the analysed characteristics in these women were related with the consumption of injected drug rather than with the HIV infection, such as the greater frequency of elective abortions, criminal antecedents, parental abandonment, multiple drug abuse and pathological precedents like hepatitis B or C.

HIV and reproduction

Semprini AE and Fiore S

Current Opinion Obstetrics and Gynecology 2004 June 16(3):257-62

This study explores reproductive behaviour within HIV-positive and serodiscordant couples. It was found that semen washing, reproductive technology, antiretroviral therapy and obstetrical care can work in sequence to allow safe reproduction in couples infected with HIV, and offer a sharp reduction in both sexual and vertical transmission rates.

Prospective cohort study of children born to human immunodeficiency virus-infected mothers, 1985 through 1997: Trends in the risk of vertical transmission, mortality and acquired immunodeficiency syndrome indicator diseases in the era before highly active antiretroviral therapy

Simpson BJ, Shapiro ED and Andiman WA

Pediatric Infectious Disease Journal 2000 July 19(7):618-24

The study assesses changes in the risk of vertical transmission of HIV and changes in both mortality and morbidity among 347 children in southern Connecticut with HIV infection after the introduction of treatment of HIV-infected pregnant women with antiretroviral drugs and of regimens to prevent or to treat AIDS indicator diseases in infected children. A significant decline in the risk of vertical transmission of HIV-1 occurred during the 12-year study period.

Impact of single session post-partum counselling of HIV infected women on their subsequent reproductive behaviour

Temmerman M, Moses S, Kiragu D, Fusallah S, Wamola IA and Piot P

AIDS Care 1990 2(3):247-52

This ongoing study investigates the impact of maternal HIV infection on pregnancy outcome at a large maternity hospital in Nairobi, Kenya, where asymptomatic HIV positive women who had recently delivered were informed of their HIV sero-status and counselled by a trained nurse regarding contraception and reproductive behaviour in a single session. The single session of counselling for the HIV positive women did not seem to influence decisions on subsequent condom use or reproductive behaviour. More intensive approaches to counselling need to be developed and evaluated, but may be difficult to implement in the busy maternity and antenatal clinics commonly found in developing countries.

Are girls more at risk of intrauterine-acquired HIV infection than boys?

Thorne C, Newell ML; European Collaborative Study

AIDS 2004 Jan 23;18(2):344-7

This study was set up to examine some of the gender effects in HIV infection by looking at 3,231 mother-child pairs from Europe. They noted that baby girls were 1.5 times more likely to become HIV infected, but this was limited to caesarean section deliveries.

Characteristics of pregnant HIV-1 infected women in Europe. European Collaborative Study

Thorne C, Newell ML, Dunn D and Peckham C

AIDS Care 1996 February 8(1):33-42

In this paper the authors examine the socio-demographic characteristics and trends in mode of acquisition of infection of 1690 infected women from seven countries enrolled in the European Collaborative Study, a prospective multi-centre study of children born to women known to be HIV infected at or before the time of delivery. Although patterns of transmission varied by centre, there was a relative increase in heterosexual transmission over the study period. A history of needle-sharing among injection drug users was common, but needle-sharing during pregnancy significantly declined between 1987 and 1994.

Management of vertically HIV-infected children in Europe

Thorne C, Gray L and Newell ML; European Collaborative Study

Acta Paediatr. 2003;92(2):246-50

The authors describe policies for the therapeutic management of vertically HIV-infected children, and to compare these with practice, using children enrolled in a cohort study in the same setting. It was found that therapeutic management of paediatric HIV disease requires a balance between preventing disease progression and minimizing adherence problems and side effects.

Antenatal and neonatal antiretroviral therapy in HIV-infected women and their infants: A review of safety issues

Thorne C and Newell ML

Med Wieku Rozwoj 2003 October - December 7(4 Part 1):425-36

This study examined specific interventions to prevent MTCT, including antiretroviral therapy, elective caesarean section and avoidance of breastfeeding. Rates of MTCT below 1–2% are now achievable in developed-country settings. However, although the vast majority of infants born to HIV-infected mothers are protected from acquisition of infection, most are exposed to antiretroviral drugs for which there is only limited information on toxicity. Increasing use of complex and potent combinations of antiretroviral drugs in pregnancy, particularly during the period of organogenesis, has raised many questions relating to pregnancy outcome and safety issues for the exposed children, both in the short and longer term.

Social development

Although it is difficult to draw clear demarcations between psychological and social factors, these studies shed some light on social issues in development in the presence of HIV challenges.

Sociodemographic profile of children affected by AIDS in Addis Ababa

Bedri A, Kebede S and Negassa H

Ethiop Med J. 1995 Oct;33(4):227-34

A survey in Ethiopia in 1993 traced 1,047 AIDS cases, where 59% had died (and 16% of spouses had died). 2,186 children had been born to these individuals, 40% under 15 years of age. 30% had lost either one or two parents. Children also faced illness, school exclusion, abandonment, displacement and a lack of medical care. The authors set out the needs of the children and the importance of community awareness and strengthening.

The HIV/AIDS epidemic in Thailand: Addressing the impact on children

Brown T, Sittitrai W

Asia Pac Pop Policy 1995 Jul-Aug(35):1-4.

This paper describes the high, rapidly growing rate of HIV in children. The authors note the need for action and provide a summary of reports on the impact of HIV on children in Thailand. They describe and explore the structural, legal and social needs and methodologies for responding and reacting to the crisis.

Effects of home environment, socioeconomic status, and health status on cognitive functioning in children with HIV-1 infection

Coscia JM, Christensen BK, Henry RR, Wallston K, Radcliffe J and Rutstein R

Journal of Pediatric Psychology 2001 September 26(6):321-9

This study investigates the effects of the home environment, socioeconomic status (SES) and health status on cognitive functioning in a sample of children with HIV-1 infection. The home environment is associated with cognitive functioning among children with HIV-1 infection. Moreover, interventions aimed at enhancing the quality of the home environment may have a positive impact on these children's cognitive development.

Testing the sexually abused child for the HIV antibody: Issues for the social worker

Gellert GA, Berkowitz CD, Gellert MJ and Durfee MJ

Social Work 1993 July 38(4):389-94

This article discusses the benefits of identifying children who have been infected with HIV through sexual abuse, and it reviews guidelines for testing. Social workers can contribute to test decision-making in instances when perinatal HIV transmission is a possibility, when it may be possible to test the assailant, and when parents or legal guardians insist on testing the child. Other issues discussed include family education and coping, physical education and support, social casework and research with pedophiles and service needs for care and follow-up of children found to be HIV infected as a result of sexual abuse.

Behavioral adaptation to human immunodeficiency virus-seropositive status in children and adolescents with hemophilia

Hooper SR, Whitt JK, Tennison M, Burchinal M, Gold S and Hall C

American Journal of Dis Children 1993 May 147(5):541-5

The study examines the behavioural adaptation to HIV-seropositive status in 46 male children and adolescents with hemophilia. The findings fail to confirm any clear evidence of behavioural problems in an asymptomatic group of HIV-seropositive children and adolescents with hemophilia.

Developmental and service needs of school-age children with human immunodeficiency virus infection: A descriptive study

Papola P, Alvarez M and Cohen HJ

Pediatrics 1994 December 94(6 Pt 1):914-8

This paper describes the developmental functioning and service needs of a group of 90 school-age children with HIV infection. Most of the children in this study demonstrated deficits in the cognitive and learning areas, although they are clearly functioning better than earlier studies of children with HIV infection would have predicted. Their service needs include alternative living arrangements, remedial education and psychotherapeutic interventions. The children's increasing longevity will place strains on the respective service systems.

Children affected by HIV. Clinical experience and research findings

Pilowsky DJ, Wissow L and Hutton N

Child and Adolescent Psychiatry Clinic North America 2000 April 9(2):451 – 64 viii

This article describes the plight of HIV-affected children, and the work of mental health professionals with HIV-affected children and their families, and presents pertinent research findings on the topics. The concepts of prevention, resilience, and family and child development are applied to the organizing of mental health care for HIV affected children.;

Social and family characteristics in children born to women infected by the human immunodeficiency virus

Sanz Aliaga SA, Sancho Izquierdo E, Asensi Botet F and Otero Reigada MC

Aten Primaria 2000 January 25(1):5-10

The study evaluates the social and family characteristics of children born to women infected by HIV. As secondary objectives, it analyses the schooling and the number of hospital admissions and lengths of stay that these children required. Infected children and non-infected children had similar social and family characteristics. However, less schooling, problems of school integration, and more and longer hospital admissions were related to HIV infection in children, and not so much to their status as children of seropositive mothers.

Symptoms in young children

Children with HIV infection may experience a variety of symptoms, with various psychosocial ramifications and needs. This section gives a very brief insight into studies exploring these needs, covering areas such as pain, sleep and illness.

Hospitalization of children born to human immunodeficiency virus-infected women in Europe

European Collaborative Study

Pediatric and Infectious Disease Journal 1997 December 16(12):1151-6

The objective of this study was to describe the pattern of in-patient hospital service use in the first 5 years of life of all children born to HIV-infected women in 10 pediatric centers of the European Collaborative Study. Whereas hospitalisation of infected children poses an expected burden on the health care system, the use of such services by uninfected children is largely explained by their social background and provides an argument for better support for families affected by HIV.

Pain

The prevalence of pain in pediatric human immunodeficiency virus/acquired immunodeficiency syndrome as reported by participants in the Pediatric Late Outcomes Study (PACTG 219)

Gaughan DM, Hughes MD, Seage GR 3rd, Selwyn PA, Carey VJ, Gortmaker SL and Oleske JM

Pediatrics 2002 June 109(6):1144-52

This study examines the prevalence of pain in adults with AIDS. It was concluded that pain is a frequently encountered symptom in children and youth with HIV disease and is also associated with increased mortality. These findings emphasise the importance of pain management in this population.

Pain in pediatric human immunodeficiency virus infection: Incidence and characteristics in a single-institution pilot study

Hirschfeld S, Moss H, Dragisic K, Smith W and Pizzo PA

Pediatrics 1996 September 98(3 Part 1):449-52

The authors examined the incidence and characteristics of the perception of pain in a cohort of families with children with HIV infection. It was found that pain is common among children infected with HIV and can adversely impact on their lives, and its management should be a component of the general care of these patients.

Sleep

Sleep disturbances in children with human immunodeficiency virus infection

Franck LS, Johnson LM, Lee K, Hepner C, Lambert L, Passeri M, Manio E, Dorenbaum A and Wara D

Pediatrics 1999 November 104(5): e62

The objective of the study was to describe the sleep patterns and level of fatigue in children and adolescents (6–18 years of age) with HIV infection, compared with ethnic-, gender-, and age-matched healthy children in the home setting. The findings from this study suggest that sleep disturbances occur in HIV-infected children, similar to findings previously described in HIV-infected adults.

Illness

Malignancies in UK children with HIV infection acquired from mother to child transmission

Evans JA, Gibb DM, Holland FJ, Tookey PA, Pritchard J and Ades AE

Arch Dis Child 1997 April 76(4):330-3

This study reports cases of vertically acquired HIV infection where children had developed an AIDS indicator disease, including malignancies. In children less than 5 years of age the incidence of NHL was approximately 2500 times greater than expected in the UK child population. Although comparatively rare, malignancies occur in children infected with HIV and may be the presenting illness.

Respiratory diseases in the first year of life in children born to HIV-1-infected women

Kattan M, Platzker A, Mellins RB, Schluchter MD, Chen XC, Peavy H, Steinbach S, Wohl ME, Hiatt P, Hunter J and Colin AA

Pediatric Pulmonol 2001 April 31(4):267-76

The objective was to describe the respiratory complications, clinical findings, and chest radiographic changes in the first year of life in infected and uninfected children born to HIV-1-infected women. Rates of pneumonia remain high in HIV-infected children in the first year of life. The incidence of pneumonia in uninfected infants born to HIV-1-infected mothers is low. Chest X-ray abnormalities and tachypnea suggest that subacute disease is present in infected infants.

Cardiac manifestations of HIV infection in infants and children

Keesler MJ, Fisher SD and Lipshultz SE

Ann N Y Acad Sci. 2001 Nov;946:169-78

This paper reviews the work of the Pediatric Pulmonary and Cardiovascular Complications of HIV for infants infected at birth. The study follows children over time and note that cardiovascular problems associated with HIV infection exist. Left ventricular dysfunction and increased left ventricular mass are noted and are relevant for clinical management and survival.

Treatment

Evolving medical science has provided a number of treatment pathways. Although this is complex in terms of efficacy, long-term outcomes, availability, access and the effects of compounds themselves, it is important that the issue of treatment and the psychosocial ramifications of treatment are understood and studied.

Children with human immunodeficiency virus admitted to a paediatric intensive care unit in the United Kingdom over a 10-year period

Cooper S, Lyall H, Walters S, Tudor-Williams G, Habibi P, De Munter C, Britto J and Nadel S

Intensive Care Medicine 2004 January 30(1):113-8

The authors describe the outcome of children with HIV infection in a hospital over a 10-year period. Although there is significant mortality among children with HIV infection admitted, many of them survive, and over 80% of the survivors have good outcomes with the currently available highly active anti-retroviral therapy. This provides evidence that intensive care treatment is appropriate for this group of patients in the UK.

Zidovudine, didanosine, or both as the initial treatment for symptomatic HIV-infected children. AIDS Clinical Trials Group (ACTG) Study 152 Team

Englund JA, Baker CJ, Raskino C, McKinney RE, Petrie B, Fowler MG, Pearson D, Gershon A, McSherry GD, Abrams EJ, Schliozberg J and Sullivan JL

New England Journal of Medicine 1997 June 12;336(24):1704-12

This trial was designed to assess the efficacy and safety of treatment with zidovudine alone as compared with either didanosine alone or combination therapy with zidovudine plus didanosine. In symptomatic HIV-infected children, treatment with either didanosine alone or zidovudine plus didanosine was more effective than treatment with zidovudine alone. The efficacy of didanosine alone was similar to that of the combination therapy and was associated with less hematologic toxicity.

Risks for conduct disorder symptoms associated with parental alcoholism in stepfather families versus intact families from a community sample

Foley DL, Pickles A, Rutter M, Gardner CO, Maes HH, Silberg JL and Eaves LJ

Journal of Child Psychology and Psychiatry 2004 May 45(4):687-96

The study compared the prevalence of parental psychiatric disorders between stepfather and intact families. It was found that parents from stepfather families had a higher lifetime prevalence of alcoholism, antisocial personality disorder, depression and social phobia than parents from intact families, and so children living in stepfather families are exposed to more parental psychiatric risk factors than children from intact families.

Adherence to prescribed antiretroviral therapy in human immunodeficiency virus-infected children in the PENTA 5 trial

Gibb DM, Goodall RL, Giacomet V, McGee L, Compagnucci A and Lyall H; Paediatric European Network for Treatment of AIDS Steering Committee

Pediatric Infectious Disease Journal 2003 January 22(1):56-62

Using questionnaires completed at different time intervals, the authors assess adherence with taking prescribed medication in previously untreated HIV-infected children. Good adherence with taking prescribed medication was associated with virologic response. Social factors were important in explaining nonadherence.

Adherence issues in children and adolescents receiving highly active antiretroviral therapy

Goode M, McMaugh A, Crisp J, Wales S and Ziegler JB

AIDS Care 2003 June 15(3):403-8

This preliminary survey of 18 parents of children receiving HAART in Australia showed that although parents report high level of child adherence to HAART, specific features of the medication regimen, such as taste and number of medications made administration of HAART extremely difficult. Moreover, interaction between the treatment regimen and the day-to-day lives of families increases the adherence challenge. While some agreement exists in relation to the concerns families have about negative aspects of HAART; the diversity of issues suggests the need for ongoing and individualised support and information to families.

Combination treatment with zidovudine, didanosine, and nevirapine in infants with human immunodeficiency virus type 1 infection

Luzuriaga K, Bryson Y, Krogstad P, Robinson J, Stechenberg B, Lamson M, Cort S and Sullivan JL

New England Journal of Medicine 1997 May 8;336(19):1343-9

The authors study the safety and efficacy of a three-drug regimen in a small group of maternally infected infants. Although further observations are needed, it appears that in infants with maternally acquired HIV-1 infection, combined treatment with zidovudine, didanosine, and nevirapine is well tolerated and has sustained efficacy against HIV-1.

Antiretroviral drug resistance among HIV-1 infected children failing treatment

Mullen J, Leech S, O'Shea S, Chrystie IL, Du Mont G, Ball C, Sharland M, Cottam F, Zuckerman M, Rice P and Easterbrook P

Journal of Medical Virology 2002 Nov;68(3):299-304

This study evaluates the prevalence of drug resistance among 26 children and assesses the contribution of adherence to failing therapy. Antiretroviral drug resistance was common among this group of children failing therapy, the majority of whom were infected with non-B subtypes of HIV-1. As adherence to treatment was low in 50%, this was likely to be an important contributory factor.

A 12-month study of the effects of oral zidovudine on neurodevelopmental functioning in a cohort of vertically HIV-infected inner-city children

Nozyce M, Hoberman M, Arpadi S, Wiznia A, Lambert G, Dobroszycki J, Chang CJ and St Louis Y

AIDS 1994 May 8(5):635-9

The authors examine the effects of oral zidovudine on the neurodevelopmental functioning of 54 HIV-infected children. The results showed that in contrast to previously published data, the present study observed no improvement in neurodevelopmental functioning in HIV-infected children treated with oral zidovudine.

Impact of human immunodeficiency virus 1 infection on clinical presentation, treatment outcome and survival in a cohort of Ethiopian children with tuberculosis

Palme IB, Gudetta B, Bruchfeld J, Muhe L and Giesecke J

Pediatric Infectious Diseases 2002 November 21(11):1053-61

This study examines the impact of HIV infection on clinical presentation, diagnostic criteria and treatment outcome of TB in Ethiopian children. HIV-positive children are at risk of diagnostic error as well as delayed diagnosis of TB. TB manifestations are more severe and progression to death is more rapid than in HIV-negative children. Weight for age may be used to identify children at high risk of a fatal outcome.

Guidelines

This section provides some overview guidelines for handling, treating and understanding programmes and provision for children in light of HIV. These documents are referenced briefly with some indication of a few resources to relevant guidelines.

Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings

WHO, July 2004.

www.who.int/hiv/pub/mtct/en/arvdrugsguidelines.pdf (PDF, 504K)

British HIV Association. Series of treatment and adherence guidelines, regularly updated.

www.bhiva.org/guidelines.html

Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection

www.aidsinfo.nih.gov/guidelines/default_db2.asp?id=51

Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children convened by the National Resource Center at the François Xavier Bagnoud Center, UMDNJ, Health Resources and Services Administration, and National Institutes of Health, updated January 20, 2004.

Pediatric and adolescent HIV guidelines

New York State Department of Health AIDS Institute, Committee for the Care of Children and Adolescents with HIV Infection

www.hivguidelines.org/public_html/center/clinical-guidelines/ped_adolescent_hiv_guidelines/peds-adolescents.htm

PENTA guidelines for the use of antiretroviral therapy

Sharland M, Blanche S, Castelli G, di Zub G, Ramos JT, Gibb DM.

Paediatric European Network for the Treatment of AIDS (PENTA), July 2004.

www.ctu.mrc.ac.uk/penta/guidelin.pdf (PDF, 218K)

Review of recent guidelines for antiretroviral treatment of HIV-infected children

Oleske JM. Topics in HIV Medicine, December 2003.

www.iasusa.org/pub/topics/2003/issue6/nov_dec_2003.pdf (PDF, 821K)

Safety/toxicity and drug resistance issues related to single-dose NVP prophylaxis

Mofenson LM, MD, WHO Consultative Meeting on the Use of NVP for the Prevention of Mother to Child Transmission in Women of Unknown Serostatus, December 2001

www.womenchildrenhiv.org/pdf/p07-cw/cw-07-01.pdf

Scaling up antiretroviral therapy in resource-limited settings: Treatment guidelines for a public health approach – 2003 revision

WHO, 2004. In English and French.

<www.who.int/3by5/publications/documents/arv_guidelines/en>

The PIH guide to the community-based treatment of HIV in resource-poor settings

Partners in Health, July 2004

<www.pih.org/library/aids/PIH_HIV_Handbook_Bangkok_edition.pdf> (PDF, 2.4MB)

Internet sources

For those who do not have direct access to libraries and academic journals, there is a wealth of information on the Internet. This brief list serves to identify some key areas.

A Family is for Lifetime Synergy

<www.synergyaids.com/documents/AFamilyForALifetimeVersion_1March04.pdf>

Academy for Educational Development (AED)

<www.aed.org>

AIDS Foundation for South Africa (2004)

<www.aids.org.za/about.htm>

AMANI Trust Foundation Early Childhood Care and Development

<amanieccd.iec@cats-net.com>

An African Resource for Early Childhood Development

<www.inasp.info/ajol/journals/sajcamh/vol13no2abs.html>

Are girls at more risk of intrauterine-acquired HIV infection than boys?

<www.aidsmap.com/news>

Bernard van Leer Foundation

<www.bernardvanleer.org>

Early Childhood Development Virtual University

<www.ecdву.org>

Early Learning Resource Unit ELRU

<www.elru.co.za>

Exchange Lunchtime Discussion – HIV/AIDS: What about very young children?

<www.healthcomms.org>

Grandmothers Action Support

<www.aegis.com/news/nv/2003/NV030904.html>

Help Age International and International HIV/AIDS Alliance

<www.helpage.org>

HIV-Insight website – Community Based Care in the Developing World: Related Resources

<<http://hivinsite.ucsf.edu>>

ID21

<www.id21.org>

ID21 Education

<www.id21.org/Education>

Impact of HIV on South Africa children underestimated

<www.aidsmap.com>

International HIV/AIDS-The Working Group on Early Childhood Development

<www.adeanet.org/workgroups/en_wgecd.html>

Kenya AIDS NGOs Consortium (KANCO)

<www.unhchr.ch/html>

Kondwa Day Care Centre

<www.christian-aid.org.uk>

Listening to Young Children

<www.coram.org.uk/listening.htm>

Mother's Welfare Group

<www.healthlink.org.uk/world/ewa04.htm>

Programs for Africa

<www1.worldbank.org/sp/safetynets/OVCWorkshop_5-03/OVC_Young.ppt>

Regional Psycho-social Support Initiative (REPSSI)

<www.repssi.org>

Takalani Sesame: Department of Education, South Africa (SABC Education)

<www.sabceducation.co.za/schooltv/TakHome.htm>

Terre des Hommes Switzerland

<www.terredeshommes.ch/humuliza/manual/manual_titel.html>

The Communication Initiative

<www.comminit.com>

The Consultative Group on Early Childhood Care and Development

<www.ecdgroup.com>

TREE - Training and Resources in Early Education. PO Box 35173, Northway, 4065, KZN, South Africa

<www.tree-ecd.co.za>

UNAIDS

<www.unaids.com>

United Nations Millennium Development Goals

<www.un.org/millenniumgoals/>

UNGASS Declaration of Commitment on HIV/AIDS

<www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html>

UNHCR

<www.unhcr.ch/html>

World Bank and UNICEF

<www.worldbank.org/children/ECD%20HIVAIDS%20manual.pdf>

World Bank Early Childhood Development Website

<www.worldbank.org/children/>

World Health Organization

<www.who.int>

Working Paper Series February

<www.worldbank.org/children/LISTEN~1.DOC>

About the Bernard van Leer Foundation

The Bernard van Leer Foundation, established in 1949, is based in the Netherlands. We actively engage in supporting early childhood development activities in around 40 countries. Our income is derived from the bequest of Bernard van Leer, a Dutch industrialist and philanthropist, who lived from 1883 to 1958.

Our mission is to improve opportunities for vulnerable children younger than eight years old, growing up in socially and economically difficult circumstances. The objective is to enable young children to develop their innate potential to the full. Early childhood development is crucial to creating opportunities for children and to shaping the prospects of society as a whole.

We fulfil our mission through two interdependent strategies:

- Making grants and supporting programmes for culturally and contextually appropriate approaches to early childhood development;
- Sharing knowledge and expertise in early childhood development, with the aim of informing and influencing policy and practice.

The Foundation currently supports about 150 major projects for young children in both developing and industrialised countries. Projects are implemented by local actors which may be public, private or community-based organisations. Documenting, learning and communicating are integral to all that we do. We are committed to systematically sharing the rich variety of knowledge, know-how and lessons

learned that emerge from the projects and networks we support. We facilitate and create a variety of products for different audiences about work in the field of early childhood development.

Information on the series and sub-series

Working Papers in Early Childhood Development is a 'work in progress' series that presents relevant findings and reflection on issues relating to early childhood care and development. The series acts primarily as a forum for the exchange of ideas, often arising out of field work, evaluations and training experiences.

The purpose of the *Young children and HIV/AIDS sub-series* is to share information, ideas and emerging lessons with readers who are concerned with young children affected by HIV/AIDS. As 'think pieces' we hope these papers will evoke responses and lead to further information sharing from among the readership.

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