

## Research paper

# Telling children about HIV in transnational African families: tensions about rights

Martha Chinouya PhD

Nuffield Foundation New Career Development Fellow, Department of Applied Social Sciences, London Metropolitan University, UK

## ABSTRACT

Increasingly, children are construed as persons with rights to information on matters that affect their wellbeing, including the presence of the human immune deficiency virus (HIV) in their lives. This paper, based on interviews with 60 HIV-positive migrant African parents recruited in London and the home counties, shows how these parents made sense of the language of children's rights and disclosed to their children that HIV affected them. The word *affected* refers to HIV-positive children and those whose parent or guardian is also HIV positive. The parents reported 164 children, a majority (81%) less than 18 years, 10% 19–24 years and 9% above the age of 25 years. Most (73%) were their biological children. The remaining children (27%) were orphans for whom they had a parental responsibility. Forty-eight per cent of the children were left behind in the country from which their

parents emigrated. Parents expressed concerns about the language of rights, which they perceived as bestowing 'too much liberties' on children. However, parents also believed that children, depending on their age, had a right to know that the virus affected them. One-third of the children, most above age 18 years, were more likely to know that their parents were HIV positive. The child's residency influenced the parents' decision to tell HIV-positive children about their own status. Non-resident children, back home, were less likely to know that they were living with the virus. Gender compromised a parent's confidentiality, with mothers more likely to be linked to their child's HIV status than the child's biological father.

**Keywords:** African, disclosure, HIV, rights, transnational families

## Introduction

This paper is focused on how migrant black African families living transnational family lives make sense of the human immune deficiency virus (HIV) and help promote their children's rights to HIV-related information. Transnational families have been defined as families that live some or most of the time separated from each other, and yet hold together and create something that can be seen as a feeling of collective welfare and unity, namely 'familyhood', across national boundaries (Bryceson and Vuorela, 2002, p. 3). HIV has been recognised as a global public health issue. Globally, children whose parents or guardians are living with the HIV are a vulnerable group that bears the direct social, economic and biological impact of HIV in their families. First, if no interventions are in place to help reduce the risk of mother-to-child transmission,

babies born to HIV-positive mothers could contract HIV from their mothers during breast-feeding or birth. Because of migration, HIV could affect children and their parents who are resident within different national boundaries.

According to the collaborative study of USAID and the UN the proportion of orphans are greatest in sub-Saharan Africa, with some children having lost one or both parents. Some single parents/guardians of these children whose other parents have died, are immigrants to the UK. Some of these parents/guardians are the subject of this study. It is common for children affected by HIV and whose parents are from sub-Saharan Africa to be separated from their siblings left behind in their home country, upon migration (Chinouya, 2002). For children who contracted HIV

vertically from their mothers, a London-based study with 10 HIV-positive children (over half the children had parents from sub-Saharan Africa) reports that for seven children, the child's illnesses was the first indication to the family of an HIV-positive diagnosis (Barrett and Victor, 1998). Barrett and Victor comment on the late presentation of the children with AIDS-related complications which, if monitored from birth, could have been treated earlier. Children, if infected, could often experience HIV-related morbidity and face a childhood taking 'strong medicines' (Boulton *et al*, 1999). They could be orphaned through the death of a parent from AIDS-related complications, a loss that affects children differently, depending on the age of the child when the death of the parent(s) occurs (Foster and Williamson, 2000). It remains unclear how children whose parents are living in other national boundaries, if infected, manage their conditions. The migration of women to seek financial fortunes for the upbringing of their children has been reported as having costs and benefits for the children's, and their own, health. Women with unemployed husbands have left their children with the fathers, only to expose their children to economic hardships or health risks as the husbands use the remittances from the children's mothers to finance extra-marital activities, thereby introducing HIV in their relationships (Mupedziswa and Gumbo, 2001). Some parents living with HIV, unemployed in the UK, also send money to children left behind, in the hope the monies will be used to promote their children's right to education, health, accommodation and nutrition.

Increasingly children are construed as social actors, shaped by and shaping their own circumstances and childhood as a socially produced historically located experience (James and Prout, 1990). Such conceptual discourses, focused on the autonomous child with rights to be heard and consulted on matters that affect his or her wellbeing, have implications for policy and practice in respect of the presence of HIV in children's lives. Globally, children have rights to protection, survival and participation, codified in the United Nations Convention on the Rights of the Child (1989; see Flekkøy and Kaufman, 1997, Appendix 2). Defining a child as someone under the age of 18 years, the Office of the High Commissioner on Human Rights and the joint UN program on HIV and AIDS (OHCHR and UNAIDS, 1996) have issued international guidelines specifying that children are accorded the same rights as adults. These rights include non-discrimination, freedom of expression, liberty and education. Within the context of HIV:

under the Convention, [there is] the right to non-discrimination and privacy for children living with HIV/AIDS and finally the rights of children to be actors in their own development and to express opinions and have them taken into account in making decisions about their lives ... (OHCHR and UNAIDS, 1996, paragraph 95)

Most important is the right to express a view on matters affecting the child (Alderson, 2000) as well as having a say about HIV in their lives. Human rights instruments, and all guidance to professionals, emphasise that information should be provided to children in line with 'their evolving capacities', accord entitlement rights to families, and identify parents as central to support for child development. In all actions concerning children, whether taken by public or private institutions such as the family, the best interest of the child should be a primary consideration. However, children's rights instruments are clear that 'the best interest of the child' is a very difficult guideline, as each child's best interests cannot be reducible to that of the family. As legal concepts, rights concern freedoms and obligations, which can be deliberately honoured or withheld (Alderson, 2000). Consequently, the exercise of children's rights to information that HIV affects them may be negotiated in a variety of ways by their HIV-positive parents or their guardians. This is important, as medical specialists often present a child's HIV diagnosis, either positive or negative, to the child's parent or guardian. The parent's or a guardian's HIV results are always given to that parent or guardian. Privileged with the information, because of their adult status, parents then have to negotiate, in various ways, taking into account a number of factors in the child's life, whether to tell the child that HIV affects them.

Globally, HIV affects a substantial number of children. It is estimated that globally the number of people living with HIV is on the increase, with 40.3 million people living with the virus (UNAIDS, 2005). The numbers of people infected show signs of decrease in some countries, including Zimbabwe (Gregson *et al*, 2006). In the UK, the number of people living with HIV is around 58 300, with a majority of the new heterosexually contracted infections likely to have been contracted in Africa (Health Protection Agency, 2005). Thirty-four per cent of those living with HIV (19 700) (Health Protection Agency, 2005) remain undiagnosed, and this has implications for onward transmission to sexual partners as well as for their future children. Africans account for 60% (17 900) of all heterosexuals living with HIV in the UK. The Health Protection Agency (2005) reports that the presence of sub-Saharan Africans as reflected in UK HIV statistics is due to the migration of people from the African continent. In the 1980s, when the epidemic was highly concentrated in East Africa, East Africans from Uganda, Kenya and Tanzania were significantly more affected, and when the epidemic shifted in the late 1990s to South East Africa, Zimbabweans were disproportionately affected, accounting for 36% of the reported HIV rates in the UK (Sinka *et al*, 2003). How HIV-positive African immigrants manage family 'secrets' across national and international boundaries is central to this paper.

The geographical distribution of HIV cases has changed with regions outside London reporting a fourfold increase since 2000. The Health Protection Agency also notes that by the end of 2004, 1650 HIV diagnoses had been reported in children aged under 15 years. A majority (77%) (1119) acquired their infection from their mothers, with three-quarters of these mothers reported to have been infected in Africa. It is highly problematic to give the precise numbers of children who are affected by HIV, in the sense that they have a significant person in their lives living with HIV. Some estimates indicate that they are likely to number above 10 000 (Conway and Blake, 2004; Conway, 2005).

Despite the prominence of African children and their parents in the British HIV statistics, there is limited evidence on how African parents make sense of children's rights discourses that emphasise that children have the right to information on matters that affect their health, including the presence of HIV in their lives. Most studies that focus on telling children that HIV affects them have been conducted in the USA, and indicate that the disclosure of HIV to children is one of the stressors facing parents (Wiener *et al*, 1996; Niebuhr *et al*, 1998; Armistead *et al*, 2001; Murphy *et al*, 2002; Lee and Rotheram-Borus, 2002). Although some parents report that more than half of the children aged over four years knew of their parent's diagnosis, a majority of these parents did not perceive their children as being in need of emotional support. According to the authors, this raises questions of a possible failure of parents to recognise their children's emotional needs and the fear of asking for help (Niebuhr *et al*, 1998). A Tanzanian-based study found that when asked about the choice of a significant other with whom to share their HIV-positive diagnosis, the adult respondents were more likely to name someone of the same sex and generation as them, with children less likely to be mentioned (Lie and Baswilo, 1998, pp. 14–27). A European study found that the disclosure of both the child's and the parent's infection status was rare, and that disclosure was associated with the child's age and residency. Infected children living with their parents were less likely to know their diagnosis than those living in alternative care (Thorne *et al*, 2000). Thorne and her colleagues also found that parents and carers who were not infected with HIV were significantly more likely than infected parents to want professional help with disclosing to an infected child. In the UK, concerns were raised regarding the lack of national guidance on HIV prevention and treatment in schools, including school absence brought about by HIV-related illnesses (Conway and Blake, 2004).

This research set out to examine how African parents, living transnational family lives, made sense of the language of children's rights and helped co-resident and non-resident children exercise their

right to HIV-related information. The term non-resident is used to refer to children left behind by parents when they migrated. The study also explored how parents made sense of their own and their children's diagnosis, within the context of transnational family lives. The reasons for telling or not telling children that HIV affects them were also explored. Prior to the commencement of the investigation, the London Metropolitan University Ethics Committee, a NHS multi-site research ethics committee, and local NHS research ethics committees granted ethical approval for the study.

## Methods

This was a qualitative study that involved semi-structured interviews with HIV-positive African parents accessing HIV clinics and support groups in London and the home counties, to find out their views and experiences of children's rights and telling children that HIV affected them. Understanding children's experiences of HIV through their parents and guardians is recognition, as set in the UN Convention, that parents or guardians have the primary responsibility for the care, support and upbringing of children. However, some scholars may argue that parental accounts may be viewed as misleading as they reflect parental perceptions about children's awareness of how HIV affects them. Others argue that parental accounts are also regressive when positioned within the historical contexts of knowledge production about the 'woman question', which was through men. Such arguments hinge on the conceptual developments about children as persons and social actors with 'voices' and opinions on matters that affect their lives. However, ethical concerns related to the harm to children caused by knowing about HIV in the family, through their participation in research, were critical in this study and allowed children's experiences to be understood within the context of their families. It is also harmful to interview children about a sensitive topic such as HIV in the family, when children are not aware that the virus affects them. When faced with this dilemma, researchers in Tanzania also excluded children under the age of 16 years from their study of HIV disclosure 'because their parents were the ones who decided for them' (Lie and Baswilo, 1998). Earlier work with HIV-positive African parents in London also revealed that most children were unaware that HIV affected them, as their parents rather than they themselves had access to this privileged information (Melvin, 2000; Chinouya, 2002). The protection of children from the harm of knowing about HIV in their lives through this research was paramount. Informed by ethical decisions of not interviewing children about

a condition in their family that they are not aware of, children's experiences were then understood from their parents' views.

## Recruiting parents

Various strategies were in place for the recruitment of parents. First, information about the study was displayed on notice boards in support groups and clinics where recruitment was taking place. Clinic and support group attendees would ring the researchers to arrange for times and venues for interviews. Second, the researchers would be given a date and time to attend the clinic and would, on the day, be provided with a room by the clinic staff. Interested respondents would come to the room and ask if they could take part in the study. This often happened after clinic consultations, as HIV nurse specialists and consultants passed on the patient information sheet to potential respondents. Some patients would identify themselves to the researcher and ask for alternative interview times as they had other appointments. The third method involved tapping into the networks of parents living with HIV. As it has long been established that women living with HIV often provide support to each other outside support group settings (Hogg, unpublished, 1995), some parents, after the interview, were asked if they had friends living with HIV who were parents and might be interested in taking part in the study. If they did, they would be asked to pass on information about the study (the patient information sheet) to these parents, who would then telephone the researchers to make arrangements for interviews.

## The interviews

Interviews lasted an average duration of 45 minutes. All interviews were recorded with the interview guide designed to focus on a number of issues including: demographics (parents and children), duties and responsibilities of parents and children, children's rights, disclosure patterns and processes. A moral position when undertaking research with Africans affected by HIV, who are often deemed hard to reach by statutory providers, has been to offer interventions that benefit the respondents (Chinouya, 2004). This ethical or moral argument is based on the belief that it is unjustifiable not to provide interventions to such a population, once access to this population has been achieved. As migrant Africans affected by HIV are often unaware of locally available support services, all respondents were given information packs after the interview. These information packs contained information about local health, child and social care services.

The recorded interviews were transcribed verbatim and analysed using the framework method. The framework method is a dynamic and systematically grounded approach to analysing interview transcripts. The approach allows a systematic sifting, charting and sorting of materials according to the key issues and themes (Ritchie and Spencer, 1993) in line with the aim of exploring how parents make sense of children's rights and telling children that HIV affects them. Using parental narratives, the demographic characteristics of their children were compiled, and their circumstances analysed using both quantitative (to get frequencies) and qualitative methods. Although parental accounts gave an insight into the ways they negotiated and made sense of HIV and disclosure to children, child-centred methods were used. Child-centred methods emphasise that children are the unit of observation and childhood the area of analysis (Saporiti, 1994). Narratives from parents put a spotlight on children as the unit of observation, allowing qualitative data to be transformed into quantitative descriptive statistics. The analysis of these descriptive accounts facilitated insight into how parents made sense of childhood and children's rights to information. Childhood as a social status should be understood in relation to other social statuses (Saporiti, 1994), in this instance in relation to parenthood.

## Findings

### The parents

Sixty parents took part in this study. They were immigrants born in, and who had travelled from, sub-Saharan African countries. Most of them were mothers ( $n=46$ ) and there were a lot fewer fathers ( $n=14$ ). The sex and nationality profile of the sample reflected the current pattern of the heterosexual HIV epidemic in the UK, dominated by Zimbabwean and Ugandan nationals, mostly women. More than half of the respondents were from Zimbabwe (56%), and slightly less than a quarter from Uganda (24%). The rest were from countries that included Nigeria, Zambia, Burundi, Somalia, South Africa, Kenya and Malawi. Most of them had arrived in the UK after 2000. Over three-quarters reported that they were 'single mothers'. When asked to explain further what they meant by the term 'single mother', it emerged that some were widows (predominantly from HIV) or had never been married. There was a sense of stigma associated with being a 'young widow', as this was construed by some as a form of disclosure of HIV in their lives. It is not surprising that there were overwhelming numbers of mothers in the study, as epidemiological data show the gendered nature of the HIV epidemic, with more

heterosexual women than men diagnosed in sub-Saharan Africa (UNAIDS, 2005) and locally in the UK (Health Protection Agency, 2005).

Respondents had a mean age of 41 years. A majority (76%) reported that they were unemployed, with 10% in part-time employment and 7% in full-time employment. A few (7%) did not disclose their employment status. Most parents reported that they found out about their HIV status in England, after an illness that often required medical attention. This knowledge was often coupled with shock and an element of surprise brought on by the diagnosis. Most parents reported that the future of their children in the context of HIV was a primary concern.

## The affected children

Respondents were asked, 'How many children do you have?' to give an insight into the numbers of children affected by HIV through their links with the respondent. A total of 164 children were reported. The age of each child was asked, and it emerged that a majority of the children (81%) were under the age of 18 years, 10% were aged between 19 and 24 years, and 9% were above the age of 25 years. The biological links of the respondents and the children were ascertained. Most of the children were biological children (73%). In this paper, biological children are also referred to as 'uterine' children to mark their relationship with the parent, in particular the mother, and differentiate them from other (27%) children towards whom the adults had parental responsibilities. Respondents were asked the residential pattern of each child, and it emerged that almost half (48%) of these children were living in the respondents' country of birth, with a majority (37%) in Zimbabwe, Uganda (33%) and Zambia (27%) and some reported in South Africa (2%) and Kenya (1%). Grandparents, in particular maternal grandmothers, the respondents' parents, cared for most (70%) of the non-resident children. Uncles and aunts looked after 26%, and a few (4%) were cared for by the children's other parent.

## Making sense of children's rights

Parents were asked their views about children's participation and decision making in the family. The views of most parents were that the children, in particular those under the age of 16 years, were still dependent on adults and perceived as less able to make important decisions that affect their lives. According to one mother:

'A child ... well he doesn't make a decision. The parents make a decision for children ... They may have a say but they don't make decisions.' (mother)

There were contradictions in the ways parents construed children's participation and decision making. Although some parents construed children as being less able to make important decisions, children had responsibility for supporting the realisation of the interests of the family. There were sex differences, with girls expected to be more active in supporting their mothers with housework.

Parents' views about participation were also shaped, in part, by their own experiences of participation during their own childhood, growing up in Africa. In all actions that involved people who were older than they, parents reflected that respect for those older was paramount. This meant, as an example, not arguing with adults. However, their children in England were construed as adopting 'new' cultures, and losing their 'African' cultures, which placed emphasis on this component of respect for those who were older. Children left behind were construed as more disciplined and respectful of adults than those in England. Some parents, in particular the fathers, believed that an important role for them was to discipline children. Children's rights were perceived as interfering with their parenting, in particular when comparing the way their own fathers enforced discipline on them. When they positioned their role as disciplinarians, most fathers perceived this aspect of fathering weakening because they could not discipline their children, an issue that was said to be contributing to high rates of teenage pregnancies in the UK. A father talked about the challenge and said:

'The children's rights I think they interfere with the discipline of children in a way. That is why teenage pregnancies have actually gone up and the children are misbehaving. In Africa you cannot have a boyfriend and [it] is not your right. In this country at 16 as a child you are allowed to have sex even before marriage. But in Africa if you are not married even if you are 21 you have no right to have sex and having a boyfriend.' (father)

From the text above, the parent equates 'misbehaving' with sex, arguing that the right to have sex at the age of 16 years even before marriage is responsible for increase in teenage pregnancy. He compares this experience with his imaginations of Africa, arguing that young people do not have a right to sex as long as they are not married. If some parents equate sex with 'misbehaving' then questions are raised about their communications about HIV in the family, when HIV is sexually transmitted. Some parents reported that their 'hands are tied' by social services, and they cannot discipline their children. This is how a mother described the situation:

'We fear the law so much and if you say ... like back home you say you have refused to do this so and so you can't have this ... but you can't do that in this country. Instead the children have the rights and they have this child

benefit which the children know about and they know that you are supposed to give them this money. So it's very very difficult. It makes a child ... it empowers the child before they are actually mature.' (mother)

The fear of the law for some was increased by anxieties brought on by the delays in the Home Office making decisions about immigration applications for some members of their communities. Some parents reported differences when comparing their own childhood with that of their children. Parents reported that they were not brought up in families where they were informed of their rights. A mother reflected on her own childhood, growing up in rural South Africa:

'I was not brought up in family where I was told I had rights. To know about rights you should have had rights yourself. If you haven't had them you will not believe in them anyway ... I did not have the freedom as a child ... I was told this time you must be home. You can't be out after this time. I had no freedom even if I wanted to be out ... In this country they have that right ... a child can go out anytime.' (mother)

When asked if children had the right to know that HIV affected them, most parents were of the opinion that children who are infected with the virus had some 'sort of right' to know that they were living with the virus. The next section describes how parents made sense of children's rights to information within the context of a negative diagnosis.

## Telling children about a negative HIV result

Some parents found out their HIV status after the birth of their 'uterine' children. Due to the risk associated with mother-to-child transmission, a uterine mother's diagnosis raised what some referred to as distressing questions about the HIV status of her children. This risk often prompted parents, in particular 'uterine' mothers, to subject children to HIV antibody tests. Thirty-four children between the ages of three and 15 years were taken for testing for HIV antibodies by their parents/guardians, and the results of such tests confirmed that the children were HIV negative. Although they were relieved with the diagnosis, not all parents communicated the results to the children. Communicating such a result would raise questions from the children, which the parents then were not in a position to answer. Some parents reported that they were concerned that the children would ask questions about why they were tested for HIV, and whether the parents (the respondent) had had an HIV test too. For a child who was not sexually active and informed about HIV and how it is transmitted, this would increase suspicion that his/her 'uterine' mother was infected with the virus. The

children were tested for HIV without clear information about the diagnostic test and why it had to be done.

Some parents who had disclosed their HIV status to their children's carers back home asked the caregivers to take the children for HIV testing. In such cases, again, the children were not informed about either the diagnostic test or the outcome of the test. The parents and the children's carers back home colluded in keeping the 'secrets'. Some parents reported that the children were not told that they were being tested for HIV because they were still too young to understand HIV-related issues, and in addition children could not be trusted with information about such tests. A father noted:

'No. I would not trust an under 10 ... They would just talk that there is HIV or whatever at home, but then it's what comes after that. 'Cause if their class mates they will take the information to their parents and the other children will be told do not associate with those people. That is why I say that it's too early for them. They may share the information with their friends, and their friends will go and tell their parents, and the parents will say you must not play with them and the kids will suffer.' (father)

## Telling children of a parent's diagnosis

Parents were asked if they had told their children that they, the parent, were living with the virus. The numbers of children aware that their parent was living with the virus were counted. The results show that almost one-third of all the children had been informed of the parents' diagnosis, with age a critical component when making decisions of telling children about HIV. Older children were more likely to be aware that the respondent was living with HIV: 13% of the children under the age of 18 years, over half (56%) of those aged between 19 and 24 years, and nearly all the children above the age of 25 years were aware of the respondent's diagnosis. Parents reported that they also considered how they thought the child would react to that information and the benefit of that information to the child's life.

Some parents believed that by sharing the information with their older children who were assumed to be sexually active, they were educating their children about HIV and how to protect themselves from the virus. Parents also reported that children offered support after disclosure. A Ugandan mother put it this way:

'What drove me to tell him was his age. He is now a man and I think he can handle the shock. I also told him to be aware that this disease is there and if you do not use protection it might happen to you as well. I also gave him some newsletters, which I get from support groups, so he could read and understand what HIV is all about. It was not easy for him when I told him. He was so worried he did not say anything as well as ask questions, he just kept

quiet; I could see it really hit him hard. Now he is getting better, if I tell him I am not well he understands, he will come and help in the house.' (mother)

Others reported that they disclosed so as to help the children be aware of their property rights in case they, the parent, passed away. This is how one father described the situation:

'I had a bad experience when I told my relatives ... Family members are not all sympathetic, some were happy, some were very much disappointed ... your own relatives can wish you were dead. Even your brothers can feel jealousy because they can inherit your property when you die.' (father)

By disclosing their HIV status to their children back home, parents were able to make plans with their older children, in most cases those above the age of 15 years, about how their property back home (e.g. land, cattle, and houses) should be distributed in case they died in England. This had to be done so as to ensure that their children were not destitute after the death of a parent.

Parents were also asked the reasons why they had not disclosed to their children. The redefinition of HIV from being an acute to a chronic condition brought about by the introduction of highly active antiretroviral therapies (HAART) in the developed countries such as England also raised questions about the benefits of helping children exercise their rights to HIV-related information regarding a parent's diagnosis. A mother spoke of the dilemma:

'I am taking medication and my health is going right. I went to my doctor and the treatment is OK. If I keep everything as it's supposed to, I will be all right. So the only thing is that ... I am not saying that I am never going to tell them, but right now I have not told them because there are so many people who are ignorant about HIV and that might be my kids.' (mother)

Some parents reported that their children had witnessed 'too many deaths' in their families due to AIDS, making it highly problematic to tell children that their parent, the respondent, was also living with HIV. They reported that some of their children had lost the other parent from an AIDS-related death. In such cases the children had witnessed the decline in health and subsequent death of the parent and this, according to some parents, was the reason they did not disclose their own HIV status. This is how a mother described the situation when asked why she had not disclosed her positive diagnosis to her children who were looked after by her mother, the children's grandmother, in Zimbabwe:

'Ahhh! I watched them the time their father died and I can imagine if I tell them, they have seen other people die of HIV ... me being here and them being in Africa where there is no medication and say look here children I am HIV positive ... I can imagine what damage I am going to do. If they were going to be upset I was going to comfort them but then I would give the burden to my mother.' (mother)

Although they were hiding their diagnosis, some parents faced a dilemma that the children could find out on their own that their parents were HIV positive. Some feared that not sharing their diagnosis with their children would damage their relationship and the trust between them. Parents were concerned that younger children were unable to understand the significance of HIV, and parents were anxious that the children might tell their friends who may in turn tell others, resulting in subsequent stigmatisation of the children. Parents were concerned that their children would be stigmatised because of their parents' (the respondents') diagnosis. Lack of disclosure was a way of protecting children from stigmatisation. The perceived stigmatisation of children, families and individuals had to be balanced with the children's best interests when parents were negotiating the exercise of children's rights to information about HIV in the family. In this instance it was not in the children's best interests, in particular those of the younger children, to know that the respondent was living with the virus.

## Telling children that they have the virus

Children living with HIV can face a childhood underscored by HIV-related morbidity. Their views about their health are critical in shaping their care. Respondents also reported that children, if infected with the virus, have the right to know that they are living with the virus. However, a balance has to be negotiated between the right age, the right time to tell, and the potential negative consequences of disclosure for the family as a whole *and* children themselves.

Parents reported that some children (4%) under the age of 18 years were HIV positive, and over half of them were unaware that they were infected. Disclosure was a process with some parents initially telling their children that there was 'something wrong with their blood', to full disclosure in which children became aware that they were infected with HIV. The children's residential patterns had an influence on parents' decisions to disclose. All children who were co-resident with the respondents were reported as being aware to various degrees that there was 'something wrong with their blood', although in some cases that involved older children HIV had been named as the cause.

Non-resident HIV-positive children, living back home, were less likely to know that they were infected with HIV. Some parents reported that, through non-disclosure, they were protecting their children in sub-Saharan Africa from the pain of knowing the diagnosis, as HIV in some parts of sub-Saharan Africa was often associated with death. The reported numbers of HIV-related deaths in their families was another reason, as parents did not wish their children to think that they were the next to die. To help promote their

children's rights to HIV-related information, the respondents would have to discuss the diagnosis with the children's caregivers such as the respondents' parents, the children's grandparents. Telling such children that they, the parents, and the children were infected with HIV raised complex questions for the 'uterine' mothers, related to the enmeshment of children's HIV status with that of their mothers, who might or might not have passed on the virus to the children during birth or breast-feeding. For some mothers, the link between HIV-positive 'uterine' mothers and HIV-positive children, due to mother-to-child transmission, was cause for concern, as this compromised their right to privacy and confidentiality. This was particularly the case for mothers of children who could not have independently acquired HIV, that is to say, where the proximal source of the HIV infection was the 'uterine' mother. Biologically, through vertical transmission, it is uterine mothers who pass on HIV to their babies, sometimes during birth and/or breast-feeding, with the father's own HIV status potentially the distal source of the child's positive status. Mothers of teenage children whose HIV status had never been confirmed when the children were younger, or teenage children who had had a positive diagnosis, faced a dilemma within the context of transnational family life.

Because of distance, in some cases it became problematic for the mothers to ascertain the source of their non-resident children's HIV infection. Some of the uterine mothers were not sure if their children were sexually active and had contracted HIV independently. Telling children in such circumstances about HIV had to be balanced, namely ensuring the individual parent's rights to confidentiality and the rights of children to know of matters affecting their sexual health.

Children who were suspected of living with HIV had not been tested for HIV before the respondents moved to England, as nearly all the respondents found out about their own diagnosis in England. Balancing the parents', in particular the 'uterine' mothers', right to confidentiality and the children's rights to information on how HIV affected them was very complicated in such cases, especially when parents suspected that a child left behind could be HIV positive. As most parents rarely disclosed to the children's caregivers back home that they, the parents, were HIV positive, this became problematic in managing children's suspected HIV infections. It became very problematic to ask the children's carers back home to take the children for antibody tests. There were concerns that the children's caregivers would not be able to uphold the respondent's and the child's rights to confidentiality. A 'uterine' mother explained this dilemma:

'I feel that I cannot say to my mother take the child for a test. She may not be able to contain the results you see ... I

cannot do anything now ... 'cause the grandmother may feel that she [the child] is dying.' (mother)

Asking children left behind to be subjected to HIV antibody tests was a way of disclosing to other relatives left behind that they, the parents, in particular the 'uterine' mothers, were infected with HIV. There were sex differences with this view, as some biological fathers indicated that a positive diagnosis does not mean that they, the fathers, are positive. A father said:

'It does not mean that if she [my child] is positive I am positive. Everyone will know she got it from the mother.' (father)

For 'uterine' mothers in particular, even if the children left behind would subsequently have a negative HIV result, questions would be raised as to why the parent in England requested such a test. Such fears compromise the respondent's right to privacy, while increasing the emotional strain back home that the respondents were in poor health, because back home HIV is often associated with immediate death. Parents also reported that they did not uphold their non-resident children's rights to HIV-related information because of distance, and that such sensitive information needs to be discussed face to face, not on the telephone. A mother put it this way when talking of her daughter whom she suspected to be positive:

'I cannot tell her on the phone, she has to see my face and show her my emotions how I feel about it. I feel I should be there. Face to face. She will then know how I am, because home if someone is HIV they are dying ... already they are wasting away. I just feel that I have to be with her. I have to have a face-to-face talk. Tell her how I am and how I feel.' (mother)

Importantly HIV has been a public health concern for slightly over two decades, and there were instances of repeated generational cycles of HIV. In the respondents' nuclear families, over a quarter (28%) of the respondents' 'uterine' children aged 25 years and above were reported as HIV positive, having contracted the virus independently of their parents. Some of these older children were now parents to the respondents' grandchildren. In such situations, the respondents, now grandmothers to their children's children, had shared information about HIV in their lives. The most cited reason for such disclosure was to support each other as the respondents and their HIV-positive children above age 25 were adults. In such cases, at least three generations had experienced family life with HIV. The challenge for health workers is of breaking the chain for HIV, which now appears to be part and parcel of life for each passing generation.

Some parents with HIV-positive children left behind wished for medical help for their children. Some questioned the benefit of disclosure to children who might not get access to 'HIV tablets' (antiretroviral

drugs). The disclosure to children who had no access to medical care raised moral and ethical questions related to balancing children's rights to information about HIV, and the loss of a childhood, brought about by knowing that they are infected with HIV, which in some sub-Saharan countries is the leading cause of death. In such cases parents argued that the right to HIV-related information in their transnational family lives should be coupled with the right to health-promoting interventions such as access to 'HIV tablets'.

## Discussion

By putting a spotlight on transnational family lives within the context of HIV, this paper shows how HIV as a global phenomenon affects family members in households scattered across different national boundaries. Such a global family network as shown in this study renders it very complex to uphold children's rights to sensitive information, including the presence of HIV in their families. This study has shown how family lives changed by the complex intersections of migration, HIV, and the north/south divide in the availability of HAART have an impact on the health and wellbeing of children, in particular those left behind. Most of the respondents in this study were on HAART, and they were experiencing life with HIV as a chronic condition. The introduction of HAART in the developed world has redefined HIV from being an acute, life-threatening condition to a chronic condition. In the sub-Saharan source countries from which these parents migrated, HIV still remains an immediate life-threatening condition. The north/south divide in the availability of antiretroviral drugs influenced parental decisions to help their children exercise their right to HIV-related information. Children left behind were said to be more enmeshed in the epidemic, and were witnessing the acute nature of the virus, with higher numbers of HIV-related illnesses and deaths in their family and social networks back home. Children and their families left behind were said to be unaware of the benefits of HAART, and to them a positive HIV diagnosis often resulted in an early death. Telling children that their parents in England were living with the virus was a risk that parents were not willing to take, as their children would experience a childhood in fear that their parent would be the next to die from AIDS. Telling some of the children left behind that they were infected with the virus also raised complex questions for the respondents. First, their children had limited access to HAART and the respondents were not in financial positions to pay for these antiretroviral drugs, which were said to be very expensive in their source countries. Parents argued that the right to information for their children should be equally

matched with treatment made available back home. Telling their children left behind that they, the children, were living with HIV raised moral questions about children being pre-occupied with their diagnosis.

Children who had undergone an HIV test and were found not to have the virus were also less likely to be informed about the diagnostic test and why they were being tested. This raises complex ethical and moral questions, for the parents and the healthcare providers who are conducting the test. Depending on the age of the child, and whether the child is able to make an informed choice, it is debatable whether healthcare workers should tell children that they are undergoing an HIV test, even if the result of such tests indicate that the child does not have HIV antibodies. More ethical and moral questions are raised: should these children be offered the required HIV pre- and post-counselling sessions? Do these HIV-negative children need to know their results so as to prevent future infections? This lack of disclosure within the context of transnational family life also had implications for public health and the risk of onward transmission.

The UN Convention on the Rights of the Child (1989) notes that 'State Parties shall render appropriate assistance to parents and legal guardians in the performance of their child rearing duties'. The state has a supporting role for parents. Because of their links to HIV-positive respondents, most of them unemployed, children connected to these HIV-positive migrants would be deemed 'children in need' and vulnerable. This could explain the state's intervention in supporting parents in their child-rearing duties. Results from this study indicate that parents construe the state, through statutory bodies including social workers, as interfering and rendering it almost impossible for parents to discipline their children. This study has also revealed the respondents' lack of clarity about the roles and responsibilities of statutory providers, including social workers, in supporting parents in their parenting duties. It should be stressed that most respondents are newly arrived migrants from sub-Saharan countries, where state parties, though they have signed their commitment to the UN Convention on the Rights of the Child, do not often have the resources (e.g. qualified social workers, financial resources) to support parenting and ensure that children's rights are being upheld. There seems to be lack of understanding about the role of statutory providers in supporting parents in realising what is in the best interest of their child. However, the concept of 'best interest of the child' is one that was very complex to agree on, in particular around issues related to a stigmatising condition such as HIV, where in some cases the stigma is targeted at the family, including children.

## ACKNOWLEDGEMENT

The Economic and Social Research Council funded this project. Grant No. RES-000-22-0871.

## REFERENCES

Alderson P (2000) *Young Children's Rights: exploring beliefs, principles and practice*. London: Jessica Kingsley.

Armistead L, Tannenbaum L, Forehand R, Morse E and Morse P (2001) Disclosing HIV status: are mothers telling their children? *Journal of Pediatric Psychology* 26:11-20.

Barrett G and Victor CR (1998) We just want to be a normal family: paediatric HIV/AIDS services at an inner London teaching hospital. In: Bor R and Elford J (eds). *The Family and HIV Today: recent research and practice*. London: Cassell, pp. 238-50.

Boulton P, Pepper K, Walter S, Beck E and Miller D (1999) Getting on with life: the experiences of children with HIV infection. In: Aggleton P and Hart G (eds). *Families and Communities Responding to AIDS*. London: UCL Press.

Bryceson DF and Vuorela U (2002) Transnational families in the twenty first century. In: Bryceson DF and Vuorela U (eds) *The Transnational Family: European frontiers and global networks*. Oxford: Berg.

Chinouya M (2002) *HIV Disclosure Patterns amongst African Families Affected by HIV and AIDS in London*. PhD thesis. London: University of North London.

Chinouya (2004) Zimbabweans in Luton: The Pachedu-Zeezele Model. Luton: Luton Primary Care Trust.

Collaborative Study of USAIDS, United Nations Children's Fund and Joint United Nations Program on HIV/AIDS (2002) *Children on the Brink: a joint report on orphan estimates and program strategies*. Washington: Tvt Associates.

Conway M (2005) *HIV in Schools: good practice guide to supporting children infected or affected by HIV*. London: National Children's Bureau.

Conway M and Blake S (2004) 'Will Someone Listen?' *Meeting the needs of children and young people living with HIV. Report on UK Seminars April-July 2003*. London: National Children's Bureau.

Flekkøy M and Kaufman NH (1997) *The Participation Rights of the Family: rights and responsibilities in family and society*. London: Jessica Kingsley Publishers.

Foster G and Williamson J (2000) Impact of HIV/AIDS on children in Africa: a review of current knowledge. *AIDS* 14 (suppl 3):S275-S284.

Gregson S, Garnett GP, Nyamukapa C et al (2006) HIV decline associated with behaviour change in Eastern Zimbabwe. *Science* 311:644-6.

Health Protection Agency (2005) *AIDS/HIV Quarterly Surveillance Tables Cumulative UK Data to end March 2005*. No. 66:05/1. [www.hpa.org.uk/infections/topics\\_az/hiv\\_and\\_sti/hiv/epidemiology/epidemiology.htm#top](http://www.hpa.org.uk/infections/topics_az/hiv_and_sti/hiv/epidemiology/epidemiology.htm#top) (accessed 13 April 2006).

Hogg C (1995) *Positively Women Services Review*. Unpublished needs assessment study of Positively Women Services in London.

James A and Prout A (1990) Representing childhood: time and transition in the study of childhood. In: James A and Prout A (eds). *Constructing and Reconstructing Childhood*. Basingstoke: Falmer Press.

Lee MB and Rotheram-Borus MJ (2002) Parents' disclosure of HIV to their children. *AIDS* 16:2201-7.

Lie GT and Baswilo P (1998) HIV-positive patients' choice of a significant other to be informed about the HIV test result. Findings from an HIV/AIDS counselling programme in regional hospitals of Arusha and Kilimanjaro, Tanzania. In: Bor R and Elford J (eds). *The Family and HIV Today: recent research and practice*. London: Cassell, pp. 14-27.

Melvin D (2000) Do words really say it? European Forum on HIV/AIDS. *Newsletter* 10: 1 and 4.

Mupedziswa R and Gumbo P (2001) *Women, Informal Traders and the Struggle for Survival in an Environment of Economic Reforms*. Uppsala: Nordiska Afrikainstitut.

Murphy D, Roberts K and Hoffman D (2002) Stigma and ostracism associated with HIV/AIDS: children carrying the secret of their mother's HIV seropositive status. *Journal of Child and Family Studies* 11:191-202.

Niebuhr VN, Hughes R and Pollard R (1998) Parents with human immune deficiency virus infection: perceptions of their children's emotional needs. In: Bor R and Elford J (eds). *The Family and HIV Today: recent research and practice*. London: Cassell, pp. 251-61.

OHCHR and UNAIDS (1996) *HIV/AIDS and Human Rights: international guidelines*. New York and Geneva: United Nations.

Ritchie J and Spencer L (1993) Qualitative data analysis for applied policy research. In: Bryman A and Burghes R (eds). *Analysing Qualitative Data*. London: Routledge, pp. 174-94.

Saporiti A (1994) A methodology of making children count. In: Qvortrup J, Bardy M, Sgritta G and Wintersberger H (eds). *Childhood Matters: social theory, practice and politics*. Vienna: Averbury.

Sinka K, Mortimer J, Evans B and Morgan D (2003) Impact of the HIV epidemic in sub-Saharan Africa on the pattern of HIV in the UK. *AIDS* 17:1683-90.

Thorne C, Newell ML and Peckham C (2000) Disclosure of diagnosis and planning for the future in HIV-affected families in Europe. *Child: Care, Health and Development* 26:29-40.

UNAIDS/WHO AIDS Epidemic Update: December 2005. [www.unaids.org/epi/2005/doc/EPIupdate2005\\_pdf\\_en/Epi05\\_03\\_en.pdf](http://www.unaids.org/epi/2005/doc/EPIupdate2005_pdf_en/Epi05_03_en.pdf) (accessed 13 April 2006).

UN Conventions on the Rights of the Child (1989) Appendix 2 In: Flekkøy M and Kaufman NH (1997) *The Participation Rights of the Family: rights and responsibilities in family and society*. London: Jessica Kingsley Publishers, pp. 142-63.

Wiener LS, Battles HB, Heilman N, Sigelman CK and Pizzo PA (1996) Factors associated with disclosure of diagnosis to children with HIV/AIDS. *Pediatric AIDS and HIV Infection* 7:310-24.

**CONFLICTS OF INTEREST**

None.

**ADDRESS FOR CORRESPONDENCE**

Martha Chinouya, Department of Applied Social Sciences, London Metropolitan University, Ladbroke House, 62–66 Highbury Grove, London N5 2AD, UK.  
Tel: +44 (0)207 6072789; email: [mchinouya@aol.com](mailto:mchinouya@aol.com)  
or [m.chinouya@londonmet.ac.uk](mailto:m.chinouya@londonmet.ac.uk)

*Received 10 February 2006*

*Accepted 20 March 2006*