



Families, children, migration and AIDS

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Migration is very often a family affair, and often involves children, directly or indirectly. It may give rise to better quality of life for an entire family, or to bitter disappointment, and may also increase vulnerability to HIV and AIDS. This review, carried out for the Joint Learning Initiative on Children and AIDS, links the literature on “migration”, on “HIV and AIDS” and on “families”. Three themes are sketched: (1) As both HIV prevalence and circular migration increase, former migrant workers affected by AIDS may return to their families for care and support, especially at the end of life, often under crisis conditions. Families thus lose promising members, as well as sources of support. However, very little is known about the children of such migrants. (2) Following patterns of migration established for far different reasons, children may have to relocate to different places, sometimes over long distances, if their AIDS-affected parents can no longer care for them. They face the same adaptation challenges as other children who move, but complicated by loss of parent(s), AIDS stigma, and often poverty. (3) The issue of migrant families living with HIV has been studied to some extent, but mainly in developed countries with a long history of migration, and with little attention paid to the children in such families. Difficulties include involuntary separation from family members, isolation and lack of support, disclosure and planning for children’s care should the parent(s) die and differences in treatment access within the same family. Numerous research and policy gaps are defined regarding the three themes, and a call is made for thinking about migration, families and AIDS to go beyond description to include resilience theory, and to go beyond prevention to include care.

Keywords: families; migration; HIV and AIDS

Migration has always been a part of human endeavour, and shows every sign of continuing to be. HIV and AIDS also promise to be with us for generations to come, even if progress has been made in AIDS prevention and treatment. This review, carried out for the Joint Learning Initiative on Children and AIDS (JLICA), factors families in, reviewing the literature on “migration”, “HIV and AIDS” and “families”.

Background and methods

The theme of migration has been present in the AIDS literature practically since the beginning of the epidemic. Early approaches – which mainly concerned how communities might prevent the spread of HIV through population mobility – shifted in the late 1980s and early 1990s, in parallel with wider shifts in thinking about HIV. Thus, researchers and policy makers began to explore the factors that increase migrants’ HIV vulnerability, and the most appropriate programme responses to reduce vulnerability (cf. Decosas, Kane, Anarfi, Sodji, & Wagner, 1995; Haour-Knipe & Rector, 1996; International Migration, 1998).

Approaches have widened more recently: a specific focus on “migrants” now includes a broader range of “people who move” for various reasons, and emphasis is reaching beyond prevention to address access to HIV care (cf. Duckett, 2001). Families have also been present to some extent in the HIV literature (cf. Aggleton, Hart, Davies, & Ebrary, 1999; Ankrah, 1993; Belsey, 2005; Rotheram-Borus, Flannery, Rice, & Lester, 2005) as discussed in other JLICA papers. An entirely different body of literature, finally, discusses families in relation to migration.

The part of the review that is presented here, which attempts to define where the three bodies of literature might overlap, started with a set of documents on HIV and children assembled by the JLICA working group, a number of which contained references to migration. Literature on the links between population mobility and HIV as an effect of AIDS – and the way such movement pertains to families – was then identified with the help of searches in the major engines, such as PubMed, Sociological Abstracts, PsycINFO and Google scholar.¹ The sources cited in the most relevant articles were traced, and relevant net sites

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were searched, until saturation was reached (repeated consultations revealed only publications that had already been identified).

Some extremely powerful themes emerged when the literatures on migration, families, and AIDS were put together:

- migration may be a very positive quest, especially at the outset;
- Migration is often a family project. Families often send their “best and brightest” members to find employment elsewhere, in hopes of improving the wellbeing of the entire group;
- at destination, migrants live under conditions that are all too often disappointing, and that may include vulnerability to HIV infection;
- some sub-groups of migrants, or of people who are mobile, are disproportionately affected by HIV because of these vulnerabilities;
- in case of HIV and AIDS:
 - people who have migrated may return to their families for care and support, especially at the end of life. Many will bring their own children with them;
 - children whose parents can no longer care for them may have to migrate in order to live with the guardians that can; and
 - transnational families may live on both sides of the treatment divide, where some members of the same family have access to highly effective HIV treatment, while others do not. In some instances parents needing treatment will be able to receive it, while other family members, including some of their own children, cannot.

This article focuses on the last three points, sketching selected items from the literature and identifying gaps.

Migrating to families for care and support

Studies have shown that people with HIV may return to their families at the end of their lives, in developed countries (cf. Berk, Schur, Dunbar, Bozzette, & Shapiro, 2003; Harris, Dean, & Fleming, 2005) and also in developing, where the extended family may well serve as the primary social safety net (cf. Booyesen, 2006; Hosegood, Preston-Whyte, Busza, Moitse, & Timaeus, 2007). Particularly well conducted studies in South Africa (Clark, Collinson, Kahn, Drullinger, & Tollman, 2007) and in Thailand (Knodel & VanLandingham, 2003), for example,

have shown that increases in circular migration in recent years, combined with high HIV prevalence at migration destinations, have given rise to increased infections amongst migrant workers. As their infections progress to AIDS, increasing numbers of seriously ill former migrant workers are now returning to their rural homes to convalesce and possibly to die. The same studies show that former migrant workers very often return to their families under the worst of circumstances: the return is postponed as long as possible, thus taking place in crisis conditions, when HIV disease is advanced, care needs are pronounced, and other resources have been exhausted. Several studies note, in addition, that migrant workers who return to their own parents for care at the end of their lives quite often bring their own children with them – indeed the need for help with child care is one of the main reasons migrants give for returning (Knodel & VanLandingham, 2003; Schatz, 2007; Ssengonzi, 2007). However, no studies examining needs of such children were found.

The strains for the families involved are the same as for any families in such circumstances. They include seeing children become ill and caring for them as they die, and losing a possible source of support in old age, an accumulation that leaves older adults with “a burden of sadness which today pervades (their) lives” (Williams & Tumwekwase, 2001). However, as pointed out in the studies from South Africa, in particular, those who had migrated in the first place were usually those with more resources. For example, better educated women were more likely to become temporary migrants, and their children experienced lower mortality risks (Collinson 2007, cited in Clark et al., 2007), and in rural households temporary migration was positively correlated with ownership of modern assets (Collinson, Tollman, Kahn, Clark, & Garenne, 2006). The authors of these studies observe that such findings bear out the hypothesis by which it is the healthiest and the most resourceful who migrate, but add “a new and tragic twist”: the family members now being lost were the most talented and ambitious. They were also the members in whose education the family may have invested, and the bread winners (Clark et al., 2007; Collinson et al., 2006; Hosegood, McGrath, Herbst, & Timaeus, 2004).

Migration of children affected by AIDS

The migration of children affected by AIDS has been studied in Africa, particularly, where in many countries migration is widespread, and where voluntary fostering of children has been a feature of family life since long before HIV appeared (Madhavan,

2004). The movement of children whose parents can no longer take care of them may involve travelling long distances, and it follows migration patterns established for far different reasons. Foster and Williamson's review of the literature on "the impact of HIV/AIDS on children in sub-Saharan Africa", published in the year 2000, contained a number of findings related to migration: for example, AIDS-affected children were particularly likely to be relocated; few households liked the idea of separating orphaned siblings, yet they often did so, especially when some of the children concerned were very young; such children might be sent out to work, thus forfeiting their education; and children of migrant workers were particularly vulnerable (Foster & Williamson, 2000). Since then, demographic analysis in KwaZulu Natal has shown that parental mortality doubled the risk of a child moving. Younger children, girls, children with weak kinship ties to the household, and those in households with fewer assets were especially likely to be sent elsewhere. The same study pointed out that an AIDS-related move to another household may take place quite some time before the parent dies (Ford & Hosegood, 2005).

Another study examining children's AIDS-related migration, carried out in Malawi and Lesotho, found that it was adults in the family who decided where children should live – the children were generally not consulted. Decisions were made on the basis of who is responsible for the children, who would be best able to provide for them, and who might need their help with various tasks, including caring for the ill or dying² (Young & Ansell, 2003). AIDS-affected children faced the same difficulties as any child who moves, such as learning new places and ways of life, and perhaps a new language; changes at school; and missing old friends and needing to make new ones. They had to deal with a host of other difficulties, however, starting with the loss of a parent: newcomers were said to be often withdrawn, and to find it difficult to engage with other children. Many were separated from their former siblings, and relations with their new siblings were not necessarily easy. AIDS complicated their adaptation: stigma often made their integration more difficult, and as did the poverty created by extended AIDS care. Repeated illnesses and multiple deaths in their families meant that some children had to move several times between caregivers. Finally, such migration often took place under poor circumstances: it was likely to be unaccompanied and sometimes happened suddenly, with the child unprepared and education disrupted (Ansell & van Blerk, 2004).

Migrant families living with HIV

As world prevalence rises, it is inevitable that some people living with HIV will migrate, although very often without being aware of their infection. The literature on migrants living with HIV comes mainly from Europe, especially the UK. A number of problems are reported, including concerns about immigration status, social and economic difficulties, unfamiliarity with the local health system, concerns about confidentiality and stigma that increases migrants' isolation and reduces possibilities for social support (cf. Burns, Imrie, Nazroo, Johnson, & Fenton, 2007; Green & Smith, 2004; Prost, 2005). A study of African women receiving HIV treatment in London points out that many of the patients are mothers. Those who have children living with them are very often the primary caregivers, and they must cope without support from extended family: "I'm the mum, the dad, the auntie – I'm everything". Many of the mothers had also left children with caregivers in the home country. Their attempts to bring their children to live with them had often been unsuccessful, and the women felt unable to return to their home countries if treatment was not available. Return would cut off their supply of life-saving drugs, and: "what use would I be to him dead?" The situation was especially distressing when changing circumstances meant the children at home had to be passed between carers: "... that is the thing that is really eating me up... I am here and my children are on their own" (Anderson & Doyal, 2004; Doyal & Anderson, 2005).

Two of the most delicate questions within such families concern disclosure of HIV status, and planning for care, where migration complicates a process that is already extremely difficult. Again, most of the studies come from Europe, where rates of disclosure to children have been found to be lower amongst African than among European parents living with HIV (Åsander, Belfrage, Pehrson, Lindstein, & Björkman, 2004; Nostlinger et al., 2004), and where migrant parents are less likely to make long-term care plans (Thorne, Newell, & Peckham, 2000). The question is further complicated by the fact that the parent's death may jeopardise a migrant child's continuing residence in the host country, which may be the only country he or she knows (Miller & Murray, 1999). A study of African families living with HIV in London has explored the tensions surrounding disclosure among transnational families. Most of the migrant parents reported that they had found out about their infection only after they moved, mainly after an illness or during childbirth. They were more likely to disclose their HIV status to

the children who lived with them, but some said they had told children left in the home country in case the parent died abroad, so that decisions could be made about their property. Other parents said they had not told their children about their HIV because they were receiving treatment: they assumed they would be fine, and reasoned that telling children in countries where treatment was not available would just make the children worry, needlessly, that the parent was going to die soon. Worry about a child's HIV status had prompted the uterine mothers, especially, to take some of the younger children for HIV tests, but it was very awkward to ask a caregiver to arrange for a child to have an HIV test in the home country without disclosing the mother's status. Some had simply let the matter slide. They also rationalised that in any case knowing would make little sense if the child would not have access to appropriate medical care in the home country . . . (Chinouya, 2006).

Discussion

In putting together the literature on migration, on HIV or AIDS, and on families, the review reveals numerous gaps, and numerous needs for research and policy formulation. A first major gap concerns the extent to which children are left out: studies of migrants very often mention that they have children, and sometimes that they left children at home while they went abroad to work, but surprisingly few then elaborate, even simply to count the number of children thus affected. These gaps are even more flagrant when HIV and AIDS are factored in: publications may well note that the families concerned have children, but very few then take the story any further. A second research gap concerns coverage: the studies that were presented here, those available in the published and grey literature, undoubtedly shed only a partial light on a situation that is complex, and that shifts rapidly.

However, the studies do begin to reveal a coherent picture: the three themes that emerged from the literature are connected, and they echo the consequences of worldwide increases in temporary labour migration and in HIV prevalence. In the absence of appropriate HIV prevention, increasing numbers of migrant workers have acquired HIV. In the absence of appropriate treatment, care and support, and as HIV disease progresses, many former migrant workers will return to their parents at the end of their lives. The theme of *migrating to families for care and support* deserves a major review of its own, part of which should focus on the long-term consequences for the children involved. Nothing is known about what happens to the children when a family's migration

project fails, especially when it fails because the migrant worker has died. The effects of cumulative loss – and the subsequent burden on families – cannot help but have long-term implications, not only for the families directly involved, but also for their communities.

Migration has long been an important aspect of families' lives in many parts of the world. It is thus logical that the most appropriate person to care for the children when an AIDS-affected parent can no longer do so may live in a different community, country or continent. The studies available on this theme, as well as those on the previous one, show that children's moves often happen under extremely difficult circumstances: poorly prepared, suddenly and disruptively. A key question for both research and policy formulation is thus how to best ensure that such moves take place under the most peaceful and favourable circumstances possible, with support for affected migrants, their children and their parents.

Some studies of *migration of children after the death of a parent* have been carried out in highly impacted countries, and policy recommendations for supporting such children have been formulated (Young & Ansell, 2003), but these need to be evaluated and followed up. Staying in the same community is undoubtedly the least disruptive solution for most AIDS-affected children, but sometimes the most appropriate new caregiver will live in another country. Research should be carried out as to the circumstances under which it would be most appropriate to send children abroad, and several difficult issues require policy attention, such as what definition of "family" is most appropriate (genetic links or wider kinship ties), and how an immigrant family caring for an extra child might best be supported (UNICEF & ISS, 2004).

As mobility becomes easier, and especially as migration is increasingly meant to be temporary, more parents will have children living in different countries. Discovering that they have HIV then places such parents in a complicated situation, especially when treatment is available in the destination country but not in the country of origin. Concerning *children in HIV-affected migrant families*, the review was largely dependent on studies from one country, which may not necessarily reflect experiences elsewhere. Studies from countries highly affected by HIV, especially, are sorely lacking. The lack is particularly serious in that migrant children (for example, those of farm workers) are likely to be among the most vulnerable. When research on each of these themes is carried out it would be helpful to go beyond description, to put analysis into the context of the literatures on family stress and coping and on

family resilience (cf. Fergus & Zimmerman, 2005; Walsh, 2006). Reviews beyond the space limitations of this summary show that – even under very difficult circumstances – moving to new places and new responsibilities may cause children satisfaction and pride, and foster resilience. More lateral thinking needs to be done, drawing on from what can be learned from family coping with migration and applied to a growing literature on families, coping, AIDS and resilience (cf. Cook & Du Toit, 2005; Daniel, Apila, Bjorgo, & Lie, 2007; Richter & Rama, 2006).

As discussed in the introduction, the literature on migration and AIDS has moved beyond thinking primarily in terms of control and containment, towards understanding the mobility-related factors that increase HIV risk and vulnerability, then attempting to reduce these to prevent HIV infections. This review demonstrates the need to take the discussion further, to care. There is need to understand the consequences – for migrants, their children, their families and their communities – when HIV infection occurs, and also to mitigate these consequences. As part of such mitigation, the situation of transnational families living across the treatment divide gives heart-rending life to the need to provide universal access to HIV care and treatment. In a more equitable world, with minimum adequate health care assured everywhere, families would not find themselves in a situation in which some members who need treatment can receive it, whereas others cannot, or in which parents must choose between receiving medical care or living with their children.

Notes

1. For more details on the methods used see: <http://www.jlica.org/userfiles/file/Haour-Knipe%20Migration%20and%20families%20in%20the%20context%20of%20HIV%20and.pdf>. This document also discusses the literature on migration and families and that on migration and AIDS.
2. A study of young carers in Zimbabwe noted that children who move to care for an AIDS-affected relative are often especially isolated: they are removed from their former friends, and their movement is limited by their care-giving duties (Robson, 2004).

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