Placing HIV-positive Mothers at the Centre of Planning for Orphans and Vulnerable Children: A Case Study of South Africa

Amy Norman, Suneetha Kadiyala and Mickey Chopra

October 2005

Amy Norman
Department of Geography
University of Calgary
2500 University Dr NW
Calgary, AB T2N 1N4, Canada

Suneetha Kadiyala
International Food Policy Research Institute
2033 K Street, NW
Washington, DC 20006-1002, USA

Mickey Chopra
Health Systems Research Unit
Medical Research Council
P O Box 19070
Tygerberg 7505, South Africa

Abstract

Worldwide, more than 14 million children have lost a parent to HIV/AIDS. In South Africa, the current epicentre of the epidemic, it is estimated that by 2010, 16% of children will be orphaned by AIDS. The implication of the term “AIDS orphan” has been that parents with AIDS have no plan in place to provide for the care of their children in the event of their deaths. In the majority of policy discourse, women are not seen as agents in the process of preparing their children and future caregivers, or of planning for the future. Effective responses to the challenge of AIDS-induced orphanhood require an understanding of the challenges HIV-positive women face in mothering, as well as the dynamics and strategies used in planning for the future of their children. The inclusion of mothers before the death of a parent is necessary so as to privilege a thus far underutilized resource. The aim of this paper is to present the results of a study that examined the experiences of women undergoing shocks related to the impact of HIV/AIDS in two South Africa communities- Paarl and Umzimkhulu. A total of 25 HIV/AIDS-affected people from 18 households were interviewed, as well as ten key informants. This paper highlights the challenge of maternal disclosure in the African context, the planning for future caregiving, the financial constraints mothers face, and the opportunity undertaken by women to foster future resistance and resilience in their children.

Acknowledgements

The authors would like to thank RENEWAL-- Regional Network on HIV/AIDS, Rural Livelihoods and Food Security (http://www.ifpri.org/renewal/), coordinated by the International Food Policy Research Institute. The authors would also like to thank the following individuals for their roles in the research study upon which this paper is based: Stuart Gillespie for help in conceptualizing the study and ongoing guidance and comments on previous drafts. Elizabeth Byron for assistance with development of methodology and field guide; Lungiswa Tsolekile, University of Western Cape, for assistance with development of methodology and field guide and for carrying out the fieldwork with Amy Norman; Weliswa Binza, University of Western Cape, Ikhwezi Community Centre and Mbekweni Community Health Project for facilitating the fieldwork logistics. Amy Norman would also like to thank University Services at the University of Calgary and the Canadian Institutes of Health Research (CIHR) for their continued support of her graduate research.

Placing HIV-positive Mothers at the Centre of Planning for Orphans and Vulnerable Children: A Case Study of South Africa

Re-locating women in OVC discourse

Worldwide, more than 14 million children have lost a parent to AIDS (Rotherum, 2004). A recent analysis by UNAIDS/UNICEF/USAID (2004) estimates that in South Africa, of 17 million children between zero and 17 years, 13 percent or 2.2 million are orphans. The total number of orphans due to AIDS is estimated to be approximately half of that figure or 1.1 million. It is estimated that by 2010, 16% of children in South Africa will be orphaned by AIDS (UNICEF, 2003). As Bray (2004) discusses, much of the current discussion on orphans and vulnerable children (OVCs) revolves around this impending future and the potential for chaos and social breakdown. As Bicego et al (2003) point out, HIV/AIDS is a 'family crisis' which marks the beginning of the deterioration of the family unit and the trauma in the emotional, psychological and material life of the child. Currently, there are already an estimated 5 million adults living with HIV in South Africa; a majority of them women. The provision of HIV testing for all pregnant women as part of the prevention of mother to child transmission (PMTCT) program has resulted in hundreds of thousands of mothers coming to terms with their HIV status. Despite the increasing rate of HIV infection among women, the fact that most HIV infected women are of child-bearing age, and the unique challenges faced by these mothers, few studies have explored the experiences of HIV-positive mothers and the impact they may have on the future well-being of their children.

In the context of southern Africa, which is still the epicentre of the epidemic, we could find no studies that explore the experiences of HIV-positive mothers and the dynamics of planning. The implication of the term "AIDS orphans" has been that parents with AIDS have no plan or support system in place to provide for the care of their children in the event of their deaths. Although this may be the case for some families, it is not known to what extent HIV-positive mothers have given thought to, and planned for, the future care of their children. (Marcenko and Samost, 1999). In much of the policy discourse women are not seen as agents in the process of preparing their children and future caregivers, or of planning for their futures. Infected women "have been described as isolated, unsupported, powerless, and invisible, primarily because of their status as women and the fact that the majority of HIV-positive women are of colour and poor- leading to further devaluation" (Marcenko and Samost, 1999). Effective responses to the challenge of AIDS-induced orphanhood require an understanding of the challenges HIV-positive mothers face, as well as the dynamics and strategies used in planning the future. The inclusion of mothers *before* the death of a parent is necessary so as to privilege a thus far underutilized resource in discussions which surround the impending AIDS orphan crisis. In doing so, this paper also re-orients the discourse of OVCs so as to illuminate the roles mothers are already playing, so as to bolster their capacity to ensure the future well-being of their children.

The aim of this paper is to present the results of a study which examined the experiences of women undergoing shocks related to the impact of HIV/AIDS. We highlight the challenge of maternal disclosure in the African context, the planning for future caregiving, the financial constraints mothers face, and the opportunity many mothers take to foster future resistance and resilience in their children.

Setting

The research took place at two South African communities – Paarl in the Western Cape and Umzimkhulu in the Eastern Cape. The communities are geographically diverse in that one is peri-urban and one is rural and they lie in different provinces. However, culturally they are similar in that both communities are rooted in the Xhosa population.

Paarl is a peri-urban/rural commercial farming area in the Western Cape which, despite its relative wealth, has high levels of socio-economic inequality (Drakenstein:2004). The study was conducted in an area where the majority of people are unemployed or seasonally employed on nearby grape farms. HIV prevalence is fast escalating in Paarl., increasing from 4.5 percent in 2000 to 15 percent in 2004 (Drakenstein Municipality, 2005).

Umzimkhulu lies in one of the poorest rural areas of South Africa, the former Transkei homeland in the Eastern Cape. Employment levels are very low, with only about 12% of residents in the municipality employed. There is a marked dependency on government services, pensions and migrant workers, with 38% of households reporting no income at all.

Methods

This study was part of a larger study which examined the dynamics of responding to the impact of HIV/AIDS-related shocks. The identified 'shocks' were AIDS-related mortality, prolonged illness, coping with the loss of a productive household member, taking in orphaned children, and the experience of being abandoned and/or rejected by family members and loved ones. In Paarl we utilized two local NGOs that support households who are caring for AIDS-orphans and employed community health workers and a fieldworker from a national Preventing Mother To Child Transmission (PMTCT) study that is based in both sites. In Umzimkhulu, we worked with local field workers employed by the PMTCT study to locate those in the community who were not only HIV-positive, but who had experienced HIV/AIDS-related shocks.

In both communities, introductions were made with potential respondents through local contacts. None of the potential respondents approached refused to participate in the study. The study protocol was ethically approved by the Institutional Review Board at the University of Western Cape. as well as the Ethics Review Board at the University of Calgary.

A total of 25 HIV/AIDS-affected people from 18 households were interviewed. 14 respondents came from Paarl, and 11 came from Umzimkhulu. Ten key informants were also interviewed, including health care professionals, counsellors, educators, and local NGO workers. The interviews were semi-structured and lasted between one and two hours. The interviews were conducted by experienced researchers, one whom is fluent in the two dominant local languages. Thematic content analyses were used to identify key themes within the interviews. All names utilized in this paper have been changed in order to protect the confidentiality of respondents.

Maternal Disclosure to Children

Mothering with HIV is imbued with a variety of dilemmas and challenges. In studies which explore the impact of HIV/AIDS on mothering, disclosure of serostatus to children has emerged as one of the main concerns (Murphy et al, 2002). Whether disclosure benefits or hinders a child's development is highly contested in the literature, and is rarely mentioned in literature pertaining to the African context (Barnes et al, 1997; Lee and Johann-Liang,1999; Letteney & LaPorte, 2004, Murphy et al, 2002; Marcenko & Samost,1999, Murphy et al, 2003; Shaffer et al, 2001; Simoni et al, 2000). However, in Gilborn et al's (2001) study of Ugandan parents, the great majority (91.3%) thought it was a good idea to talk to their older children about HIV/AIDS. In our study, many of the women also expressed a desire to disclose to children. Among our respondents, there were a range of experiences expressed, with the majority describing the process in a matter-of-fact way:

> All her children know about her status. She disclosed to them alone and the children accepted it.
>
> She has disclosed to her two eldest children and it was not difficult for her to tell them. Both her children have gone for counseling and both children can now counsel others.

For others, although they had a desire to be open with their children, the process seemed too difficult to carry out. While counseling services may exist for this purpose, we did not find evidence of this among our respondents. HIV-positive mothers are left without the information or guidance they require to make the decision:

> She would like to disclose her status to her other children but can not do it alone. She is currently not open about her status. She would like to access some counseling on how to do this.

Exacerbating the complexity of the issue is the traditional living arrangements of children in South Africa; many mothers do not reside with their children, with children raised by their grandmothers or other relatives. Amongst respondents, there was a lack of awareness on how to handle this predicament:

> Her children do not yet know of her status. She thinks it is possible though that her mother has told them. She hasn't really thought of telling them, in large part because they are not around each other.

The debate surrounding the merits of disclosure to children continues due to fears that it may lead to divisiveness within the family, and to confusion and anxiety in children who may be aware that something is wrong. However, we found that in cases where mothers had disclosed to their children and were able to discuss their illness with them, respondents felt their children were well-adjusted and prepared. Further, in some cases, children were able to take on key roles in the support network of their HIV-positive mothers (Adato et al, 2005). Indeed, researchers (Reyland et al, 2002) have found that caretaking behaviours have the potential to act as a protective factor in providing adolescents feelings of competence and mastery over circumstances in their lives. A prime example of this was in a child-headed household where we were able to interview a young man about his experiences of living with an HIV-positive mother and his realties since she had passed away:

> Before his mother passed away she spoke with him about a time when she would not be around. She told him that times would be difficult and that he would have to deal with it on his own. In fact, this made things easier for him because he knew what was to come.

While there are risks with maternal disclosure, there are a variety of potential advantages. These include the increased closeness between mothers and children, and the elimination of the burden of keeping such a stressful secret (Thomkins et al, 1999). We found evidence to suggest that women feel it is an important issue and would like to discuss their status with their children. In the vast majority of cases, outcomes were positive both for mother and child.

Planning for Future Caregiving

One of the most painful realizations for HIV-positive mothers is the possibility that they may be unable to care for their children or see them grow to maturity. For a mother infected with HIV, there is an urgent and poignant need to face the possibility of death and make alternative caregiving arrangements (Rotherum, 2004). When parents fail to make adequate custody plans, their children are at a higher risk for emotional and behavioural problems than when parents have made a plan (Rotherum, 2004). Future planning for children can create a peace of mind for parents by providing assurance that the children will be cared in accordance to their parents' wishes (Committee on Pediatric AIDS). In a study of American women, almost all (91%) had reported having thought about who would be responsible for their children should their health prevent them from continuing to parent (Thomkins et al, 1999). In a Ugandan study (Gilborn et al, 2001), 86.7% of parents believed that there is a need to make explicit arrangements to appoint a guardian in order to ensure future care for the child, to reduce children's anxiety, to allow guardians to prepare, and to reduce their own worries. However, only half (51.7%) had actually arranged for a guardian.

In this study, the most important and often-identified type of planning was that of the future child caregiving arrangements. As one respondent stated:

> Mothers will usually identify family members in advance who could care for their children and sometimes even speak with them about this. It is usually family members because they are the ones who will care for the children as their mother's did- raise them as their own.

Our research found that the identification of family members as potential caregivers was a common trend amongst HIV-positive mothers. Grandmothers were by far the most significant source identified by mothers. Six of eighteen mothers indicated that their children would be living with their maternal grandmothers. Only one mother who was currently living with in-laws stated that the child would continue to live with her paternal grandmother once she had passed on. As one key informant working with orphans described, "in most cases, before the parents pass away they send the children to the home they are going to be living in" so that the transition is relatively painless for the child. Previous research has shown that familiarity with a guardian before the parent dies is associated with greater emotional well-being once the child is living in a foster household (Gilborn et al, 2001).

An example of the active participation of elder women in sustaining the strength of family networks comes from the Paarl site. In this case a young mother had been abandoned by her husband, and her mother had taken her in to her home. When we interviewed the respondent about future planning for her daughter, she described the following:

> She finds it difficult for herself to do this [planning] because she does not have the financial means to plan certain things. Right now, no one in her immediate family could look after her daughter. She has told them that should something happen to her today she thinks the best place for her daughter would be the orphanage. Her mother wouldn't really have the strength or capacity to do it and she doesn't know what would happen to her.

However, when we interviewed the 59-year old grandmother of the child it was clear that she was already playing a central care-giving role. Further, this grandmother had her own idea of what she was capable of and the role she would play:

> If anything happens to my daughter I would help and care for my granddaughter. If I was too old to do this then my other daughter would be the ideal person to care of her and would raise her.

This case attests to the reality that not only do mothers plan for their children, but in some cases the extended family may be doing so as well. Further, while some women may feel that children would be a burden on elderly grandmothers, grandmothers themselves may feel up to the challenge. There is more research required on how elderly women

themselves interpret their roles in the era of HIV/AIDS, and how this can be bolstered as part of an effective response to the crisis of future child caregiving.

When grandmothers were not present, available, or capable, sisters were often the next choice. Five mothers indicated that their children would be living with aunts. Three mothers in our sample already hosted maternal orphans who were their nephews or nieces, demonstrating how common this practice is. The following story (Box 1) demonstrates many of the dynamics associated with the process of securing future caregivers:

Box 1: Going to Live with Your 'Other Mother'

Mafu, 36, is a mother of four and lives with her husband in Umzimkhulu. In 2003 she tested positive for HIV after the birth of her daughter. Recently she and her baby were diagnosed with TB and are currently being treated. The first person she disclosed to was her sister-in-law who has been incredibly supportive of her emotionally as well as through caregiving and frequent visits. When she became very ill both of her sisters offered to take her baby to alleviate the burden on her, and the child is currently in the care of her sister who lives closer to her so that they can visit.

When she was especially sick she spoke to her sister about caring for her children when she passes away and her sister agreed. The 3 youngest children will go to live with her and she has even spoken to them about it. She has said that "there will come a time when you will go and live with your other mother." She says that "even when you ask the children who their *other* mother is, they know."

Mafu trusted both of her sisters to watch over her infant daughter and was in a position to ask either to take in her children when she passes away. This story attests to the strong ties between families, and especially women. Children are aware of their extended families as their most intimate support networks, to the point where children not only have one mother, but can claim to have multiple mother figures ready to watch over them.

Apart from the three mothers who had poor relationships with their mothers, all of the mothers in the sample trusted the identified future caregivers to care for their children. Significantly, none expressed fear of abuse, neglect or property grabbing. This has profound implications for the positive living of the mother as well as the future well being of children affected by the illness.

Financial Planning

Overwhelmingly, the most common constraint expressed by mothers for financial planning was poverty. More than half of the mothers in our sample had not yet started to save for their children's financial future. The available research on factors affecting the informal fostering or adopting of children in the context of AIDS shows clearly that the

principal constraints for South African families are economic (Bray, 2004). The common occurrence of general abandonment by husbands or fathers of children has exacerbated the vulnerability of families and made the potential to save impossible. Indeed, only one family in our sample was described as 'nuclear' in that both parents and children were present and still residing with one another. However, even in this case the father also described the constraints of poverty in his efforts to plan for his children's future.

Despite such poverty and the lack of stable incomes, several examples illustrate mothers who were actively saving for the future financial security of their children. Mothers typically started saving whatever they could and made statements such as, "although it is not a lot, it is something." Further, in two examples where the father of the children was still alive, two mothers in our sample were legally seeking child maintenance support. In both cases their efforts had been successful.

Knowledge Transfer and Future Resistance

The current landscape of HIV/AIDS discourse often poses the question of building future resistance in vulnerable populations to protect them from the HIV/AIDS epidemic. An interesting aspect of planning and of mother-centred discussions of children is the impact they may have in preparing their children for future resistance to HIV. Mothers hold great potential to protect their 'vulnerable' children from contracting the disease, a topic rarely broached in the literature. All of the mothers interviewed in this study who had children at the age of puberty had spoken to their children about sex education and HIV/AIDS. The following are a few examples:

> His mother empowered him with HIV education. Because of this support, he feels he has strength to support others/his peers. He is now very open about the subject of HIV/AIDS.
>
> She says that she will speak with her children about HIV/AIDS. She believes that those who are open *do* talk to their children about it. Had her own mother spoken to her about the risks, she thinks that she probably would not be positive today.

While our evidence is limited in quantity, its findings are important to future prevention interventions. Mothers should be included in working to protect their children from future risk so as to minimize their 'vulnerability.' Our study demonstrates the reality of mothers already doing this, and the importance of their own education of the disease. Mothers have a stake in working to prepare their children, and they have demonstrated the importance of passing on knowledge. This agency once again needs to be highlighted and utilized so as to *centre* mothers in the responses and programs aimed at their children.

Conclusions and Future Implications

HIV-positive mothers face a number of unique challenges. Beyond managing their illness and the personal stressors associated with the disease, they are also responsible for

their household livelihoods and the rearing and well-being of their children. This paper makes three main points: first, we must address women and mothers directly about their future plans, as this research has done. Second, we must *reorient* the debate so as to include mothers in the future policy and planning surrounding the issue of OVCs in South Africa, as well as in the region; mothers are aware of their constraints and need to be included in the discourse. Lastly, in order to strengthen the roles of mothers, we must understand the dynamics of planning, the challenges HIV-positive women face in mothering, and some of the strategies they employ in their efforts to plan. Ultimately, this paper calls for the inclusion of mothers and families *before* the death of a parent, so as to privilege a thus far underutilized resource in discussions surrounding the impending AIDS orphan crisis. As the advent of an AIDS orphan crisis looms, who better to include in the planning process than the mothers who are still alive?

References

Adato, M., Kadiyala, S., Roopnaraine, T., Biermayr-Jenzano, P and Norman, A. (2005). *Children in the Shadow of AIDS: Studies of Vulnerable Children and Orphans in Three Provinces in South Africa*. Washington DC: International Food Policy Research Institute (IFPRI).

Barnes, D., Taylor-Brown, S. & Wiener, L. (1997). "I didn't leave y'all on purpose": HIV-infected mothers' videotaped legacies for their children. *Qualitative Sociology* 20(1): 7-32.

Bicego, G., Rutstein, S & Johnson, K. (2003). Dimensions of the emerging orphan crisis in sub-Saharan Africa. *Social Science and Medicine* 56: 1235-1247.

Bray, R. (2004). 'AIDS orphans and the future: A second look at our predictors. Human Sciences Research Council.

Committee on Pediatric AIDS, American Academy of Pediatrics. (1999). Planning for children whose parents are dying of HIV/AIDS. *Pediatrics* 103(2): 509-511.

Drakenstein Municipality. (2004). Manifestations of poverty in Drakenstein: A brief quantitative and qualitative overview. 12 March 2004.

Gilborn, L., Nyonyinton, R., Kabumbuli, R., & Jagwe-Wadda, G. (2001). *Making a difference for children affected by AIDS: Baseline findings from operations research in Uganda*, The Population Council.

Kadiyala, S., Norman, A. & Chopra, M. (2005). Children *before* they are Orphans. International Food Policy Research Institute.

Lee, C. & Johann-Liang, R. (1999). Disclosure of the diagnosis of HIV/AIDS to children born of HIV-infected mothers. *AIDS Patient Care and STDs* 13(1): 41-45.

Letteney, S. & Heft LaPorte, H. (2004). Deconstructing stigma: Perceptions of HIV-seropositive mothers and their disclosure to children. *Social Work in Health Care* 38(3): 105-123.

Marcenko, M. & Samost, L. (1999). Living with HIV/AIDS: The voices of HIV-positive mothers. *Social Work* 44(1): 36-45.

Murphy, D., Johnston Roberts, K. & Hoffman, D. (2003). Regrets and advice from mothers who have disclosed their HIV + serostatus to their young children. *Journal of Child and Family Studies* 12(3): 307-318.

Murphy, D., Johnston Roberts, K., & Hoffman, D. (2002). Stigma and ostracism

associated with HIV/AIDS: Children carrying the secret of their mothers' HIV+ serostatus. *Journal of Child and Family Studies*, 11(2): 191-202.

Reyland, S., Higgins- D'Allessandro, A. & Mcmahon, T. (2002). "Tell them you love them because you never know when things will change:" Voices of adolescents living with HIV-positive mothers. *AIDS CARE* 14(2): 285-294.

Rotheram-Borus, M., Draimin, B., Reid, H., & Murphy, D. (1997). The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. *AIDS* (11): 1159–1164.

Rotheram-Borus, M., Lester, P., Wang, P., & Shen, O. (2004). Custody plans among parents living with human immunodeficiency virus infection. *Arch Pediatr Adolesc Med*. (15):327-332.

Shaffer, A., Johns, D., Kotchick, B., Forehand, R., & The Family Health Project Research Group. (2001). Telling the children: Disclosure of maternal HIV Infection and its effects on child psychosocial adjustment. *Journal of Child and Family Studies*. 10(3): 301-313.

Simoni, J., Davis, M., Drossman, J., & Weinberg, B. (2000). Mothers with HIV/AIDS and their children: Disclosure and guardianship issues. *Women and Health* 31(1): 39-54.

Thompkins, T.,Henker., B., Whalen, C., Axelrod, J., & Comer, L.. (1999). Motherhood in the context of HIV infection: Reading between the numbers. *Cultural Diversity and Ethnic Minority Psychology*, *5,* 197–208

UNAIDS/UNICEF/USAID (2002) *Children on the brink 2002: A joint report on orphan estimates and program strategies*.

UNICEF (2003) *Africa's orphaned generations*. New York: UNICEF.