

CENTRE FOR  
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Social Surveys Unit

**THE INFLUENCES OF AIDS-  
RELATED MORBIDITY AND  
MORTALITY ON CHANGE IN  
URBAN HOUSEHOLDS: AN  
ETHNOGRAPHIC STUDY**

Rachel Bray

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Rachel Bray is a social anthropologist affiliated to the Centre for Social Science Research and Children's Institute at the University of Cape Town.

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# The influences of AIDS-related morbidity and mortality on change in urban households: An ethnographic study

## **Abstract**

*Drawing on qualitative panel data collected in a poor township on the edge of Cape Town, this paper provides a fine-grained analysis of the residential decision-making of five HIV positive women and some of their children. HIV status and illness are found to add to the pressures exerted by income and asset poverty in ways that further incline women to seek residential security for themselves and their children. The presence of HIV intensifies the mental health implications of pre-existing socio-economic burdens and efforts to respond to these. Much of the resultant mobility cannot therefore be considered AIDS-specific. At the same time, being HIV positive and unwell (or anticipating ill-health) prompts women to organise particular domestic arrangements for themselves and their children. Previously non-resident children are moved from distant relatives to join the urban household, incurring financial and social strain on the domestic group and on infected women in particular. Infected mothers want to live with all their children so that they can nurture them, have opportunity to disclose and familiarise their children with the everyday implications of being positive and on treatment, and to ensure they have the skills to survive on their own should they themselves die. Such moves can be made without raising suspicion of HIV within the family because there is a well-established pattern of moving teenagers from the Eastern Cape to schools in Masiphumelele for reasons of improving education.*

*Other factors that act alongside, and often in relation to, women's HIV status in shaping their residential decision-making include the nature and structure of related rural and urban households, point in the domestic development-cycle of different branches of the family, a woman's personal relational history and her individual temperament. We found that close connections with a rural home reduced women's sense of vulnerability but were not always the first port of call for support owing partly to fears around disclosure and (often related) anticipated compromises in their abilities to claim resources from the rural home in future moments of greater need. The mothers in our sample were reticent to disclose to their own mothers and saw the rural maternal home as a*

*possible (but not always preferable) option for their young children but not themselves or their older children. And while siblings living close by were often those to whom women first disclosed their status, the homes of sibs who had resident children of their own were not experienced as available. The ethic of responsibility that exists between siblings includes attention to the moral integrity of individuals and the family, which can conflict with parallel efforts of care and support for those in greatest need. These dynamics appear to partly explain women's preference to live with their partner and children, or their children only, rather than with members of the wider family. Such decisions are also shaped by the increased importance of sustaining and asserting control over their own and their children's residence for women who experience their status and illness as tangible evidence that they cannot control their health or longevity.*

## **Mobility and AIDS in Southern Africa**

This paper contributes to the growing debate about how individuals respond to HIV status and illness when experienced alongside severe chronic poverty. It looks at the ways in which five HIV-infected women being treated for AIDS and a number of their close relatives manage their roles and relationships within the domestic and kinship spheres, the resultant organisation of households, and the scope of residential decision-making to mitigate or increase further vulnerability.

There is a large body of Southern African literature on residential mobility that focuses on household fluidity within the rural-urban Diaspora (Spiegel and Mehlwana 1997, Lee 2002) as well as changes in the size and structure of households (Amoateng 1997; Russell 1997 and 2003, Coen 1998). The effects of adult mortality in rural areas with high AIDS rates on household dissolution and migration have also been studied (Hosegood et al. 2004). A number of anthropologists have attended to the processes through which people construct and maintain domestic groups over time (Reynolds 1993; Ross 2003), but thus far the manner in which HIV/AIDS influences these micro-level dynamics has not been widely studied. In light of the need to understand how HIV infection within the home shapes pre-existing mobility patterns, recent efforts have been made to attune the design of surveys in order that they can capture the dynamics of migration in response to a number of different pressures (Hosegood and Timaeus 2001). Results emerging from the ACDIS data set from rural Kwa-Zulu Natal show that household instability (as measured by dissolution and out-migration from the area) is associated with younger household heads, female headship and the death of a household member the previous year. More

specifically, household dissolution was three times more likely in households that had experienced an adult AIDS death (Hosegood and Ford 2003). This study was unable to comment on the effects of AIDS-related and other illness on change in household composition.

A second smaller body of work looks at the movement of children in response to HIV/AIDS. Research in rural Kwa-Zulu Natal (Ford and Hosegood 2005; Hosegood and Ford 2003) and Lesotho (Young and Ansell 2003a:465) found that the dispersal of children is employed as a coping strategy to deal with AIDS as one of a number of pressures on poor households. Young and Ansell claim that despite the historical precedent of mobility that results in the fragmentation and re-forming of households, these processes are becoming increasingly important in an era of AIDS (ibid.). Children in the rural study sites were leaving households for four main reasons, which may be exacerbated by AIDS. A small proportion did so to care for sick relatives<sup>1</sup>, and larger numbers did so following the death of one or both parents, increased poverty due to illness or death in the family and the re-marriage of widowed parents (ibid:468). In this particular sample, the parent or care-giver's inability to care for children owing to their sickness did not appear to prompt a child's move from the home. Ethnographic work in rural Kwa-Zulu Natal points to the opposite scenario: Children living in small households were being moved when a parent became ill. The study does not shed light on the precise motivation for such moves, nor how extensive this strategy is (Hosegood and Ford 2003:22). This study also identified positive incentives for child mobility including attending better schools or accompanying parents who are seeking work in the city (Hosegood and Ford 2003).

Young and Ansell's (2003a) work sheds light on children's multiple moves, first to elderly relatives who cannot cope or die, then to orphanages or to the streets. These moves imply an absence of kin or neighbouring households who are available to absorb children or to the poor quality of relationships with households connected through kinship or other means. Young and Ansell describe a form of household fragmentation that arises from households and extended family inability to support large numbers of orphaned children (ibid. 472). Sibling separation was also commonplace, but many siblings lived close by and could visit each other often (ibid. 473). The tracing of children's mobility in rural Kwa-Zulu Natal also indicated that the majority of this movement occurs within the district, and a large proportion within the immediate neighbourhood (Hosegood and Ford 2003). Such mobility and change in domestic groups are responses to highly prevalent HIV within rural communities

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<sup>1</sup> Robson (2000 cited in Young and Ansell 2003) found that young girls in rural Zimbabwe were being sent to the city to care for sick relatives.

for almost two decades. Although the pandemic is in an earlier stage in the residential periphery of Cape Town, rising death rates in recent years are likely to be exerting similar pressures on domestic groups. This paper aims to shed light on some of the ways in which mothers, and their children, respond to these pressures.

Research in North America amongst families with an HIV positive parent shows that adolescents experience frequent changes of residence (Duggan 2000), family role reassignments (Reyland, Higgins d'Alessandro and McMahan 2002) and a lack of social supports and other resources (Hudis 1995; Reyland, Higgins d'Alessandro and McMahan 2002). Evidence of the impact of children's HIV-related movement to another household in Uganda (Barnett and Blaikie 1992) and Tanzania (Evans 2005) suggests markedly increased vulnerability, largely because most are fostered by grandparents who have no access to income because their own children are sick or have died, and there are no pensions. Research in Malawi (Mann 2003) shows that children being fostered by relatives following HIV related parental death are often subjected to discrimination and hostility. Studies in Southern Africa indicate very variable influences on well-being. Children in rural Lesotho reported that they were very seldom consulted regarding their future home (Young and Ansell 2003:473). At the same time however, they expressed a view that as children in need, it was not appropriate to impose their views on where or with whom they would like to live. Donald and Clacherty (2004) measured a range of economic, social, emotional, and developmental goals amongst Zulu children living in poor and heavily HIV affected communities on the periphery of Pietermaritzburg. As anticipated, they found that those living in households without adults ('child-headed households') were more vulnerable than their peers living with at least one adult in terms of access to social services, income (cash or kind) and resource generation, as well as in relation to unresolved grief, lack of attainable long term goals, lack of self worth, and poor internal locus of control. But these young people demonstrated specific – and perhaps unexpected – strengths rarely found amongst those living with adults in their social networking; time and money management, and family interactions. The latter findings indicate aptitudes and social competence that enable young people to draw in the resources they need when there is no adult household head. But these may not be recognised in settings where it is uncommon to consult young people regarding residential and other family decisions.

In summary, research to date suggests that AIDS in the home tends to exacerbate existing social and economic pressures that are often managed in part through the movement of one or more household member. Thus, adult sickness or death may lead to increased levels of the same kinds of mobility practised by

poor families for several generations. Knowledge of the multiple and interactive contributors to domestic fluidity is helpful in placing HIV in an appropriate historical and socio-economic context, but it does not help us understand whether it has particular influence on individual decision-making and on consequent household dynamics. We know little about the effect of illness or status and treatment on parental decisions regarding their own and their children's residence. The survey data upon which most existing work on these dynamics rely is limited in its ability to record frequent and 'small' changes in domestic arrangements, including a very temporary move, which may not even be captured as mobility. They also tend to rely on an objective assessment of change in household composition in relation to easily defined events, such as illness or death. Thus the manner in which HIV-infected adults plan and execute their own and others' mobility in response to any one aspect of their health, economic or social status, or a combination thereof, has not been properly explored within neighbourhoods with high rates of HI infection, unemployment and endemic poverty.

Teasing out the precise influences of illness and HIV status on decisions is not a straightforward process and difficult to achieve through a cross-sectional survey or a once-off qualitative study. The longitudinal nature of this data set offers unusual potential to analyse the impact of various HIV-related factors alongside other evolving social, economic, health and psychological processes. Interviews, psychological assessments and observations conducted in 2004<sup>2</sup> provide a highly detailed set of baseline information on kinship, quality of relationships, household economics, social supports, physical and emotional health, as well as medical and residential history. Four<sup>3</sup> of the same women and various co-resident kin were interviewed twice more in 2007, the focus of these conversations being actual or planned residential mobility in the intervening period. Such a data set enables the tracing of movement of people in and out of domestic groups, or the physical relocation of a domestic group, during a two and a half year period. It also permits the comparison of anticipated outcomes with the actual consequences of various moves, thereby giving insight into both objective and subjective interpretations of what can be, or was, achieved through moving. Finally, a qualitative panel of this nature presents the opportunity to

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<sup>2</sup> The original data set was compiled for a study investigating appropriate methodologies for understanding the impact of HIV/AIDS on childcare relationships (Brandt et al 2005). Lindiwe Mthembu-Salter and I collected the data for this initial study which was managed by René Brandt in collaboration with other colleagues from the HSRC and funded by OSSREA (Organisation for Social Science Research in Eastern and Southern Africa). The second phase of the study was researched by Lindiwe and I, and funded by The Rockefeller Brothers Foundation.

<sup>3</sup> One of the women from the original sample died in late 2004 and her sister, with whom this woman had lived for approximately one year, was interviewed twice in 2007.

respond to an acknowledged gap in information regarding change within and between domestic groups, namely the nature of social relationships between households in which someone is AIDS-sick and other related or unrelated households, and the manner in which the transfer of members is facilitated. The narratives collected indicate a variety of factors including the nature and structure of related households, point in the domestic development-cycle, personal relational history, and individual temperament that act alongside or in relation to women's HIV status and experiences of ill-health in shaping their decision-making over the two and a half year period.

## Research setting and sample

The five women and their co-resident family who are the focus of this paper were living in Masiphumelele, a very poor community on the outskirts of Cape Town. In terms of its demography, built environment and socio-economic profile Masiphumelele is representative of a large number of poor urban settlements in greater Cape Town that were created for workers and immigrant job-seekers classified 'black African' by the apartheid state. Recent surveys put the population at 12,800<sup>4</sup>, the majority of whom speak isiXhosa<sup>5</sup>. TB and HIV rates are high, the latter estimated at 23% (Desmond Tutu HIV Centre 2005)

Most people in Masiphumelele live in shacks, with approximately 4% residing in newly built brick houses (ibid.). Although most shacks are serviced with sanitation and electricity, a large and increasing number of families are building shacks on wetlands (unserviced, illegal and at considerable risk of fire). Unemployment is prevalent: the 2002 census puts formal and informal employment at only 47% (ibid.). A large proportion of individuals and their families rely heavily, or even solely, on state social assistance. Despite this, many residents have moved to Masiphumelele to look for work and improve their quality of life. Residents perceive there to be greater employment opportunities in this area because it is smaller and more contained than townships in other parts of greater Cape Town. Masiphumelele has a primary school, a high school, a large number of churches, a library, a community hall and a community centre used by various non-governmental organisations (NGOs) offering social support services.

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<sup>4</sup> Local residents and NGO staff working in Masiphumelele estimate the population to be in the region of 20,000, attesting to the steady immigration of young and working age people from the Eastern Cape.

<sup>5</sup> Unless specified otherwise, participants in our study are Xhosa-speaking with ancestral roots in the Eastern Cape.

Established in 1997, the primary health care clinic has operated a twice-weekly, doctor-driven HIV clinic since 2000. Government, together with a US-funded project based at UCT's Desmond Tutu HIV Centre, began the roll-out of antiretroviral therapy (ARVs) at Nomzamo Clinic in June 2004. We began our study four months later, at which point there were 104 adults and 9 children on treatment. By the end of the second phase in March 2007, these figures had risen to 524 adults and 24 children. Patients of the clinic also have access to weekly support groups and income-generating projects through a local church-based NGO.

The women in our sample are all HIV positive, had experienced periods of ill-health in part owing to the progression of the infection to AIDS, and had begun anti-retroviral therapy. None were bed-ridden during the study phase but tragically one died unexpectedly shortly at the close of the first study phase. At the time of writing, these women represent a significant and growing proportion of women in Masiphumelele who are AIDS-sick and on treatment. In light of an HIV prevalence rate of 23% and medical criteria for treatment, we can assume that they represent a small portion of those who know that they are positive, and that there is a larger but untraceable group of women who are infected but who have not tested. These and other women on treatment are distinct from the broader universe of HIV positive women firstly by virtue of the physical and psychological implications of consuming ARVs, and secondly by their regular attendance at the clinic and NGO support group, and frequently by their resultant connections to various NGO run social services<sup>6</sup>. Not only have these services provided medical, financial and psycho-social support, but they are an arena that employs particular discourses about how to protect one's physical, mental and emotional health when one is HIV positive.

Interviews in both phases of the study were conducted primarily by Lindiwe Mthembu-Salter, a Zulu-speaking professional counsellor who, like me, lives in a middle class largely English-speaking village near Masiphumelele. I accompanied Lindiwe to observe relationships in the home and initiate the interview process during the first phase of research. Lindiwe carried out the remaining three or four interviews with the five women and their relatives on her own. We spell out these details because the nature and quality of interview

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<sup>6</sup> Three of the five women in this study were recipients of a monthly food parcel and had their children's crèche or school fees and other educational expenses paid by a programme designed to relieve the pressure on poor, HIV positive mothers with young children. Although women were recruited to this programme by virtue of being social worker clients (for reasons unrelated to their status), the funder stipulated that there should be a crèche or school-age child at home and that the mother or principal carer should be HIV positive in order to qualify. Approximately 70 families were being supported through this programme in 2007.

data are highly influenced by respondents' perceptions of the researcher. Lindiwe judges that residents of Masiphumelele perceive her as a Zulu speaker<sup>7</sup>, a source of professional advice and support, as well as a friend and relative on the basis that her (late) brother lived in the community and was a prominent soccer player and coach. While respondents alluded to her residence in a more privileged area (for example by asking her to inform them of any job opportunities) as something that differentiated them, Lindiwe did not detect any reticence to discuss particular issues or topics, including those often devalued by the biomedical and church paradigms such as the honouring of ancestors and the power of witchcraft<sup>8</sup>. Moreover she was able to build trust around HIV-related issues by speaking about her own family's dilemmas in response to her brother's status, illness and recent death.

## **Narratives of residential decision-making**

The analysis of women's mobility and that of their children is structured in terms of the reproductive and development cycle of many domestic groups in Masiphumelele. I begin by considering the narratives of two young women, each of whom had one young child but were estranged from their child's father and had no subsequent partner. Both women drew support from their siblings and parents, but did so in very different ways and with different results. I then consider the narratives of a slightly older mother and the eldest of her three children. This woman had no blood relatives on whom she can call upon and relied on local friendships and the physically distant family of her partner. Her decisions regarding her children's residence and the security of their home show acute vulnerability yet are at the same time reflective of an inner strength and resourcefulness. Finally, I look at the case histories of two mothers who each have five children spanning an eighteen year period, one of whom became a grandmother during the study. These women take actions to move their children to settings they perceive to be most advantageous now and in the future, and at the same time grapple with the implications of their adolescents' residential choices.

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<sup>7</sup> Zulu and Xhosa are mutually intelligible languages and there is a growing number of first language Zulu speakers in Masiphumelele.

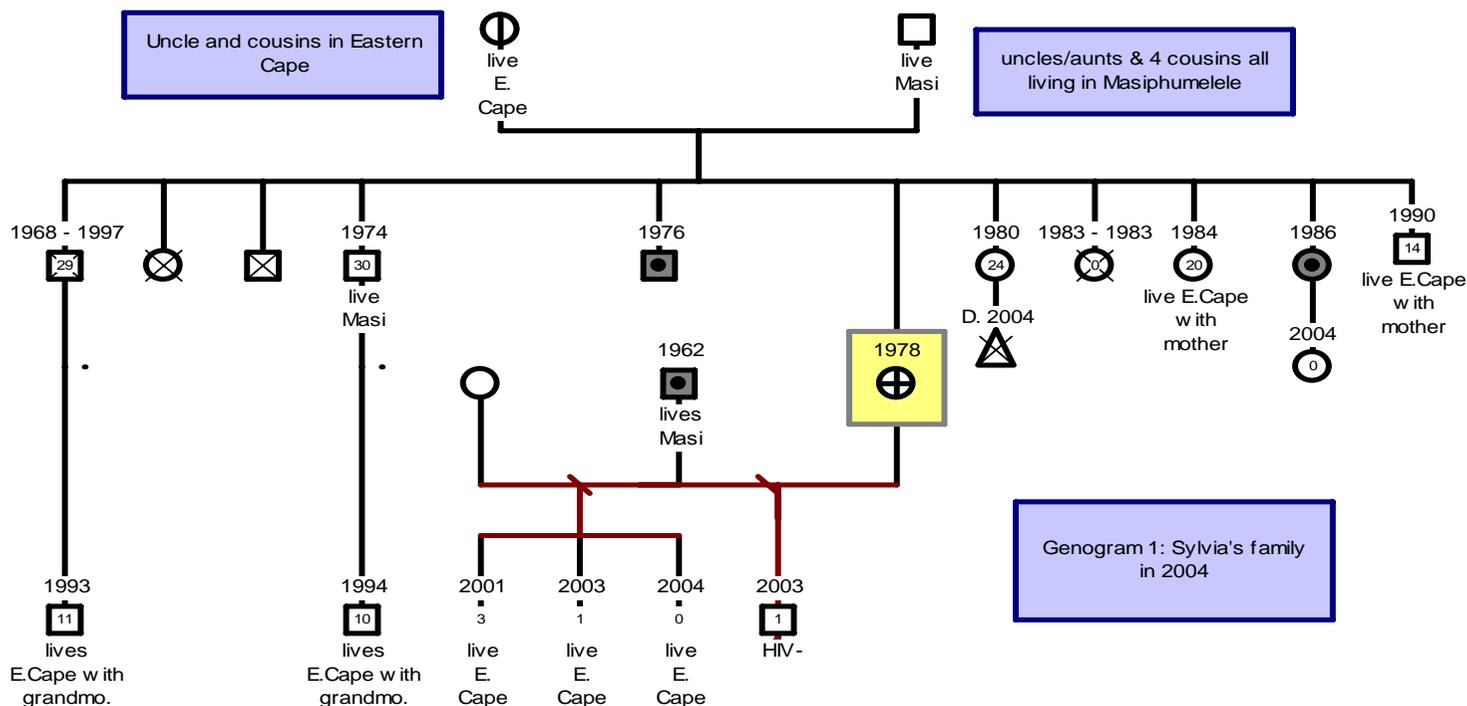
<sup>8</sup> Lindiwe also attributes respondent openness on potentially hidden and sensitive topics relating to the causes of misfortune, conflict, disease and death to her choice to wear her hair in dreadlocks, a style that denotes either Rastafarianism or a natural and 'non-modern' ethic that values so-called 'traditional' beliefs and customs, including the practice of witchcraft and respect for ancestors.

All five women and their households have some level of rural connectedness, meaning that they fall into type 1 in Neves' schematic household typology (see Neves paper 1 in series). That said, one has no connection with her own rural home but does so with her partner's in Mozambique, and another consciously detaches herself from both close and rural kin in relation to her current needs, but sees the latter as a possible future fall-back.

## **Young mothers' decisions regarding co-residence with kin**

Sylvia's story is one of her own residential stability within a large family that straddles the urban Cape Town – rural Eastern Cape Diaspora and shares human and financial resources very explicitly in order to meet the needs of its members. Sylvia has a warm and giving temperament, and partakes in this reciprocal care to the best of her means. Perhaps in accordance with her efforts, Sylvia's HIV status and her illness has gradually and quietly been incorporated into this *modus operandi*. Her own and her brother's accounts suggest that differences in the way the family have treated her as a result of her status have been very subtle (thereby respecting her wish to disclose to certain individuals), and that her status has impacted her mobility decisions insofar as it has heightened the mental health implications of financial insecurity, unemployment and the ability to care for her child in the long term.

Figure 1. Sylvia's family in 2004



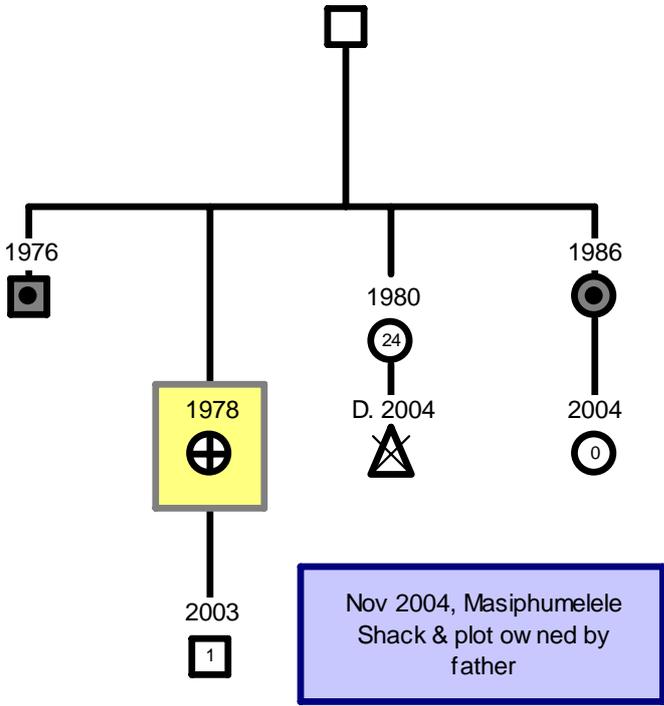
KEY: This and all subsequent diagrams use standard genealogical symbols Circles denote female, squares denote male and triangles unknown gender (such as a miscarriage). Birth dates are shown above symbols denoting related individuals and ages (in years) at time diagram describes are given inside each symbol. Symbols crossed out with an X shows deceased status. Short diagonal lines cutting across lines linking men and women denote a partnership that no longer functions.

The specific additions are as follows: Women who are the subjects of each case study are in the shaded box. A cross in the centre of the symbol denotes HIV positive status and possible HIV status is flagged in text below symbol. A vertical line down the centre of the symbol shows illness of another nature.

Shaded symbols with a bold dot in the centre denote individuals to whom the woman has disclosed her HIV status. Blank symbols with dot in centre denote an individual who has discovered this woman's HIV status.

Sylvia is one of eleven children, seven of whom survive. Since her early childhood her parents have moved between the Eastern Cape and Cape Town, but have always expressed a strong preference for their rural home. They spend time in Masiphumelele in order to earn money to maintain their homestead, to educate and support their children in the city, and to seek medical care. In late 2004 Sylvia, then aged twenty-six, lived in a three-roomed shack in Masiphumelele with her elderly father, an older brother, two sisters, the infant of her younger sister, and her eleven month old baby (see domestic group 1.1). The home and plot belongs to her father, and the family relied on her brother's wage of R1800 per month from a concrete factory, the Child Support Grant that Sylvia claims, and a small income from their father's efforts to sell wood at the roadside. A second brother who lives nearby occasionally helped out with groceries and they received a monthly food parcel from an NGO on the basis that Sylvia is AIDS-sick and had a young child. Even so, they often went without meals at the end of the month. Sylvia completed her penultimate year at high school, and apart from occasional domestic work prior to her baby's birth and her recent sale of beadwork through a local NGO supporting HIV positive people, she has never been employed.

*Domestic Group 1.1*



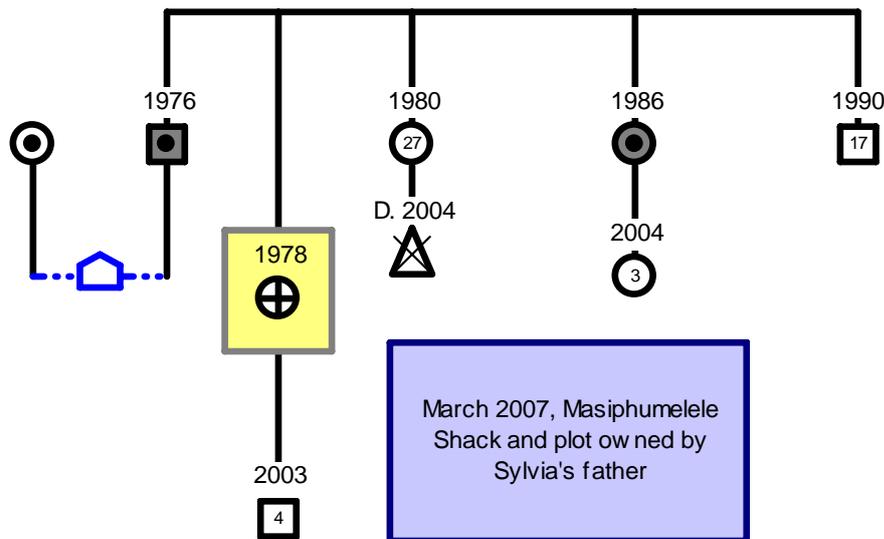
Sylvia discovered that she was HIV positive early in her pregnancy but kept her status a secret for several months. Acting on the advice of clinic nurses, she eventually told her twenty-nine year old brother, with whom she lived, shortly before she was due to give birth. She recalled his shock and efforts to console

her by saying that her status did not mean that she was going to die and that “none of us knows what the future holds, or when we will die”. Sylvia’s brother continued to support her financially and emotionally, and she suspected that his girlfriend’s increased availability and efforts to assist her with medicines for her child arose out of this woman’s knowledge of her status. Encouraged by their response, Sylvia then disclosed to both her boyfriend and her youngest sister. The latter was worried but supportive, however her boyfriend denied the possibility that he might have infected her and left Masiphumelele for two weeks. Upon his return, he questioned Sylvia again as to how she became infected and was not prepared to go to the clinic for a test (Sylvia claimed that she had been faithful and that her boyfriend had had several other partners that she knew of).

In 2004, Sylvia explained her decision against disclosing to two other close relatives: She envisaged that her mother might insult her after one of her frequent heavy drinking sessions and that her elder sister, with whom she lived, would not cope with the news because she had been emotionally unstable following her recent miscarriage late in the pregnancy. Since beginning ARV treatment two months earlier, Sylvia reported feeling stronger and had not suffered any severe side effects. She made a determined effort to follow the clinic’s advice to stay active, believing that if she succumbed to the desire to rest, the virus would take over. At the same time however, she was struggling to come to terms with her status. She reported periods of feeling sad and depressed, and reflected on her conscious use of housework to try to avoid intrusive thoughts, including feeling let down by her boyfriend’s denialism and lack of support to her or to their child. At night, when Sylvia could not work or talk to people, her sleep was often disturbed by unpleasant thoughts. Our observation revealed a warm and caring bond between Sylvia and her eleven month old son. She was able to talk about their relationship and its place in the wider family in a way that many other mothers in the community were not. For example, she explained how much she valued her brother’s financial and emotional support to both herself and her son, and how much the latter gained from her elderly father’s attentive and playful care.

Two and a half years later, Sylvia and her son are living in the same shack in Masiphumelele with many of the same family members (see domestic group 1.3). Her father had left, saying that he was returning to the Eastern Cape “for good”, and her younger brother (aged 19) had arrived in order to attend High School in Masiphumelele. These changes placed an even larger financial burden on Sylvia’s elder brother who was the only household member earning regularly through employment.

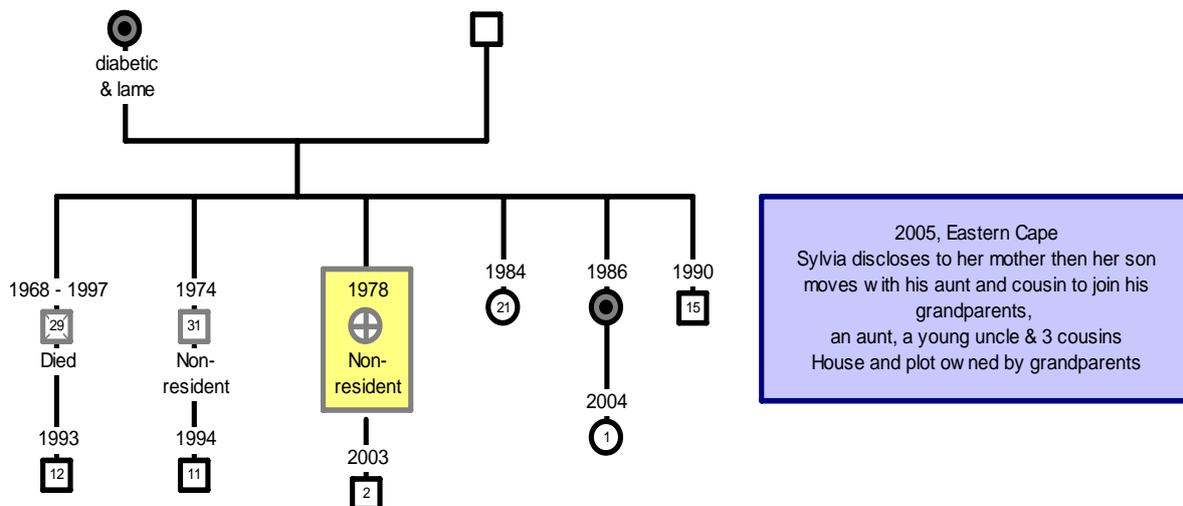
### Domestic Group 1.3



Sylvia never moved during the research period but her small son spent over a year living with her parents and other extended family in the Eastern Cape. The practice of sharing primary care responsibilities for young children across large distances is very common, but it would appear that Sylvia's status and the way she is opting to manage it have something to do with her motivating, or at least sanctioning, this move. The move followed her decision to disclose to her mother during the latter's visit to Cape Town in 2005, two years after her diagnosis. Sylvia was surprised at her mother's sympathetic and supportive response, including her offer to care for Sylvia's two year old son in order that Sylvia could seek work unfettered by childcare. She accepted on this basis, explaining to us that her decision was also influenced by her father's wish to spend time with his grandson, with whom he had developed a strong bond while sharing a home in Masiphumelele. At the same time, Sylvia's younger sister also moved to their mother's rural home with her own baby in order to assist their mother (who is diabetic and lame after a motor vehicle accident) with the manual tasks involved in caring for five children, such as fetching water (see domestic group 1.2).

Having failed to find work other than beading for the NGO, Sylvia arranged for her son to be brought back to Masiphumelele in January 2007. She was further motivated by her mother's deteriorating health, and by the fact that she missed her son's company and needed him to be present for them to qualify for NGO assistance towards crèche fees, as well as for the up-coming maintenance case she had filed against her ex-boyfriend.

## Domestic Group 1.2



In early 2007 Sylvia was still on ARVs and her CD4 had risen to 345. She had however lost weight and was suffering from frequent headaches and neck pains which she and the clinic staff attribute to ‘nerves’. Sylvia thinks her stress is a result of having insufficient money to support her child<sup>9</sup> as well as tensions within their domestic group, particularly between her brother’s girlfriend and his sisters. Now intermittently sharing their home, Sylvia’s brother’s girlfriend seems to resent the support that her partner gives his sisters. Although not articulated by either Sylvia or her brother, these new tensions must raise questions in Sylvia’s mind about the sustainability of her brother’s efforts to balance his own partnership with this level of support to his sisters.

Sylvia’s HIV status has, if anything, enhanced the family’s protective efforts towards her. She and her son have consistently been integrated in the collaborative householding practiced by her family in two physical spaces, and have gained considerable support from this. Her brother, when interviewed in 2007, said that he respects his sister’s decision not to disclose to all the family and that those who are told have a duty to be caring and supportive; “that is why it is important for me not to have a child, so that I can focus on being there for my sister’s children’s needs. We co-operate well in the home – I bring in money for food and they cover clothing and other costs.” His attitude and that of their mother following Sylvia’s disclosure raises the possibility that Sylvia

<sup>9</sup> In 2005, Sylvia started receiving the state Disability Grant of R740 per month assigned to those temporarily or permanently unable to work owing to illness. Like all patients on ARVs on the PAWC (Provincial Administration of the Western Cape) protocol, she was automatically registered for this grant and re-assessed one year later. Her grant was not renewed because her CD4 count was over 200.

purposefully chose to disclose to these family members, and at different times. Whether or not her actions were pre-meditated, they have resulted in sustained support from her elder brother and her mother, the two people who matter most in terms of economic and social status in the urban and rural home respectively.

Regardless of whether Sylvia's approach to disclosure reflects a conscious effort to maximise her own residential, economic and emotional security, it remains the case that she and/or her son still theoretically have the option to go and live in the Eastern Cape. She told us that she often thinks about moving back, but has not done so. Her rationale mirrors that of many other young parents. She would like to live close to her parents and wider family in the place she regards as 'home', but sees even fewer employment opportunities and inferior quality schools and clinics in the rural Eastern Cape. Even in the absence of work, Sylvia's economic opportunities currently lie in Masiphumelele. Like many single mothers, she hopes that her court case will result in maintenance payments by her ex-boyfriend. Her status results in a further financial reason to stay; she qualifies for NGO assistance towards crèche fees for her son. As important to Sylvia is her perception that unlike the Eastern Cape, Masiphumelele offers the possibilities of improving one's life through finding work or professional training, and that this neighbourhood provides easy access to familiar and trusted medical care, as well as to psychosocial supports. Sylvia derived friendship, advice and a sense of solidarity from her relationships with fellow HIV support-group members. She also valued her participation in the beadwork programme run by the same NGO not so much for the minimal income but because it provided a regular activity, the opportunity to be creative and the sense of working as a team.

A significant source of stress for Sylvia is feeling emotionally torn between the Eastern Cape and Masiphumelele and the experience of high costs whichever choice she makes. The combination of her current position as a young single mother, her positive status and her treatment regime<sup>10</sup> mean that the benefits of living in Masiphumelele (more robust care networks that are better able to meet her material, health and psycho-social needs) outweigh the costs. Evidence of her attempts to resolve this tension in her own mind is found in Sylvia's future planning. Reflecting on her failure to find work, Sylvia spoke of her intention to enroll in a course in home-based care that her brother has identified in another part of Cape Town, and of her long term desire to do home-based care work in the Eastern Cape. She envisaged bringing her personal experiences of learning

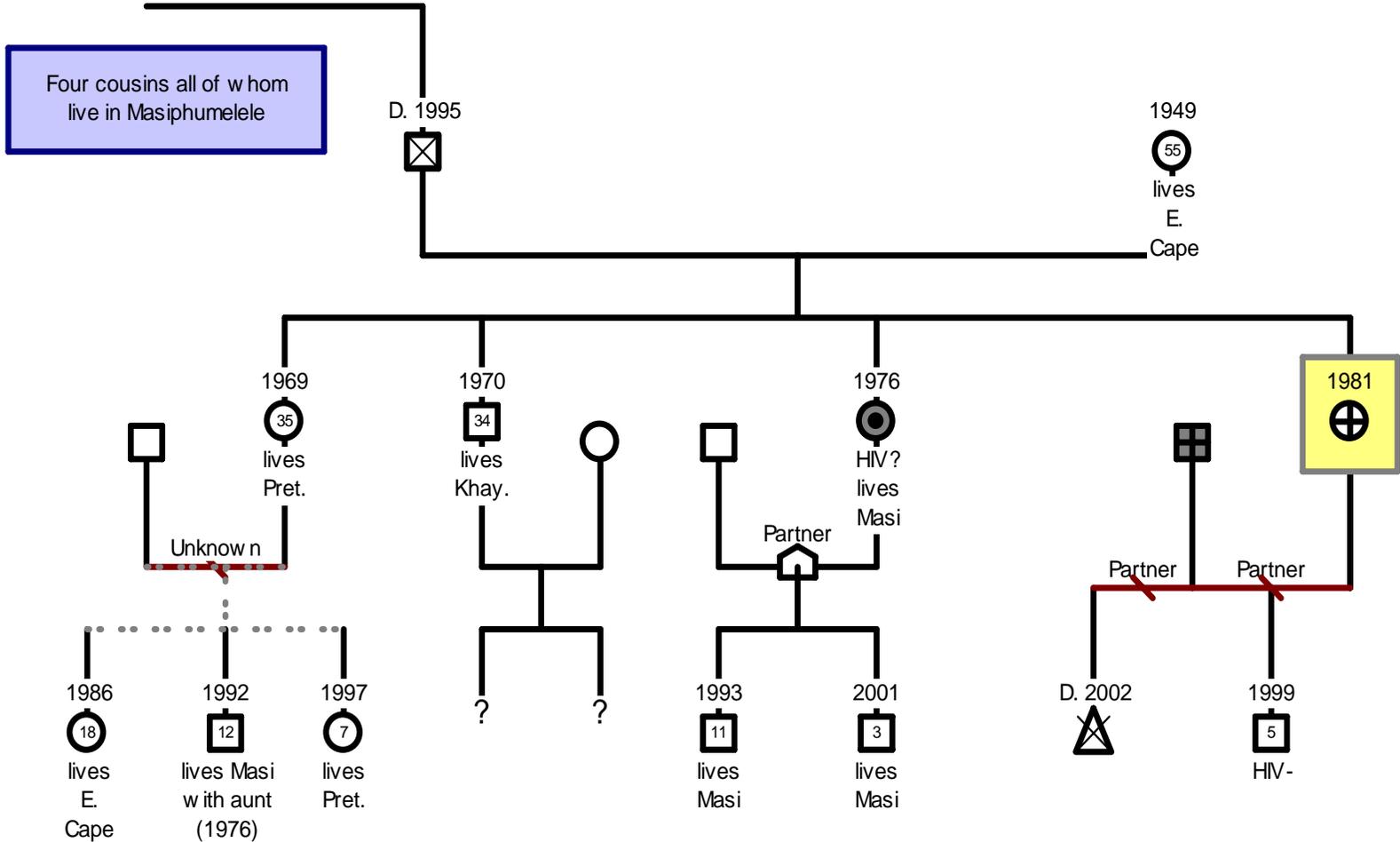
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<sup>10</sup> Sylvia expressed this tension in 2007 when she had been on treatment for over two years and was attending clinic appointments much less frequently. That said, she still needed to get pharmacy refills of ARVs on a monthly basis.

to live with her status to the rural areas where she understands other women to be going through the same process but with fewer resources.

Like Sylvia, twenty-three year old Joyce was a young HIV positive mother estranged from the father of her small child when we met her in 2004. She and her five year old son lived in a tiny (4 m<sup>2</sup>) shack that opened straight out onto one of Masiphumelele's busy taxi routes (domestic group 2.3). Her story is one of frequent movement with members of her wider family prior to and directly following her diagnosis, then a decision to establish an independent home for herself and her son only.

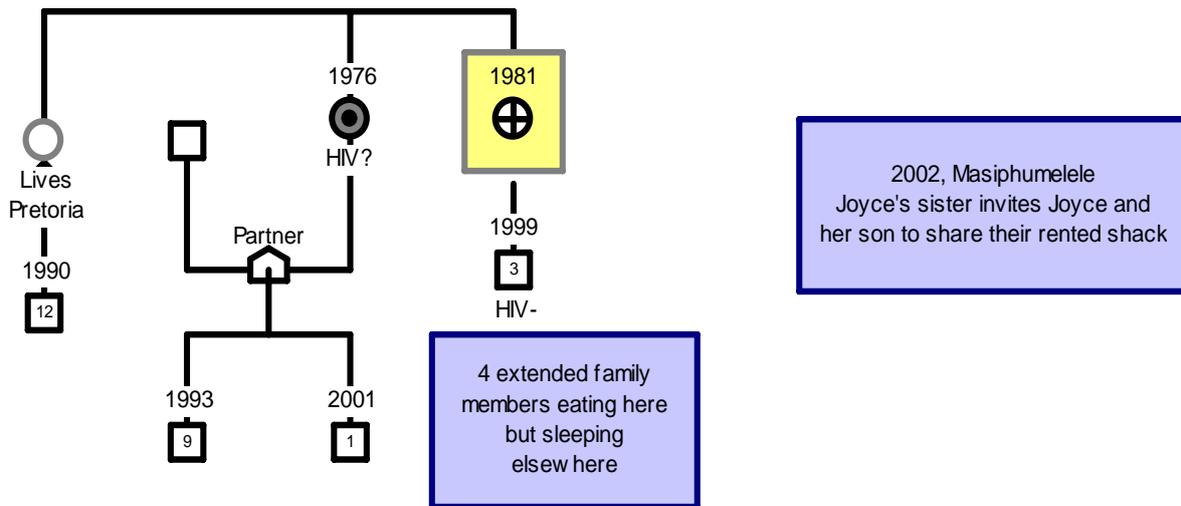
Figure 2: Joyce's family in November 2004



Joyce was diagnosed HIV positive in 2002 and immediately disclosed to her boyfriend, Themba's father, who insisted that she keep her status secret. But Joyce chose to disclose to her brother and his wife who live in Khayelitsha, a large township on the outskirts of Cape Town, as well as to one of her sisters who lives in Masiphumelele. Her relationship with Themba's father ended soon after and although he lives in Masiphumelele, there was no contact between them. Joyce's mother, who lives in the Eastern Cape, heard that she was positive through the family grapevine and apparently became ill as a result. Joyce therefore denied her status to her mother, and stated her intention to disclose during her up-coming Christmas visit. Tragically and unexpectedly, Joyce died during that visit.

In the two years between her diagnosis and her death, Joyce and her son had moved three times within Masiphumelele. The dynamics of these moves are the focus of my analysis, but should be understood in the context of preceding mobility. When Themba was born in 1999, Joyce was living with her mother, brother and brother's wife in Khayelitsha. Later that year, she, her son and her mother moved to her mother's ancestral home in the rural Eastern Cape. When Themba was two years old, Joyce left him in the care of his grandmother and moved to Masiphumelele to look for work, staying with a female friend. A year later she returned to the Eastern Cape, stayed for a few months then brought Themba back to Masiphumelele. Shortly thereafter, Joyce decided to leave her full-time domestic job because she believed that her employers were exploiting her. Joyce mentioned moving in with her sister at this point but gave no details. In 2007 this sister recalled a prior move by Joyce, explaining her memory of these events: Following Joyce's decision to resign, she and three-year-old Themba could not afford to pay bed and board at the friend's house so moved in with Themba's father. Disputes between Joyce and her boyfriend worsened, and when, on Women's Day 2002 (the same year that she was diagnosed HIV positive), Joyce made a public speech about the physical abuse she was suffering at home, her sister invited them to stay at her home in Masiphumelele (domestic group 2.1).

## Domestic group 2.1

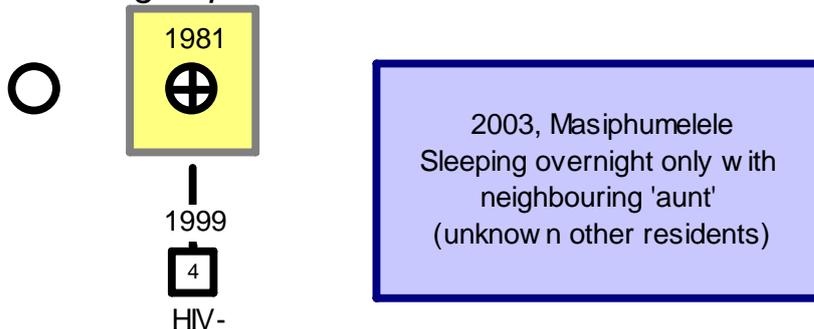


Joyce recalled that finances were initially tight as their sole income was R140 per month from the state Child Support Grant, but she then got part time domestic work and contributed to the household pot. She believed that she was in a secure position, but about a year later her sister unexpectedly asked them to leave. Joyce reported that her sister said that their presence and the daily visits by other relatives living nearby at mealtimes were becoming “too much for our household”. Her sister, whom we interviewed in 2007, gave a slightly different interpretation. She explained that she resented working to feed Joyce and her son then finding that Joyce did not pull her weight with household chores, and gossiped to neighbours accusing her sister of treating her as a domestic servant. After two failed attempts to mediate their relationship and co-habitation were made (the first by an “aunt” who comes from the same rural village and the second by their mutual brother and his wife), Joyce’s sister said that she felt it was her duty to ask her younger sister to move out in order to “teach her how to be responsible”.

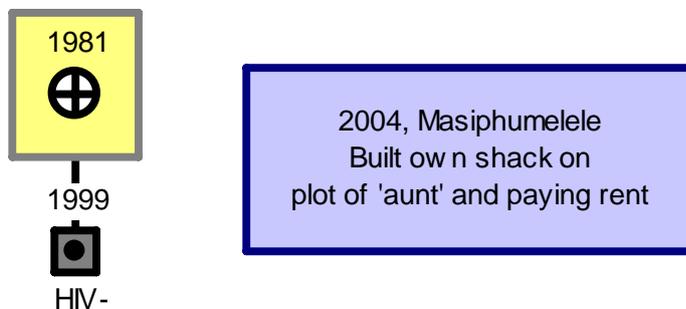
Looking back, Joyce described this moment as the “the worst time in my life ... when my sister abandoned me”. She had expected greater sympathy from a sister, the female relative to whom she was physically and emotionally closest and whom she had entrusted with knowledge of her status. Furthermore, this sister was one of the first AIDS educators working in Masiphumelele, and both she and her husband had secure employment at this time whereas Joyce did not. Joyce recalls a period of extreme stress when she and Themba were technically homeless with negligible income. The best arrangement Joyce was able to make was for them to sleep overnight as “visitors” at the home of the same “aunt” figure who mediated earlier (domestic group 2.2). Each morning they left this home and spent the entire day loitering near the clinic and finding food where

they could, keeping these activities secret from the family whose home they were sleeping in. In 2003, Joyce found work as a part time domestic worker and rented a small corner of this family's plot. Borrowing the R800 needed for the wood and tin sheeting from a neighbour, she built the tiny one-room shack where she and her son were living during phase one of our study (domestic group 2.3). Shortly before we met, she had been managing her monthly payments<sup>11</sup> comfortably but was beginning to struggle after having had to relinquish her domestic job because her employers moved to Hout Bay without offering to cover greater transport costs.

### *Domestic group 2.2*



### *Domestic group 2.3*



Joyce's decision to set up home independently of close family and to maintain domestic self-sufficiency even during periods of physical and mental ill-health seems to relate to her attitude towards herself as an HIV positive person and her growing understanding of how to care for herself, to her role as mother, as well as to her judgement of future need in relation to the support she could expect from her kin. Describing herself in 2004 as open about her status, Joyce chose to disclose to neighbours and talk openly about her illness. She took an assertive and forward-thinking stance towards HIV in her own life and more generally,

<sup>11</sup> R200 to repay a loan for housing materials and R50 for rent for use of the plot.

wanting to know more about how best to care for herself, choosing to abstain from further sexual relationships and encouraging others to be tested and to talk about being positive. Her elder brother, who resides in Khayelitsha, although initially disbelieving of and angry about her status, offered Joyce a sense of financial security for her son by putting her on his life insurance policy<sup>12</sup>. His wife visited Joyce regularly in Masiphumelele, and having stayed with them when Themba was born very prematurely, Joyce seems to have regarded them as a future fall-back support and therefore one that she did not wish to make demands of at the time. When she needed someone to look after Themba during working hours or a clinic appointment, Joyce relied upon two local friends rather than family members.

The decision Joyce made to establish a home for herself and her son provided the environment for a heightened level of emotional closeness between mother and son, which in the context of her status had particular implications for each of them. A year after she had built their small shack, Joyce developed full-blown AIDS, became very sick, and started ARV treatment. Shortly thereafter she took the very unusual decision to disclose to five year old Themba and explained the nature of HI infection and its implications to him. She said that since that time, she and her son developed an increasingly close and mutually dependent relationship. Sharing a home, mother and son spent most of the day chatting, doing domestic chores and watching television. Her life, Joyce explained, revolved around Themba, partly because she did not have a regular childcare arrangement for him but also because he provided her a sense of emotional stability. In turn, he would remind her when to take her medication, notice when she felt unwell and offer water, assistance and affection.

It is likely that the high value Joyce placed on the company of her child is linked to her sister's earlier rejection, her fluctuating physical health, and her efforts to secure their future together through her treatment routine. Unable to control her tears, she described her biggest fear as dying before Themba reached the age of fourteen or so, and was able to look after himself. Such uncertainty seems to have contributed to Joyce's need to lavish care on her son, for example by buying him the shoes and designer clothes he requested, as well as the manner in which she drew personal encouragement to fight HIV from her role as his mother. She described Themba's presence and dependence as her primary motivation for taking good care of herself, for example eating healthy foods and adhering to her medication.

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<sup>12</sup> Conversation with Joyce's sister in 2007 revealed this to have been a funeral fund only.

In turn, Themba was receiving the devoted attention of a woman he had known since birth but lived with and understood her to be his biological mother only more recently. The combination of their relative isolation from the wider family and his knowledge of his mother's status had meant that he considered himself to have various practical and social responsibilities, and in doing so had assumed an enormous psychological burden. When Joyce told him of her status, he replied "Then I've changed my mind, I'm not going back to my 'mother' in the Eastern Cape. I must take care of you. I cannot leave you alone". To date, there is limited research on the short and longer term consequences to children who assume such responsibilities, or become what psychologists refer to as the "parental child". Studies in North America show that even very young infants respond unconsciously to deficits or neediness in their mothers (Byrne, 1998). But all we know about the outcomes of such responses in a US context is that they differ according to the age at which children assume aspects of the care role (Keigher et al, 2005). Particular cultural nuances in the roles of child and parent notwithstanding, we can safely assume that a child who considers himself at least partly responsible for his mother's well-being has to manage feelings of guilt alongside those of grief and loss following her death.

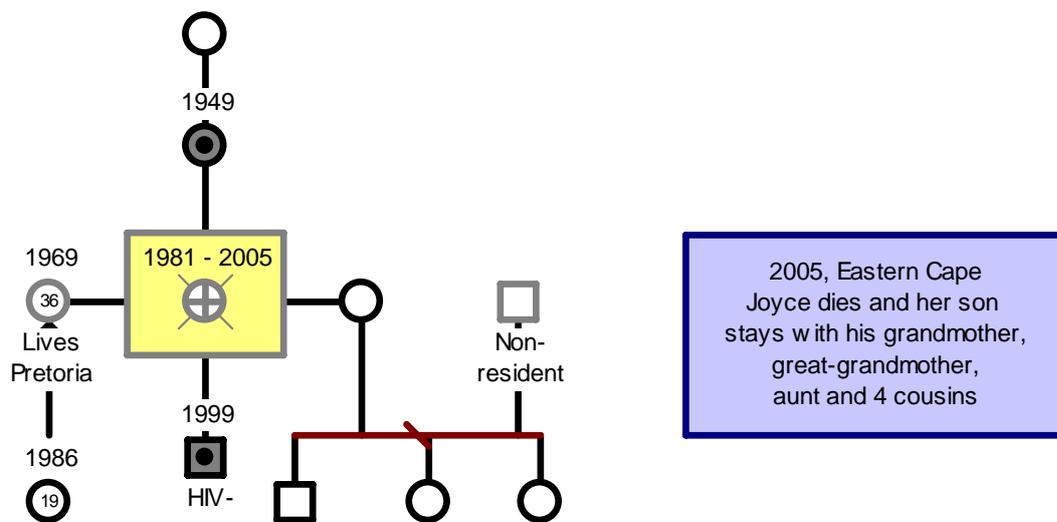
The data do not permit exploration of Themba's psychological well-being following his mother's death. We know that he stayed in the Eastern Cape with his grandmother and that he was aware that this was something his mother wished and had planned, and was supported by the wider family. Reflecting on these decisions in 2007, Joyce's sister spoke of her own mother's heart attack following news of Joyce's status and her distress at Joyce's sudden death. She and her other siblings are of the opinion that Joyce's death was too sudden to have been HIV-related, and attribute it to a combination of stress and poisoning by neighbours in the Eastern Cape<sup>13</sup>. And although she claimed that they do not yet know what the neighbours have gained from their malevolence, they believe their mother to be the target. They believe that Joyce was killed because as an adult visitor from Cape Town she represented a source of support to their mother. Because he was a young child, Themba was not seen as representing such support and was therefore considered free from danger if he stayed with his grandmother. In addition, Joyce's siblings felt that Themba and their mother would offer each other comfort and emotional support in their time of grief.

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<sup>13</sup> The medical establishment's view of the cause of Joyce's death remains unknown. Her clinic records show that she was prescribed a course of anti-depressants in early 2004, three months before starting ARVs, and may have experienced suicidal ideation at the time.

After her death, Joyce's financial resources<sup>14</sup> were directed towards her mother for Themba's care and for others sharing the home (including Themba's great-grandmother, an aunt, and four cousins, see domestic group 2.4). Although Joyce's sister is happy with the care her own mother offers to Themba, she is weighing up the possibility of suggesting that he returns to Cape Town. She wishes to give her mother some relief, thinks Themba's medical treatment<sup>15</sup> will be better in Cape Town, and wants to enrol him in what she considers to be a better quality primary school.

#### *Domestic Group 2.4*



Like many working-age adults in Masiphumelele, Joyce and Sylvia both come from families that maintain a rural base and yet are established urban residents. Both women saw their rural home as an important resource and symbolic centre for the family, and considered it available to them and their children should they decide to return. But neither chose to live there and only several years after diagnosis did they disclose to their own mothers and arrange care for their children in the rural home.

Both women had reasons for postponing disclosure to their own mothers that had implications for their status in the family and ability to draw support in the longer term. Sylvia risked her mother's alcohol-induced indiscretion and Joyce knew that her mother had collapsed upon hearing a rumour that she was positive. Having taken the risk, Sylvia was surprised by her mother's supportive

<sup>14</sup> After her death Joyce's shack was sold for R800 and the profit remaining after her debts were settled was sent to her mother's home in the Eastern Cape. Joyce's mother was also successful in becoming recipient of Themba's Child Support Grant.

<sup>15</sup> Themba was born with a rare medical condition requiring a series of operations in his early years.

reaction. We shall never know whether earlier disclosure to her mother would have altered Joyce's decision to set up home with her son independently of the wider family following their expulsion from her sister's home. Her sister thinks that their mother would have been sympathetic and supportive, citing her positive reactions to Joyce's disclosure shortly before she died and her offer to move to Masiphumelele in order to provide emotional support to this sister herself after a recent miscarriage. Quite apart from the implications of disclosure, it is likely that Joyce (like Sylvia) judged living in the Eastern Cape with her mother to be economically unviable and problematic with respect to adhering to her ARVs and to receiving advice and encouragement from nurses and other women in the NGO support group.

One of the factors explaining the difference between these two women's residential decisions is the stage in the domestic development-cycle. Sylvia's siblings are in their twenties and only one has established his own home outside the urban household living on their father's plot. Her unmarried brother had taken the decision to use his salary to support his two sisters and their children prior to Sylvia's diagnosis. Only recently have tensions arisen between his partner and his sisters regarding the distribution of his income. In contrast, the brother and sister of Joyce who had regular jobs both had spouses, dependents and homes of their own. Her siblingship had reached the next stage of the domestic development-cycle and in so-doing created several urban homes rather than one. Individuals within these continued to offer support, however as Joyce discovered, moving in with them resulted in complications relating to roles and the practical and moral responsibilities associated with these roles.

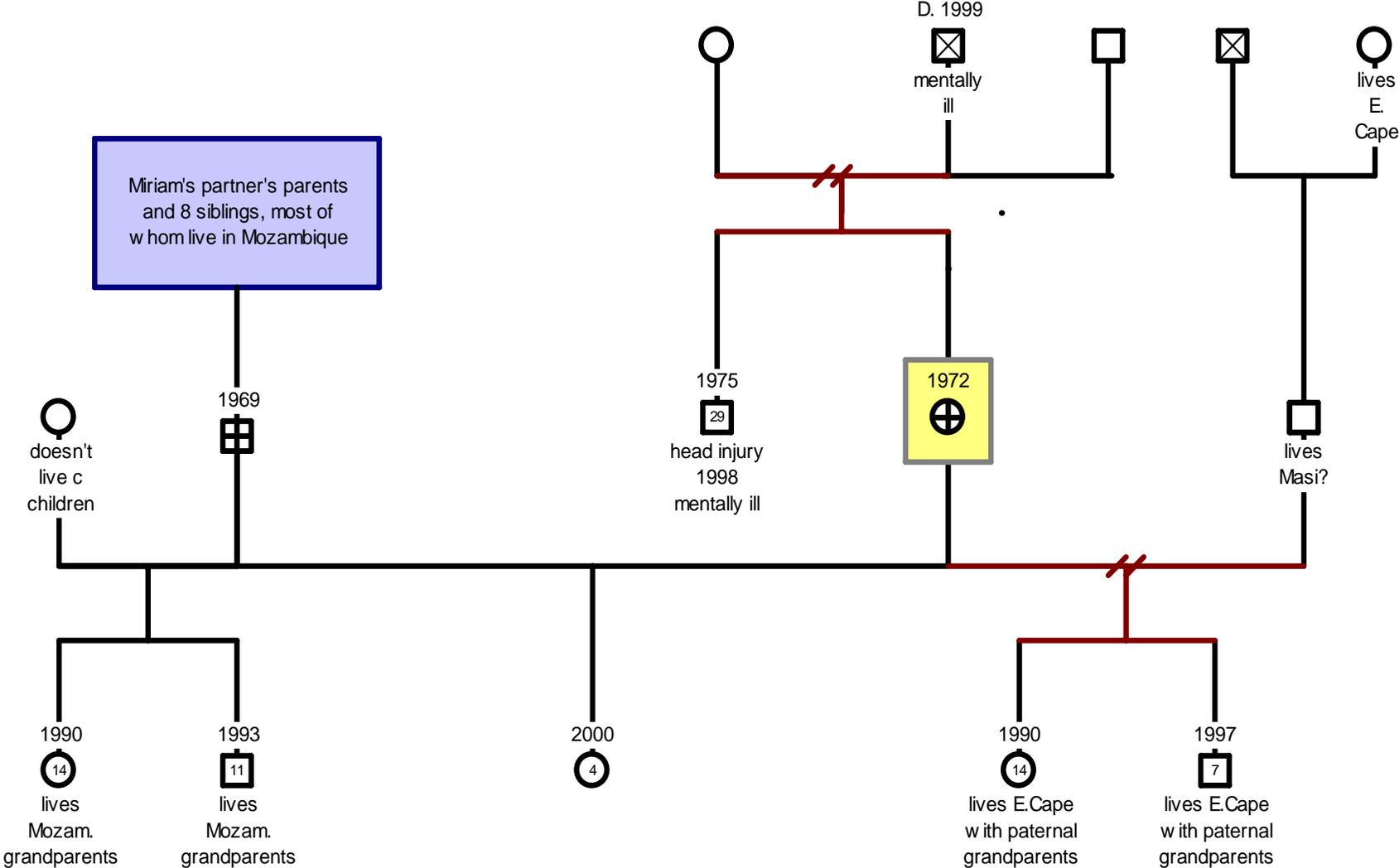
I was struck by the manner in which Sylvia's elder brother and Joyce's elder sister both explained their responses to their sisters as motivated by their understanding of their role as an elder sibling, namely to provide protection and care in times of need but also to dispense advice about, and monitor, their younger sister's behaviour. When Sylvia disclosed to her brother, he advised her that she would have to "follow a certain set of rules" about her life style and that "with this discipline, having HIV did not mean the end of the world". Joyce's sister explained that Joyce was not doing the housework when living with her family and she therefore felt it her duty to ask Joyce to move out in order to instil a sense of responsibility in her. While the data point to various other agenda underlying their behaviour, the elder siblings' explicit intention of upholding the social and moral integrity of their younger siblings and the family as a whole appears to have as great an influence on their decisions as their desire to provide care and assistance when their younger siblings are in need.

The options open to Joyce, Sylvia and their young children appear confined by both their income poverty and the nature of familial support and householding. Neither Joyce nor Sylvia had regular or well-paid work, and despite Joyce's later efforts to support herself and her son independently, they were both largely dependent on their kin. The radius of social reciprocity available to them both was narrow despite their connectedness with family in the Eastern Cape and other parts of Cape Town. Both women look to their parents and siblings at certain strategic times and experience these as not always dependable, and neither mention recourse to wider kin networks.

## **Isolation, residential choice and the possibilities for achieving control**

Miriam, aged thirty-two when we met in 2004, is the mother of three children, two of whom were fathered by her ex-husband and the third by her current partner, who comes from Mozambique. During this first research phase, she was living in a two-roomed shack in the Wetlands, an informal area of Masiphumelele without sanitation, with her partner, their 5 year-old daughter Sonia, and Miriam's 29 year-old mentally disabled brother. Two and a half years later, she was living on the same plot, in a shack constructed from different materials, with one additional family member. Despite this apparent stability, Miriam had made, and been implicated in, a number of residential decisions in the intervening period, all of which she related in some way to her ill-health and status.

Figure 3: Miriam's family in November 2004



Miriam was diagnosed with HIV in 2001 after her partner tested positive during the course of receiving TB treatment. She quickly disclosed to him and a couple of their trusted Mozambican friends but kept her status secret from her own family and neighbours. Her neighbours began to notice her declining health and frequent hospital visits, and word spread following one doctor's misjudgement: Miriam asked a neighbour to accompany her to a clinic in Langa because she had difficulties breathing and the doctor, believing them to be sisters, pushed Miriam to disclose then told the neighbour himself that she was HIV positive. In mid 2004, following two weeks in hospital, Miriam began ARV therapy and treatment for TB.

When we met Miriam later that year, she stood out as someone who was barely coping. Not only was she physically very weak following a further decline in her health (caused by the initial misdiagnosis of a TB-related open sore on her chest), but two rounds of anti-depressants, our psychological assessments<sup>16</sup> and what she said about herself indicated her fragile mental condition. It soon became evident that being unwell, and being HIV positive, had added two further stressors to both historical and current challenges in Miriam's life. I outline these briefly because they inform my interpretation of her subsequent mobility-related decisions.

Telling us that she "cursed God" for the resulting personal strife and burden of responsibility, Miriam began her account of the many rejections she had experienced since her childhood. Her parents divorced when she was fourteen, apparently due to her father's mental illness, and when her mother remarried she left Miriam and her brother in their father's care because her new family did not want anything to do with the children. Miriam's uncle provided some support in raising the children, but their mother never contacted them again. When the uncle died in 1997, both siblings and Miriam's husband and first child moved to a large township on the outskirts of Cape Town to look for work. That year, Miriam gave birth to her second child and her brother sustained a serious head injury while fighting over a girlfriend. Since then he has been "mentally disturbed", suffers from epilepsy, and is in need of constant care. Miriam and her husband divorced shortly afterwards, apparently because she wanted to take care of her brother and her husband's family would not tolerate her brother's presence in their home. In 1998, Miriam, her brother and her two children moved to Masiphumelele. In 2002, the paternal grandparents insisted that her children move to the Eastern Cape to live with them in accordance with

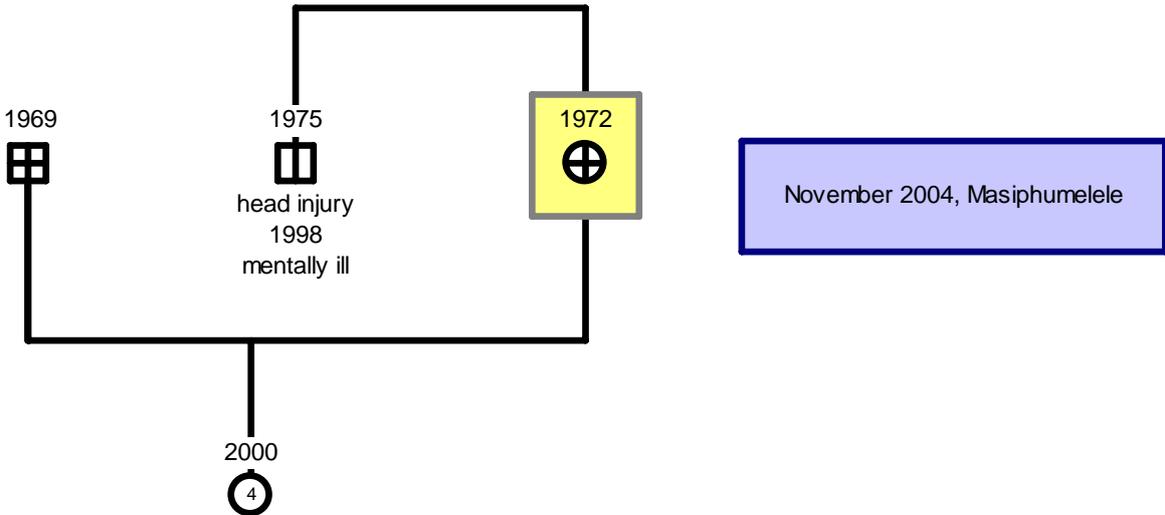
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<sup>16</sup> The first phase of study in 2004 included the administration of four standardised psychological scales, namely the Spielberger State Anxiety Inventory, the Centre for Epidemiologic Studies Depression Scale, the Brief COPE and the Medical Outcomes Study Social Support Survey.

customary law following parental divorce. When we spoke in 2004, Miriam was sad and angry that she hardly saw her elder children (because their grandmother would not let them visit in case Miriam kept them in Masiphumelele). However she was also pragmatic about the financial respite for her and the emotional benefits for her children of living with their grandparents.

The upshot of this personal history is that Miriam has no siblings or other adult family to support her. In 2004, she described her boyfriend as the first person whom she could depend on in any way, and his Mozambican family as “my family”, saying that they would care for Sonia should anything happen to her. Prior to her prolonged ill-health, Miriam had regular domestic work and when she could not sustain this she decided to open a ‘spaza’ store from her home. But because she had recently become too weak to push the trolley of goods from the supermarket to her home, she had become financially dependent on income from her boyfriend’s unreliable daily labouring jobs and the monthly Disability Grants for her brother and herself (a combined monthly income of R1650).

*Domestic Group 3.1*



Miriam herself had not moved between the first and second phases of our study, but her elder daughter had joined the household and her partner left, following an affair, then returned. Her illness is, in her eyes, one of several reasons why she wanted her daughter to live with her, and it is one factor in her determination not to move, following a series of threats to her accommodation connected to her partner’s affair.

In January 2007, Miriam’s sixteen year old daughter Barbara joined the household. Barbara’s arrival was not sanctioned by her paternal grandmother,

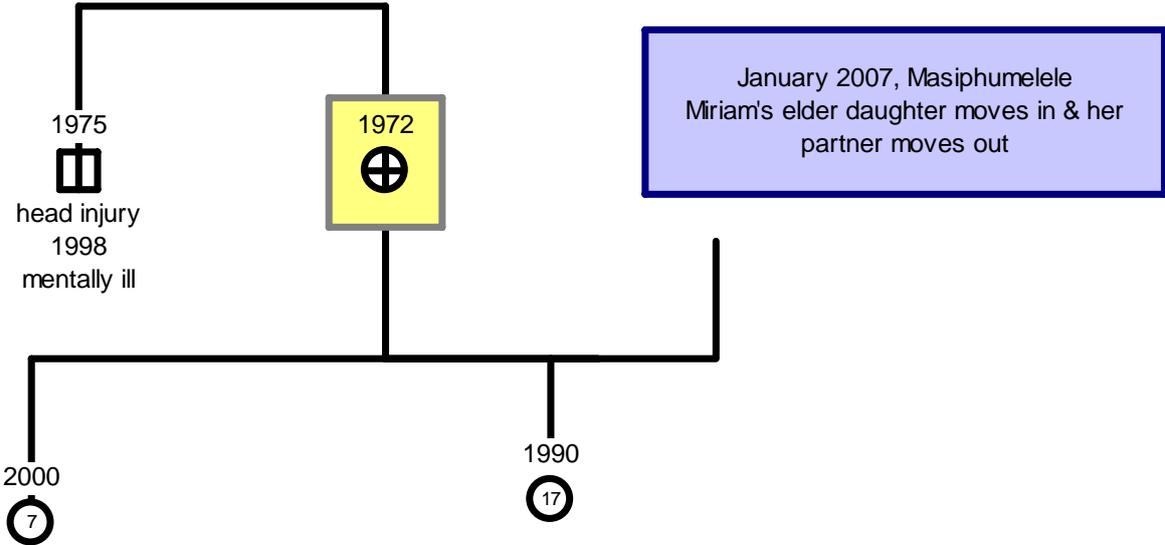
but was precipitated by Miriam's visits since 2004, her mother's and grandmother's inability to afford fees and transport costs of the distant high school in the Eastern Cape, and the pressure Miriam put on Barbara to "speak for herself". Miriam gave Barbara the "choice" between living in the Eastern Cape without attending school or coming to Masiphumelele and "surviving on whatever we have". Barbara visited Masiphumelele in the 2006 winter holidays, during which Miriam disclosed her HIV status to her. Miriam reports that Barbara responded badly, shedding many tears and expressing fear about her mother's death and what would happen to her and her siblings. Miriam's efforts to comfort Barbara included persuading her that if she was to live in Masiphumelele, she will learn more about HIV and they could be closer to each other. Barbara returned to the Eastern Cape for the second term, got good grades at the end of the year, and as a result of pressure from Miriam for Barbara to exert "her own opinion", the decision was made that that Barbara should move to Masiphumelele.

From Miriam's perspective, Barbara's arrival has resulted in increased intimacy between them, assistance with domestic chores and even better educational opportunities than she had envisaged. Both Barbara and Sonja are sponsored by an NGO affiliated to the Catholic Church to attend school in Ocean View, a neighbouring community where pass rates are generally better. They qualified for this support owing to the level of poverty in the home, Miriam's advanced stage of AIDS and her care of her dependent brother. Describing her ten year old son as "still too young to speak for himself", Miriam spoke about missing him and intending to bring him to Masiphumelele when he finishes primary school. Her opinion is that she should be close to her children, even if she is ill, because she wants to let them know how she feels and "for them to be with me in pain or joy". These feelings, she says, are intensified by the fact that she was not given a chance to nurture them in their early childhood owing to her mother-in-law's behaviour. Miriam spoke about her intense anxiety around who would care for her children in the future, and organising their physical presence in her own home seems to be an important symbol of her efforts to do so while she is able to. She also spoke of shaping the way she rears her children to her possible early death. Reflecting on the freedom from chores enjoyed by Barbara in the Eastern Cape, Miriam understood her mother-in-law's wish to spoil her grandchildren but said – out of Barbara's earshot – that it was better for her daughter to learn to be independent in order that they are prepared for her death.

Barbara's perspective on this move is that, although informed of the so-called options regarding schooling, she was given very little choice because attending high school in the Eastern Cape was not financially viable and her mother put her under pressure to move. She settled into school in Masiphumelele quite

quickly, but several months later was still feeling torn between her grandmother and mother because she felt emotionally connected to, reliant upon, and in some ways responsible for, both these women and there were tensions between them. One of her biggest fears was her mother dying and her grandmother rejecting her with the words “you decided to go so now you must stay there with your dead mother”.

*Domestic Group 3.2*



Although unforeseen by both of them, Barbara’s presence provided Miriam with some emotional stability because, during the month after she arrived, Miriam discovered that her partner was having an affair with a married neighbour who attended the same HIV support group. This woman’s husband visited Miriam threatening harm to her partner, and shortly after Miriam’s partner announced that he was “going to the townships”, which she now understands to have been fleeing from these threats. Both the woman and her husband issued a series of subsequent threats, and Miriam felt especially afraid in light of the recent murders of foreigners in Masiphumelele<sup>17</sup>, the ease with which shacks are burnt down in the Wetlands, and her own experience of losing their shack to fire the previous year. Speaking a day after her partner’s departure, Miriam said that for her and her children’s safety she would like him to move out permanently, but she is still in love with him and knows what a strong bond exists between Sonja and her father. She spoke of her intention to go straight to the police station with a neighbour after our interview to report the mistress and her husband’s threats, and inform them of the facts. Miriam feared that her partner may have bragged

<sup>17</sup> In 2006, two Somalian shopkeepers were murdered, their shops ransacked and their families driven out of their homes, apparently because they were offering goods at lower prices than Xhosa-speaking shopkeepers.

to his new mistress, saying “this my house” and that the husband would therefore try to burn it down. She spoke confidently of her sense that she herself had not acted wrongly, and added: “I’m not going anywhere, if I’m not going to be killed by HIV, I might as well be killed in and for my house”.

Her statement conveys both a sense of power and fragility in relation to her HIV status and illness. The fact that a large open TB-related wound had recently healed and that she was feeling stronger since taking her ARV therapy provided tangible evidence to Miriam of the possibility of good health. But Miriam felt doubly threatened by her partner’s affair because she had learnt from doctors that unprotected sex with a promiscuous partner increases the strength of the virus. By asserting her determination to retain her home, Miriam is demonstrating to herself and others that she has control in this arena of her life if not in others. In the context of her status, her history of physical and mental ill-health and rejection from her family, it is likely that the ability to control certain areas of her life, such as her possessions and her own and her children’s residence, have assumed greater importance.

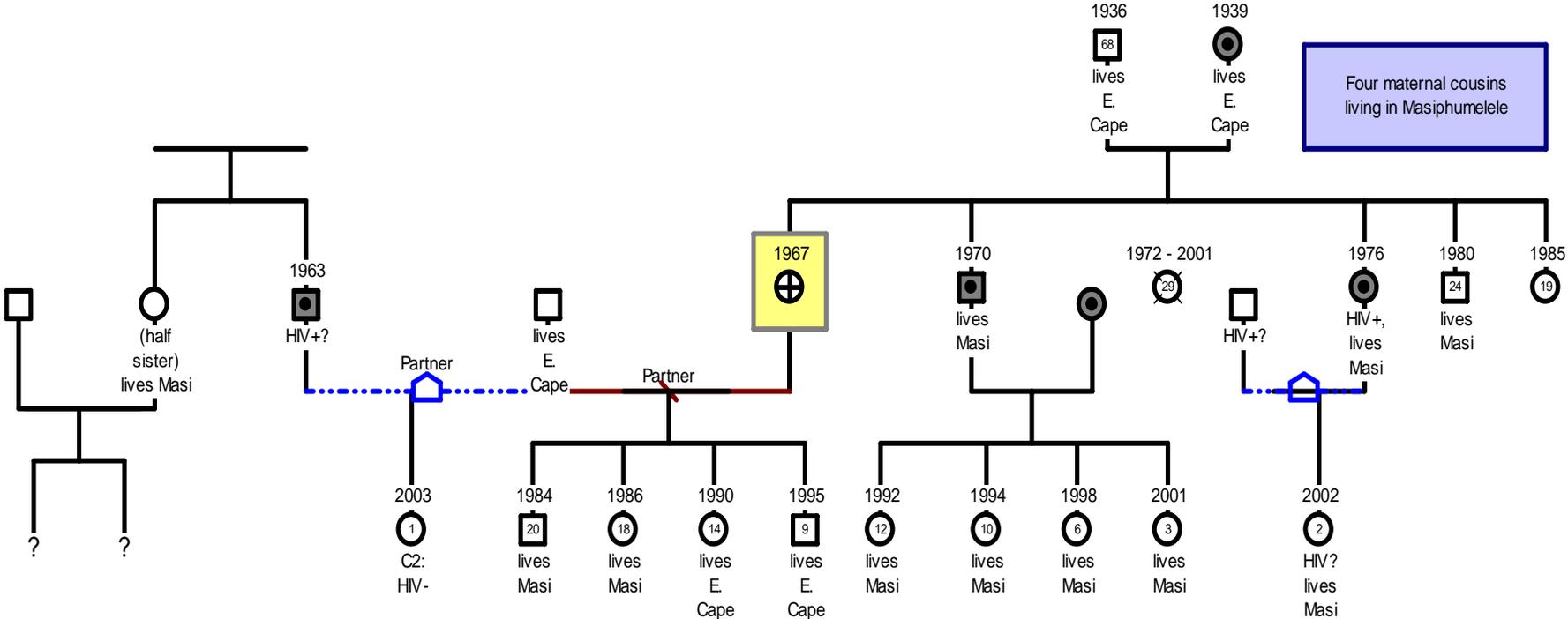
The assertion of power in the face of adversity is evident in Miriam’s history of practical and mental resourcefulness when confronted with extreme economic, health and interpersonal challenges. Her history suggests that she developed resilience much earlier in her life when she had to respond to the abandonment she experienced as a teenager and assume a parental role for herself and her younger brother. Following her diagnosis, Miriam felt helpless, despairing and suffered bouts of severe illness. She then had an internal dialogue in which she told herself that she had the disease and must live with it. Over the years prior to and during the study, Miriam continued to take her treatment and proved resourceful in dealing with her stressors, even reaching out to identify others’ needs and seeking help for a family who lived close by. Prior to 2004, Miriam’s strategies to protect herself included two alterations to residential arrangements: She went away with her child for a holiday when there were tensions with her partner, and she constructed a secret door in her shack to give her some privacy and space away from her sick brother who she experienced as a considerable burden. She was also able to organise social welfare grants for herself, her brother and her child, and used the support group and the research interviews as an opportunity to unburden herself emotionally.

Miriam’s HIV status has been a continuous threat to her sense of control over herself and intimate areas of her life. She failed to hold down a recent well-paid job obtained by a representative from the church because her CD 4 count plummeted to 10 and she was too unwell to wash dishes. Furthermore, she sensed that her colleagues who had guessed her status owing to the link with the



year old baby. Her two other children, then aged ten and fifteen years, were living in the Eastern Cape with Sally's parents. Two of the other four shacks on the same plot, which is owned by Sally's partner, were occupied by extended family; the first by Sally's younger sister, partner and their two small children, and the second by Sally's partner's half-sister. We observed adults from all these domestic units monitoring and feeding each other's children (see domestic group 4.1). Sally did not move between the first and second research phases, but her children did. These moves were arranged by Sally for a number of reasons, particularly her status. But Sally's eldest daughter moved out of her own initiative and provoked mixed reactions in Sally that she attributed partly to her illness.

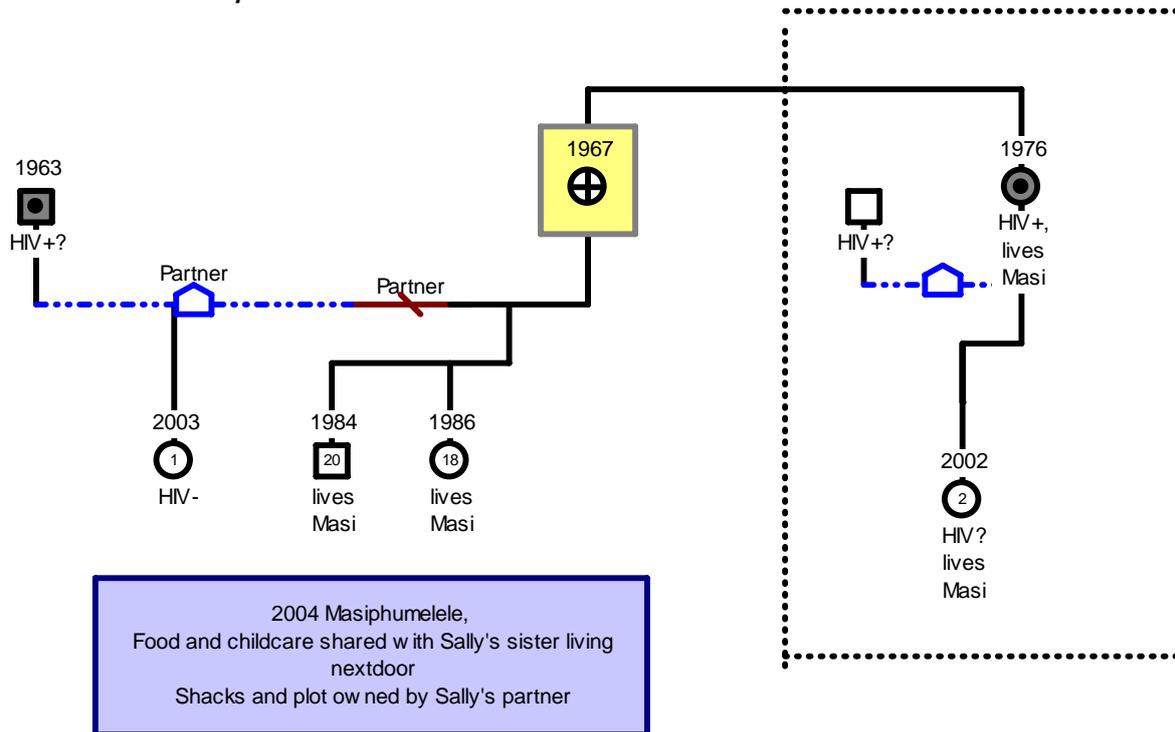
Figure 4: Sally's family in November 2004



During her fifth pregnancy in 2003, Sally was diagnosed HIV positive and immediately disclosed to her boyfriend, her brother and his wife who also reside in Masiphumelele, and her mother. She chose not to tell her sister who lived next door on the basis that the news would distress her because she has young children of her own. Prior to starting ARV treatment in late 2004, Sally was feeling weak and unwell but felt better after a few weeks of medication. Shortly thereafter, Sally's sister confronted her about her status because she had observed her attending the clinic. Sally then disclosed and her sister said that she was also positive, and had feared to disclose for the very same reasons. Her partner, too afraid to be tested when Sally first disclosed, was thin and weak when we first met. He had been unemployed for over a year and unable to contribute financially, but Sally described him as supportive of her at an emotional level. When he became very sick in 2006, Sally persuaded him to be tested for TB. The results were positive; he began treatment, and was then tested for HIV. He is also now on ARV therapy and Sally reports their relationship to have grown more intimate and open.

When she began treatment Sally said that she tried to avoid thinking and worrying about her status because it made her feel worse. She tried to adopt the attitude that we will all die eventually, but do not necessarily know how or when. Yet she remained anxious that she may die before her new baby grows up and all her children are able to live independently. During this first research phase, Sally was very concerned about lack of money and the fact that she was sometimes unable to provide her resident children with food, or to afford to visit the other two in the Eastern Cape. Sally reported that her household received only R370 per month, half of which was a Child Support Grant, the other half a combination of her informal sale of cigarettes, sewing jobs and beadwork. Even though they had no rent or utility bills to pay, and shared the costs of food with relatives on the same plot, it is difficult to imagine how this small sum met the needs of their domestic group. Having seen several empty beer crates on the property, we are aware of the possibility that they were also selling alcohol to neighbours.

## Domestic Group 4.1

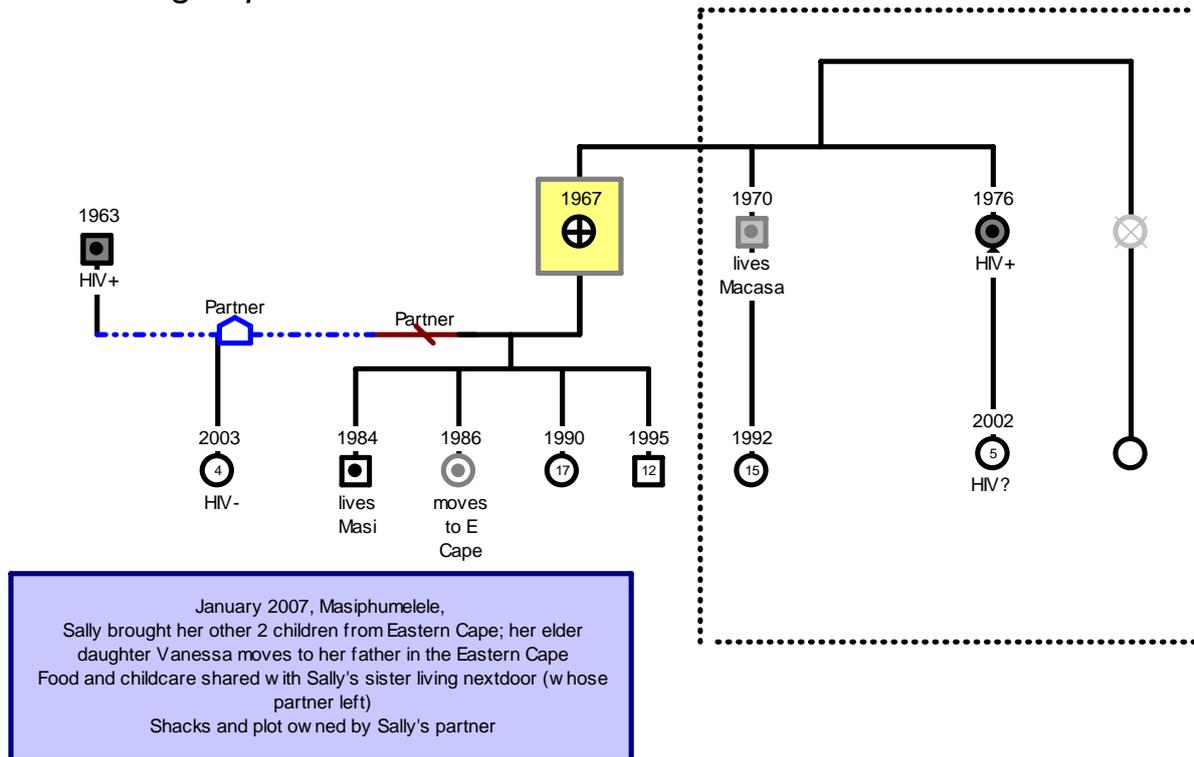


Despite their perilous financial position and their disclosure to a portion of their relatives, neither Sally nor her partner considered moving in with family members in the Eastern Cape, elsewhere in Masiphumelele or greater Cape Town. Like many, they discounted the Eastern Cape because it lacks income-generating opportunities. Sally has four siblings and four adult cousins who live in Masiphumelele, and whom she sees regularly. One of her brothers is a Zionist pastor and in 2004 Sally, her partner and children attended church in his home three streets away twice a week, eating supper there as well. In 2006, this brother sold his plot and bought a larger one in Macasa, an expanding suburb near Cape Town's airport where he is now working. He, his wife and three of his four children moved there, leaving his eldest daughter in Masiphumelele in order not to interrupt her final year at school. This niece lives in Sally's shack, sharing a bed with her second daughter, whom she brought into Masiphumelele from the Eastern Cape. Sally's brother continues to visit most weekends, bringing money for his daughter's education and her food, intending the latter to support Sally and her sister's household. Speaking to Sally in 2007, she reported the same high level of material, social and emotional support from this brother and his wife as she had done in 2004. The fact that Sally has residential security through her partner's ownership of the plot and their dwellings puts her in a position to reciprocate in some way. By accommodating her brother's daughter, Sally, her sister and their inter-linked domestic groups stand to continue benefiting from his care and recent upward mobility.

Sally, like Miriam and many other mothers in Masiphumelele, arranged that her children in their early and mid-teens leave their grandmother's care in the Eastern Cape and join her in Masiphumelele. Their education was certainly one of Sally's motivations but she stated quite explicitly; "I need to have all my children near me because of my status and my fear of being ill". Her two eldest children who have been living with Sally since she was diagnosed know of her status, but Sally regrets the means by which they discovered. Her son found her taking her ARVs, she responded affirmatively to his challenge, and neither has ever raised the topic again. Vanessa was told by a cousin and offended by her mother's secrecy, but Sally was able to have an open conversation subsequently. When we last spoke to Sally she expressed her desire to disclose to her remaining children and avoid repeating such a scenario, but had no firm plans when she might do so. Although she never articulated it, we can surmise that her children's presence in the home gives Sally a sense of opportunity to disclose when she musters the courage.

One of the ways in which this mother felt she could manage not only the question of disclosure but the uncertainties that HIV brings was to gather her children in her home, despite her extreme income poverty and the fact that her own mother was willing and financially able to care for them. As a result of Sally's decision, the arrangement with her brother described above, and the death of one of their cousins, Sally, her partner and her HIV-positive sister were between them accommodating six adolescents and three small children (see domestic group 4.2). Sally explained that because her sister only has two children of her own she has taken on the 'parenting role' for the two children of their siblings. By this she means responsibility for their food, clothing and education costs and guardian status should they be eligible for state grants. Chatting about the implications of these children's immigration, Sally described positive relationships within the home and did not resent their presence in any way. She did however hint that the care burden was too great: "It's not supposed to be this way. Every time we dish up, it is never enough".

## Domestic group 4.2



Sally appeared resigned to this scenario and perhaps unable to make changes given her dependence on the wider family outlined above. Talking to her eldest daughter Vanessa, we learnt that she herself had taken steps to relieve the pressure on her mother Sally. Following the arrival of another relative (a cousin in her early twenties expelled from her father's home by conflict with a new step-mother), Vanessa decided to call a family meeting. In this meeting, and at the risk of being labelled mean and disrespectful of her elders, Vanessa suggested that the cousin stay with other relatives in Masiphumelele. Sally, her sister and partner agreed, and the cousin is reportedly grateful for Vanessa's honesty and happy in her new home.

The objective of offering some relief to her mother's household was one of the reasons Vanessa herself decided to move to her paternal family in the Eastern Cape. Two more significant reasons, she said, were firstly her desire to rekindle and "test" the bond with her father, and secondly her sense that she had greater chance of educational success in the Eastern Cape (partly owing to fewer household chores and greater time for study, and partly because saw herself as being further ahead than her rural classmates having studied Outcomes Based Education in Masiphumelele). As it turned out, she stayed in the Eastern Cape for only two months because her paternal grandmother treated her badly, refusing to allow her access to food. Vanessa reported that her grandmother wanted to retain control over money transferred to cover Vanessa's food and

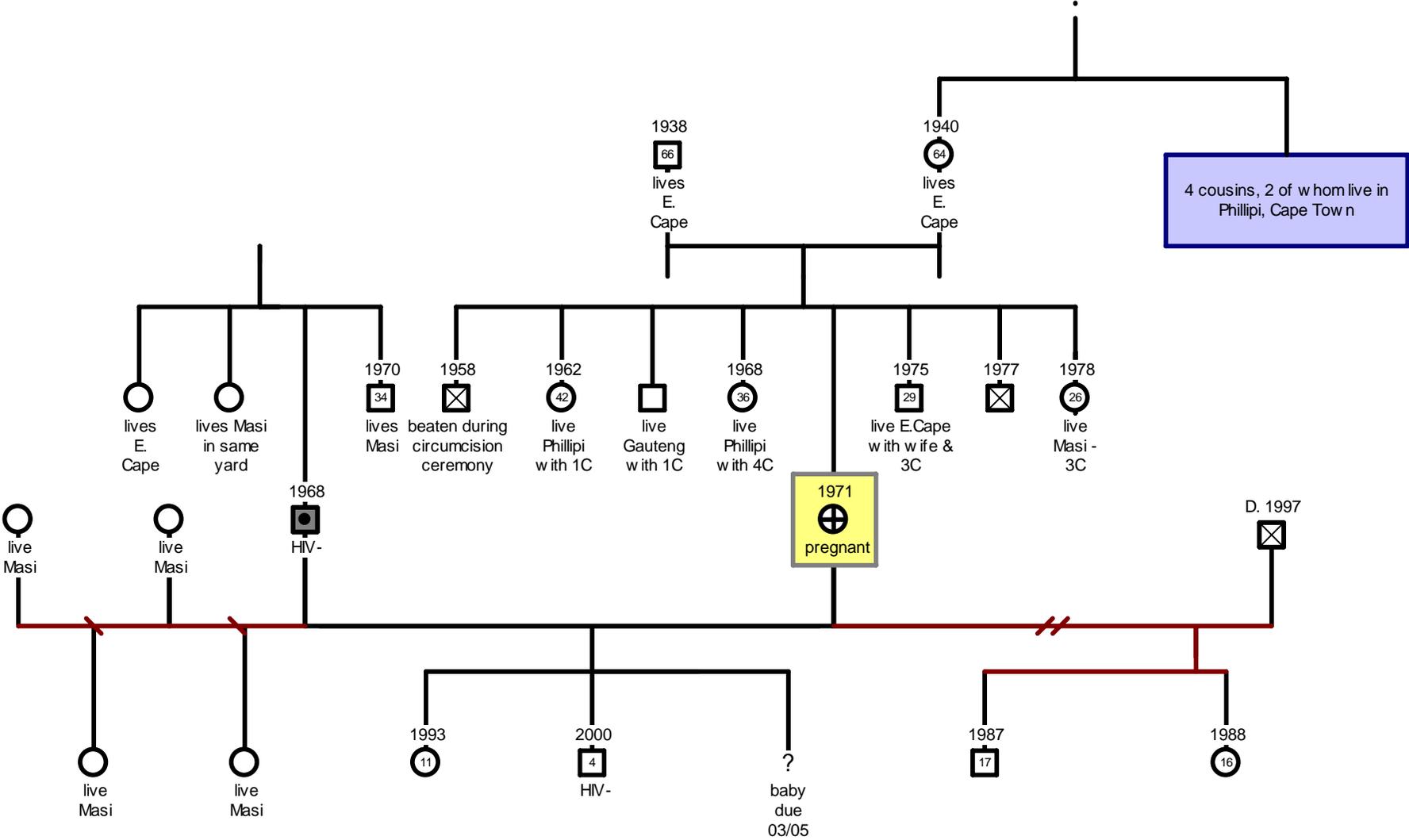
school costs, and behaved in this way because she objected to her own son's willingness to hand cash directly to his teenage daughter.

Looking back on her decision to leave Masiphumelele, Vanessa said that her mother's status and illness influenced her in that she was more worried about her mother's anxiety over how to care for all the children. She described herself as an older child in the family who wishes to learn how to be independent and keep her eyes and ears open for any opportunities that will help lift her and her family out of poverty. Vanessa knew that her mother did not want her to move, demonstrated by Sally's refusal to pay for her fare. And while she appreciated her mother's honesty and open communication, Vanessa spoke about seeking ways of demonstrating her insights and maturity to her mother. In a separate interview, Sally said that she recognised Vanessa's wish to assert herself and show how much she misses her father. At the same time as wanting her children around her, Sally's opinion is that the older ones have a right to make choices and she did not want to stand in the way of Vanessa's decision. She spoke of her appreciation of Vanessa's openness with her, for example regarding her relationship with her boyfriend. Some of the tensions that exist within these mixed feelings arise purely from inter-generational dynamics and the particular nature of mother-daughter relationships. Sally's HIV status does alter these slightly, however, adding an intensity to her desire to enhance emotional closeness by avoiding physical distance. And from her daughter's perspective gives further scope for her to relieve some of the financial pressure on her mother. At no point did Vanessa link her wish to try out her father and paternal grandmother's support to any future scenario, but it is not difficult to imagine that she wished to research her options should her mother's health decline severely.

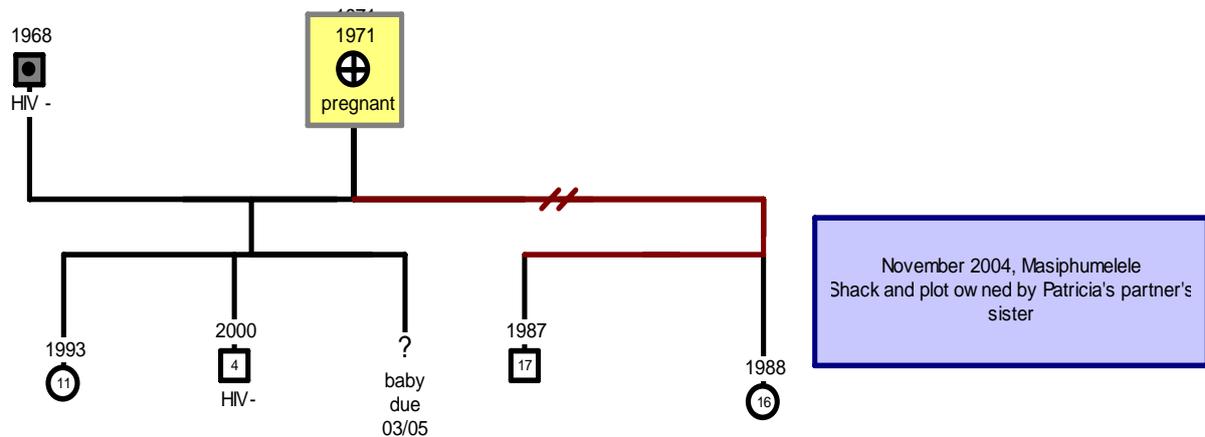
Finally, it should be noted that Vanessa and her mother negotiated this move in a manner that kept Sally's status and illness secret. Vanessa's decisions were easily explained to an outsider as relating to her educational strategy and desire to be with her father. There was therefore no reason for relatives or friends to suspect that her mother's illness, or HIV in particular, were part of the picture.

Patricia, aged thirty-three when we met in 2004 is the mother of five children, two in their late teens by her former partner and three under ten years by her current partner. At that time she lived in a spacious and relatively well-furnished shack with her partner and four children; she was about to give birth to the fifth. She ran an informal hair-salon from her home, and both the plot and structure are owned by her partner's sister who lives in the adjacent shack. Patricia's story is one of a search for residential security for herself and her children, and of a bold and short-lived move to an unknown area in an attempt to achieve this.

Figure 5: Patricia's family in November 2004

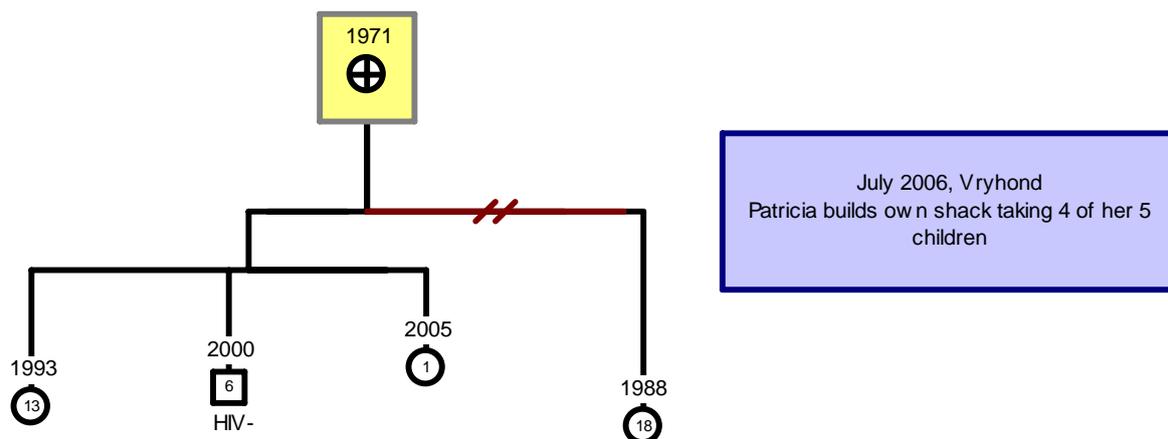


## Domestic group 5.1



Patricia discovered she was HIV positive when she and her partner overheard a conversation between nurses when she was about to be discharged from hospital having had her fourth child by caesarean section. The clinic staff said that they could not explain how she became infected because she reported being faithful and her boyfriend tested negative a few months previously. Patricia reported feelings of fear about death and using household chores to keep her mind off her status. Her partner was shocked and asked that she keep her status a secret between them. Patricia has not disclosed to any of her own family, and hardly sees her only close relative in Masiphumelele, a sister. In 2004, our observations confirmed Patricia's reports of very high levels of emotional and practical support from her partner, for example listening to her worries, and taking responsibility for many domestic and childcare tasks in addition to his salaried job as a cleaner in a local shopping centre. When we met again in 2007, Patricia reported that not only had his support and their intimacy declined steadily, but she suspected him of having an affair on the basis of some receipts she found in his pocket. Patricia was already highly anxious about her residential security in 2004 owing to cold and accusatory relationships with her partner's siblings. At that time she was eager that her partner should build the home he had allegedly promised some years previously and that they move out as a family. Thus, despite her partner's denial of an affair, the breakdown in their relationship triggered Patricia to move to Vryhond, a new 'township' 20 km from Masiphumelele, with four of her children. She reported concern that changes in the way her partner was behaving in the home may lead to problems between him and her adolescent children. Her motivation to move stemmed from her desire that these older children have an alternative place to live should this relationship deteriorate, especially in light of her unknown life expectancy and her sense of insecurity regarding their current home.

## Domestic group 5.2



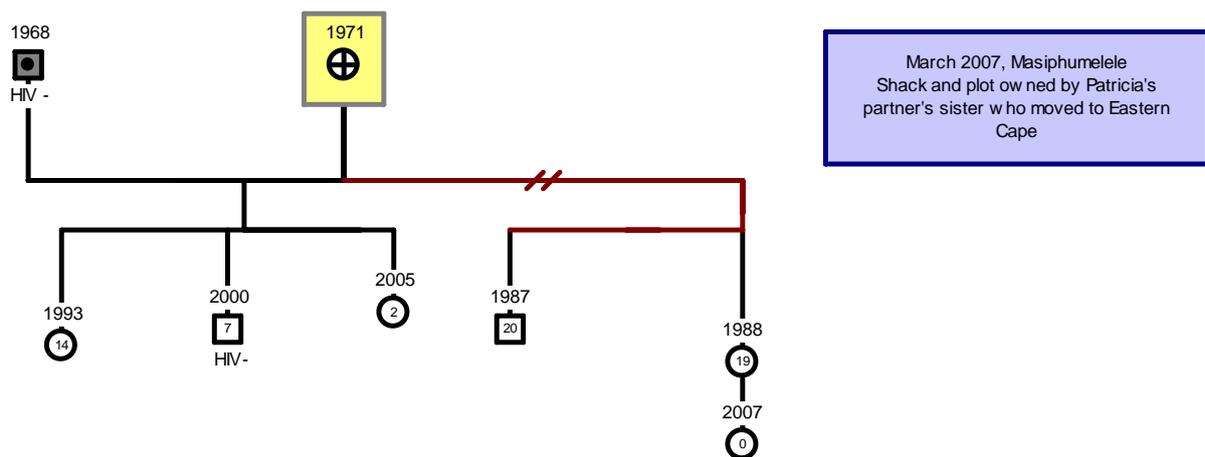
Patricia chose Vryhond because she wanted to live in a different neighbourhood where no-one would know her family problems, and she had heard from neighbours that plots could be obtained should one have built a shack on available land. She financed the building of the shack by claiming money from her partner that they had made when her own shack was sold and they moved in together. Once in Vryhond, Patricia struggled to make money because she had no network of clients for her hairdressing business. She recalled being unable to feed her children properly and their resultant ill-health, and of the difficulties in getting her eleven year old daughter to and from the 'good' school that she and her partner had invested in, which was 15 km away in Kalk Bay. The morning journey alone required waking at 5 am, taking her baby and three year-old to her sister's in a neighbouring township, then accompanying the eleven year-old in a taxi to the station, and seeing her onto a train. Her own health declined owing to the stress of managing these problems and because she stopped taking her ARV medication, apparently because she could not afford to come to the clinic in Masiphumelele to collect her prescription. The fact that she was able to return each month to collect her Child Support Grant suggests that she may have stopped her treatment to further punish her partner, whom she knew wished her to continue.

Three months later, Patricia's partner heard that his children were unwell and asked an older woman who has been a long term mutual friend of his and Patricia's to go to Vryhond and bring Patricia and the children back. This same woman, referred to as 'mama'<sup>18</sup>, mediated a discussion between Patricia and her

<sup>18</sup> In Masiphumelele, family mediation and other forms of lay counselling are roles not infrequently assumed by older men and women who are judged morally upright, benign and impartial. These 'mama' or 'tata' figures are valued for their ability to bring an outsider's perspective to domestic disputes and families tend to call on the same person whenever need

partner, and persuaded them to live together for the sake of the children (domestic group 5.3). They did so and are communicating better, but Patricia reports that she no longer trusts her partner. One retrospective interpretation of Patricia’s decision to set up home far from her partner is that it was a means of expressing to him her dissatisfaction with the housing situation and his behaviour – particularly perhaps given his knowledge of her status, and that she succeeded in addressing these problems by prompting the involvement of the ‘mama’ figure. But the critical issue of Patricia’s and – more importantly in her mind – her children’s residential security has not been resolved and continues to fuel her anxiety. She feels less able to address this problem with her partner owing to the persistent lack of intimacy in their relationship. Her belief that none of her partner’s family has ever been willing to accept her effectively removes any sense of being able to draw on wider family support in this regard, especially in light of her fear that they discover her status and attempt to marginalise her further.

### Domestic Group 5.3



Patricia’s forward thinking speaks of a vulnerability that arises out of her financial, residential and emotional dependence on her partner that is exacerbated by AIDS-related ill-health. Since she stopped taking her medication and her health declined, Patricia frequently thinks about the time when she will not be here. She dreams of finding a plot in the Eastern Cape near her parents and building a house for her children in case her partner does not stand by them. “But”, she says, “I put these at the back of my mind, as I have no savings now”. Speaking about the outcomes of her move to Vryhond, Patricia described her plan to make a home for her elder children to have “failed” on the basis that her son wished to stay in Masiphumelele to complete his schooling and her daughter

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arises. No financial transactions are involved but gifts may be given as part of the relationship.

opted to move in with a boyfriend she met in Vryhond. Her children may not regard their mother's strategy to have failed because despite having chosen to decline the new home at this point, they know that the shack still belongs to their mother and could be used by them in the future.

Patricia's efforts to secure a home for her children in the future may have inadvertently contributed to a breakdown in communication with her elder daughter Anele at a point when this teenager's mental health was very fragile. Patricia and her neighbours were very worried about Anele and her small baby on the basis that the former stayed in her room for very long periods, emerging only to wash the baby, and responded with rude remarks when Patricia tried to talk to her. Not only did Patricia suspect that Anele was severely depressed and isolating herself from her family, but Anele's boyfriend had intimated that she was pregnant again. Acting in accordance with ethical guidelines, we wrote to Anele regarding psychological assistance available locally and offered to help facilitate this. She failed to attend a number of appointments with Lindiwe made via her brother and through letters left at school. Anele's behaviour conveyed a decision to reject us in the same way as she had been rejecting her mother for the past few months, and further re-enforced our perceptions that she was extremely vulnerable.

We were unable to talk to Anele, but know enough about her mother's decision-making and relationships in the domestic group more broadly to suggest some of the reasons why she withdrew from her close family. Patricia's regular clinic appointments, periods of weakness and consumption of ARVs in the home are very likely to have alerted her teenage children to the possibility that their mother is HIV positive and even AIDS-sick. If so, they may see their step-father in a negative light, attributing blame for infecting their mother and further fuelling resentment against a man they have always felt could not replace their own father who was killed in an accident. They would also be aware that their mother had chosen not to disclose to them, and probably interpreted this as a rejection of their ability to understand and of their emotional connectedness. The fact that Patricia chose to keep her status secret meant that none of these matters were open for discussion and misunderstandings could easily develop. Her decision to move with her children, for example, did not involve any consultation with the older ones and would therefore have felt forced upon them. It is also highly probable that since Anele had her baby, both she and Patricia have become acutely aware that Patricia may not be able to be the active and caring grandmother upon whom many young mothers rely. Again, none of this is discussed. A further possibility in this scenario is that Anele herself has discovered in the course of pregnancy or childbirth that she is HIV positive. The secrecy and lack of clarity that surrounds her mother's health means that their

relationship does not contain the trust and intimacy needed for Anele to talk about her own status. Expressing her frustration and desperation about Anele, Patricia remarked that Anele has done precisely what she did in her late teens. She had her first child aged nineteen, and exactly one year later, had her second. She appears to feel trapped in a position where she cannot offer her daughter advice or support (because she herself made the same ‘mistakes’), and is unable to demonstrate love and acceptance despite the situation because she feels so anxious and disempowered by the way history is repeating itself. In this context, Patricia’s efforts to support her daughter by moving house appear to have further undermined their relationship, and Anele may be even more vulnerable as a result.

I draw attention to Anele’s apparently very fragile psychological state in the context of anecdotal evidence of increased attempted and actual suicide amongst young adults in Masiphumelele<sup>19</sup>. Circumstances that appear to have precipitated these include undiagnosed post-natal depression (Tomlinson et al 2005), a breakdown in partnerships or domestic relationships, and fear relating to educational prospects and/or health.

## **Concluding discussion**

The five women who were the focus of this study have used actual and possible moves involving themselves and their children as a means of managing multiple pressures and scarce opportunities in their everyday lives. As the case studies have amply demonstrated, HIV is in all cases one amongst several causes of anxiety and threat to their own and their family’s well-being. This research points to three key factors influencing women’s thoughts and actions regarding mobility that pre-existed their diagnosis and treatment. First are the social dynamics amongst their biological kin, within partnerships and in their partner’s kin networks. Second is their own income-generating potential and the resultant implications of this as a factor impinging on financial independence and consanguinal or kin relationships. Third are considerations for their children’s current and future well-being, most particularly their educational opportunities. Moves made or orchestrated by these mothers in the period since being diagnosed HIV positive, experiencing ill-health and starting treatment are found to arise from an interplay of pressures and motivations, only some of which relate specifically to the experiences of contracting a life-threatening infection

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<sup>19</sup> A number of Lindiwe’s own clients have relatives or friends who have killed themselves or attempted suicide, and her colleagues working in the area have also drawn attention to the apparent rise in suicides amongst adolescents and young adults.

and ill-health. In this final section I draw together the evidence of how maternal HIV infection, illness, and/or treatment has made a difference to residential decision-making by infected mothers and their teenage children, and comment on the influence of these plans and actions on the well-being of these mothers and their children of all ages.

Anthropologists working in areas with similar demographics prior to very high rates of HIV have pointed to the significance of the rural home as a practical, social and emotional resource to domestic groups, a role that has been strengthened by employment-motivated urban migration (Henderson 1999). The individuals and domestic groups in this sample have largely lived on the city's periphery for a decade or more, meaning that full insight into the manner in which they have drawn upon and supported the rural home in situations of illness and HIV would require the perspective of kin and other members of reciprocal networks living there (see Neves and du Toit papers 2 & 3 for a rural perspective on social reciprocity across the Eastern Cape – Cape Town Diaspora). This limitation notwithstanding, my data indicate that strong rural-urban connections provide mothers with a sense of having alternatives, even if the scarcity of rural employment and poor service provision greatly reduce the feasibility of rural living. Where rural-urban connections are very weak or conflictual, such as in Patricia and Miriam's cases, mothers presented themselves as more vulnerable and limited in their options regarding current supports and future homes for their children.

Neves' (2008) distinction between urban homes that have rural connections and those that do not provides a useful starting point in the investigation of residential and care strategies, but does not capture the particular ways in which individuals conceptualise and act in relation to dispersed kin or kin-like networks, both rural and urban. This analysis has shown that the material and symbolic significance of rural connectedness varies over time and is highly contingent on an individual's sense of their claim on resources, as well as their assessments of their own and their children's current economic, social and emotional needs in relation to their anticipation of such needs in the future. For Joyce and Sylvia, the frequent comings and goings of family from all generations indicate strong and mutually supportive rural-urban connections. But both women, and particularly Joyce, were circumspect in when and how they called upon these resources – largely it appears owing to anxiety around how their rural-based mothers would respond to knowledge of their status and any bearing this may have on their deservedness of support. Their fears proved unfounded and disclosure prompted greater maternal support than anticipated, meaning that the rural home in practice played a larger role in supporting HIV

positive women and their young children than would have been envisaged from their earlier decisions to stay in Masiphumelele.

The residential and child-care arrangements made by these women prior to HIV infection, and for one (Sylvia) following diagnosis, mirror the common pattern of placing young children in the care of their grandmothers or aunts in the rural Eastern Cape with the result that mothers are better able to seek employment and sustain long or erratic working hours (Bray 2003, Henderson 1999, Lee 2002). What is interesting is that during the research period none of the other mothers moved or intimated any intention to move their young children to the Eastern Cape. And Sylvia arranged for her son's return after only a few months and without having found work. These women consistently articulated that their desire to live with and care for their young children stems from the experience of HIV infection and related illness, and specifically their uncertainties regarding their future health and life-span. Additional related reasons include the physical limitations on their abilities to sustain the demands of a regular job imposed by the infection and their resultant availability to care for their children at home. Furthermore, for mothers like Sylvia and Miriam who are linked into NGO networks by virtue of their status and treatment, there may be economic and educational advantages to keeping a young child in an urban home. These include financial assistance with crèche or school fees, the provision of food parcels and support from social workers in processing child support and disability grants or in applying to the courts for maintenance.

Decisions by parents to bring older children back to Masiphumelele in order that they can help out with household chores and improve their educational opportunities are commonplace (Bray 2003). Where HIV diagnosis and resulting ill-health did seem to make a difference was in mothers' explicit desire to have all their children as close as possible, in other words co-resident. The opportunity to disclose to adolescents appears to fuel mother's motivation to bring their teenagers to their homes in Masiphumelele. Several mothers disclosed shortly after their teenager joined their home, and in other cases mothers rightly assumed their older children would deduce their mother's status and stated that they were seeking the opportunity for a frank conversation. Mothers also said that living with their children enabled the latter to learn about AIDS, and to witness firsthand the periods when they were coping as well as those when they were struggling with the virus. Practical preparations also feature strongly. All women in this group strove for the best educational opportunities possible. Sally and Miriam spoke about managing the home in a way that their elder daughters were sufficiently practised in household chores to be able to look after themselves after they had died. And Patricia attempted to secure an alternative home in Cape Town for her teenagers.

Most importantly however, sharing a home gave mothers the opportunity to provide nurture and to generate intimacy, aspects of relationship quality they appeared to value more highly in the context of anticipated ill-health and uncertain life expectancy. None judged these to be more difficult in light of children's recent residence elsewhere and care relationships formed with rural relatives, but it stands to reason that mothers saw no practical alternative to co-residence if they were to achieve the emotional closeness, sharing of knowledge, social bonds and practical preparations with and for their teenagers that they desired. Some mothers described the care they offered to their children as compromised in light of anxiety and 'stress'. In their view, being diagnosed as suffering advanced stages of AIDS was one of a number of factors undermining their mental health and their ability to care (Bray and Brandt 2007).

The fact that the movement of children to and from the Eastern Cape is so common enables mothers with AIDS to draw on the supports of wider kin and to nurture their intimate relationships with their own children in ways they deem necessary or optimal in light of their status or illness, but without drawing attention to either. It is therefore a strategy that carries few risks in terms of unintentional disclosure to, or suspicion from, the extended family or neighbours.

Teenagers who are moved from rural homes to Masiphumelele also tend to perceive the quality of education in the Cape Town area to be higher than in the Eastern Cape. But evidence from this and a larger parallel study amongst adolescents<sup>20</sup> suggests that, like Barbara, many were not consulted in a way that gave them a sense of actually having a choice regarding where they should live. Having moved, many miss their grandmothers whom they have come to know as 'mothers'. And news of their own mother's positive status adds another dimension of anxiety to an already difficult process of adjusting to living with their biological mothers in a new neighbourhood. For those like Barbara whose mothers and grandmothers are in conflict, there is real concern that their mother may die and their grandmother turns them away on the basis that they 'chose' the mother over the grandmother. Young people in this study were motivated to explore alternative places to live and study, and the level of nurture and support they may expect from them. Temporary or permanent moves away from an AIDS-sick mother may result from both a desire to reduce the mother's care burden and an attempt to locate another domestic sphere where they can nurture intimate relationships while keeping the disconcerting, and largely unknown,

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<sup>20</sup> Fieldwork for an ethnographic study of the lives of children and adolescents in Masiphumelele and two neighbouring areas was conducted from 2004 to 2005 (see Bray et al, in progress).

implications of HIV at arm's length, and which has the potential to be their home should their mother become very ill or die. The nature and extent of movement by children of all ages, and particularly adolescents, in the five households sheds useful light on the question of prevalence and significance of sibling separation raised in an earlier paper (Seekings, 2008a). Children's moves were always between the homes of relatives and were often either very short-term or involved maternal visits, meaning that relationships between siblings were by no means severed and perhaps not even undermined. As far as could be told from this data set, the more enduring moves were to the maternal home where other siblings also resided.

Scrutiny of women's decisions to join their kin – or indeed to consciously avoid doing so – points to the symbolic significance of residential moves between the homes of relatives. A decision to move into a relative's home, or to accept someone in, is interpreted as a sign of current loyalty and an indicator of future support. Rejection of an invitation or the decision to expel a family member can therefore be understood within the family as an indication that support is withdrawn or should not be taken for granted. These meanings help to explain the careful treatment of kin relationships including considerations around co-residence by women and adolescent children in our study who are aware of the implications of maternal HIV for the future well-being and support needs of both individuals and the domestic group. Having been expelled from her sister's home, Joyce's decision to set up home independently of kin meant that she had latent social and economic resources through her brother and mother that could be called upon. The data suggest that a sense of being able to access these resources in the future is particularly important for income and asset poor AIDS-sick mothers whose primary concern is often the care of their children once they have died. It is also important at a symbolic level in that the sense of belonging to a wider network of care bolsters women's mental health and helps them sustain a positive attitude to their treatment and self-care.

The cases analysed here point to a particular inter-generational dynamic that seems to be enhanced by a woman's positive status. The data suggest that mothers disclosed to their siblings and partners fairly readily but were very reticent to disclose to their parents, especially their mothers. Recent research in another demographically similar area of Cape Town revealed that only 40% of the 130 HIV-infected women in the sample disclosed to their mother as opposed to 55% to their sisters (Brandt 2007). Some of the women in this study feared that the news would seriously affect their mother's health, and had evidence to substantiate this concern. The impression given by those who waited to disclose to their mothers is that such a decision carried more weight and that the risks of rejection were higher because to have become infected was in some way to have

let one's mother down. In at least two cases, women reported unforeseen high levels of support from mothers once they had disclosed, as well as a greater emotional closeness. The offer of care for their young children was one tangible way in which these women's elderly mothers made their support known.

One of the reasons why women choose to disclose to siblings rather than, or much before, disclosing to their mothers may be the fact that their siblings live nearby whereas their mothers live in the Eastern Cape. Only 13% of women in Brandt's study had disclosed to people who lived outside Cape Town (*ibid.*). Proximity may be a consideration for women who wish to monitor their relative's response and be available for further conversations. It may also matter because it is an indication of how well-versed people are in the reality of HIV prevalence. Residents of Masiphumelele and other poor residential suburbs of Cape Town will encounter HIV through the media, local service provision and local oral networks. Rural residents are less likely to do so owing to more scattered health and social services (see Neves, Working Paper 228).

Debates about the additional or exceptional effects of HIV on social reciprocity within poor communities usually focus on the question of whether or not the extended family are able to cope with the increased demands on their resources (see Seekings, CSSR Working Paper 237). The case studies presented here show women's choices to invest in and draw upon relationships with neighbours and friends living in Masiphumelele, often in preference to or with more confidence than in relationships with biological kin. These decisions demonstrate the need to broaden our thinking around social capital for urban residents beyond that of the kin network. Some of these affective connections are kin-like and even kin-related in that urban friends providing significant support are those who have the same ancestral rural origins (for example the 'mama' figure who mediated in the dispute between Patricia and her partner and the 'aunt' who provided a temporary home to Joyce and her son). Others described as significant are friends or relatives of a partner who have shared the experience of immigrating from another country and forging relationships amidst language and cultural differences (for example Miriam's reliance on her Mozambican partner's parents and his friends). And still others have become known and trusted through the clinic, church, or NGO-run HIV support groups. In the limited sample and time frame examined in this paper, women appear to think of and experience kin relationships as more dependable in times of critical need than these friendship or neighbourly networks. That said, the material suggests a need for continued research into the diversity in sources of social capital and networks of social reciprocity for women, men and children as the character of urban environments changes, for example through growing linguistic and

cultural heterogeneity in local neighbourhoods and through significant institutional involvement relating to HIV and/or other threats to well-being.

This paper has pointed to women's access to networks catalysed through the action of medical or social services, including the actions of AIDS-focussed NGOs, but owing to the study's design I cannot comment on men's access to or use of such networks. Research in the rural Eastern Cape has shown women to be adept at participating in and drawing benefits from development initiatives whether these involve small-scale farming or handicrafts, in part through their use of strongly gendered networks (Bank 2002). Men, in contrast, are notably absent in these processes with the result that they are largely excluded from the possibility of drawing upon their related economic and social resources. In Masiphumelele, like other similar communities on Cape Town's periphery, the majority of the first tranche of patients on ARVs were women and a large proportion of these women regularly attend NGO-run support groups. Only recently has the gender ratio of patients screened for ARVs evened out, but there is still a higher proportion of women who remain on treatment, and only a handful of men who attend HIV-related NGO support groups. Moreover the professional care and advocacy roles offered to members of the community are primarily filled by women. There is ample scope for further study of these dynamics in order to understand changes in the nature and sources of social reciprocity for men, as well as the implications of any gendered dimensions to emerging sources of social capital for the way in which women and men – as individuals and as parent couples – plan and execute decisions pertaining to where they live.

Finally, the instrumental and emotional benefits of the moves these poor and HIV positive women have made or organised are strong motivators in their own right. Yet there is an important additional psychological dimension to their decisions to move, or stay put, or to arrange the movement of their children that pertains to the expression and activation of control over at least one aspect of everyday life when they are highly vulnerable in other significant aspects. Patricia, observing a deterioration in her relationship with her partner and aware of his role in her residential security, made her move out of the home with four of her children at her most vulnerable point. Likewise, Miriam made a strong stand about her home and her refusal to move at a point when she and her children were under severe threat. These women use mobility, or the possibility of moving, as a means of protecting themselves and their children from the outcomes of their relationships with their partners, their wider families and their neighbours. As importantly, it appears, decisions and actions around residence serve as a means in which women can demonstrate to themselves that they have control over the nature and character of the domestic environment by

orchestrating where they and their children live. There is every reason to suppose that individuals who have few assets, no independent means of generating an income and are suffering the emotional and physical effects of patriarchal interpersonal relationships (including domestic violence) express and exert a sense of power through their mobility-related decisions. But a sense of self-efficacy is likely to be even more important for those who are HIV positive, have experienced AIDS sickness and therefore have tangible evidence of being unable to control their physical health and their life-expectancy. Moreover, all the women in this study were acutely aware of the inter-dependence of their mental and physical health. They spoke about feeling physically better after a few weeks of treatment, more patient in their interactions with their children and therefore less mentally anxious about the effect of HIV on their ability to mother. And they saw their efforts to maintain a positive attitude towards their status and treatment as critical to their physical health. In this context, the process of planning and initiating a move, or a decision to stay put, is important because it speaks to the self and to others of being well enough to do the best for oneself and for one's children.

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