Babies of a pandemic

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Infant development and maternal HIV

The effect of maternal HIV on infant development is a major concern because the virus has become so widespread among women of childbearing age. According to a United Nations report published in October 2003, half the new cases of HIV infection that occur across the world each year are among 15–24 year olds.¹ This group, constituting two and a half million people, are the next generation of parents. The situation is particularly catastrophic in sub-Saharan Africa where widespread poverty and underdevelopment already undermine children's health and wellbeing.² It is estimated that 10 million people in this region between the ages of 15 and 24, and up to 45% of pregnant women, are infected.³

With this recognition of the high prevalence of HIV in pregnant women in parts of sub-Saharan Africa, major efforts have been directed at developing and implementing interventions to prevent mother-to-child transmission. These efforts have been largely successful: antiretroviral medication, caesarean section, and locally appropriate feeding practice can now reduce transmission from 40% to below 10%.⁴ In sub-Saharan Africa these interventions are unfortunately not widely available, but nonetheless, it is still the minority of children who are infected.⁴

Orphaning is increasing in sub-Saharan Africa as rates of adult mortality have started to accelerate.⁵ However, by far the largest group of vulnerable young children are those living with an HIV infected mother. In sub-Saharan Africa approximately 70% of infected mothers survive for at least the first five years of their children's lives,⁶ and this number will increase with the rollout of antiretroviral medication. It is known that the early years of life are crucial for a child's development, and it is likely that maternal HIV disrupts the rearing environment, thereby putting these children at risk.

A key question arises as to the nature of the impact of maternal HIV on the development of infected and uninfected children. Although research is limited, especially in the developing world, studies that have examined the impact

of maternal HIV show that vertically infected infants are at increased risk of developmental impairments in a number of domains, including mental, motor, and emotional.^{7–14} There is some inconsistency in the literature as to the exact nature of the impairments suffered. Some studies have found impaired cognitive and motor development,^{7,8,15} some have found that development is principally impaired in the motor domain,¹⁶ while others have found that the nature of impairment changes over time.¹⁷ Language delays have also been observed in infected children.¹⁸ An important gap in the research is that very few studies have followed up children beyond 24 months of age. This is crucial since many impairments (for example, in language) and disturbances (for example, in behavioural and emotional development) are most likely to become evident after this age. It is not surprising that HIV has adverse effects on child development since the HIV virus has a direct destructive effect on neuronal tissue in the central nervous system. Where encephalopathies result, they may be rapid and progressive leading to loss of developmental milestones, subacute with a variable course, or static with a failure to progress developmentally. The more severe the encephalopathy, the worse is the child's prognosis.^{19,20}

In addition to the evidence regarding vertically infected children, there is evidence that uninfected children born to mothers with HIV also manifest disturbances in their development. These children have been found in some studies to have significantly more attentional, social, and behavioural problems,^{21–23} although not all studies have found such adverse effects.⁷ Uninfected children whose mothers have HIV are important because they form the largest sub-group of young children.

An important question that follows from this is: what mechanisms can account for these indirect effects of maternal HIV on infants? The exact mechanisms are yet to be elucidated, but it is very likely that effects occur through compromised parenting and childcare practices. There are two main bodies of research that together support

this view. First, that a positive HIV diagnosis renders an individual vulnerable to depression and diminished social support; and second, from research outside the HIV context, that postnatal depression and diminished social support are associated with impairments in children's development.

There is considerable research on the psychological effects of HIV, but it has tended to focus on men in Europe and North America. The relatively few studies of women with HIV have shown consistently that the psychological impact of being HIV positive is profound and may be especially severe during pregnancy. Most women in Africa discover their HIV status during pregnancy. Thus, a mother is diagnosed with a life threatening condition, while at the same time preparing to bring a new life into the world. The studies that have been conducted suggest that a significant proportion of such women experience depression and suicidal ideation, as well as disruption of their social and material support networks.^{24–35}

It has been well established in studies not involving HIV/AIDS, that maternal depression and lack of social support have adverse effects on children's development. Postnatal depression, particularly in disadvantaged communities, has been shown to be associated with impairments in the child's growth,³⁶ and his/her social, emotional, and cognitive development.³⁷ By school age, children of women who suffer postnatal depression are at risk for showing externalising and internalising behavioural problems, and they have lower social skills and academic achievement.³⁸ A key way in which maternal depression affects children's development is by disrupting the mother-infant relationship as well as routine parenting functions,³⁷ and two studies have shown that HIV infection is associated with similar disturbances in mother-child interactions.^{13,39} Currently, no studies in the HIV literature have examined maternal psychosocial functioning in relation to mother-child interactions or child development.

The question that most urgently needs to be addressed is: what can be done to help infected women and their young children, and in particular, what intervention strategies are necessary to minimise the impact of maternal HIV? There is good reason to believe that early psychosocial interventions in this population have the potential to enhance infant development. Psychosocial interventions in disadvantaged communities (without HIV), delivered during pregnancy and early childhood, have been shown to provide long term benefits to children and their families. For

example, a 15 year follow up study by Olds and colleagues of a group of mothers randomly allocated to nurse home visiting during pregnancy and early childhood, has shown considerable benefit. Relative to the comparison groups, these children had fewer episodes of running away, less criminal behaviour, fewer sexual partners, and fewer behavioural problems related to drugs and alcohol.⁴⁰ However, not all studies have found such interventions to be effective,⁴⁰ indicating that interventions need to be evidence based and carefully formulated. Furthermore, they need to be culturally and locally appropriate, and interventions that have been established in Western countries should not simply be "lifted" without first evaluating them in an appropriate developing world context.

The needs of children who become orphaned must also be addressed. However, the issues here are complex. In parts of sub-Saharan Africa, particularly in rural areas, children are regarded as belonging to, and being the responsibility of, kin rather than to one or two parents. Several reviews have found that the overwhelming response to children affected by HIV/AIDS through orphaning is extended family care.^{41,42} However, family care for affected children is less common in urban areas. Many non-governmental organisations (NGOs) are putting in place local programmes in an attempt to support the care of these children.⁴³ Both governmental and non-governmental organisations need to work together to develop a comprehensive approach to this problem, and enormous resources will be required.

It should be emphasised that despite all the adversity, many women who suffer from HIV/AIDS seem to remain psychologically healthy, cope well, and provide sensitive care and love for their young children. It is well known from research outside the HIV/AIDS context that having a confiding relationship and a supportive family and community plays a key role.⁴⁴ However, the issue of how some families in the developing world remain functioning well in the face of HIV/AIDS, often without antiretroviral treatment, is a crucial area for future research. The extended family or clan systems may well be an important protective mechanism, but at present these relationships have not been explored.

Clearly enormous funds are needed to provide for the basic material needs of affected children and families. In addition, intervention programmes that are sustainable, culturally appropriate, and cost effective are urgently required to support mothers with HIV and their

young children. A serious gap at present is a real understanding of the processes involved in maternal HIV, mental health, and infant development. These need to be clarified by focused research, in order to help define effective programmes to promote child development in HIV affected communities. Communities themselves are clearly struggling, and may be coping bravely. In some cases local initiatives are being put in place.⁴⁵ While major resources are now available for increasing the numbers of HIV infected individuals who receive antiretrovirals, there is little attention given to the development of children who are affected, even though they are not infected themselves. New initiatives including the Global Fund to Fight AIDS, Tuberculosis and Malaria, and new money from international agencies such as the Department for International Development, provide a vital opportunity to make a contribution to this effort.

Arch Dis Child 2005;**90**:116–118.
doi: 10.1136/adc.2004.049361

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