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**“THERE IS NO OTHER WAY OUT”:  
EDUCATIONAL DECISION-MAKING  
IN AN ERA OF AIDS: HOW DO  
HIV-POSITIVE MOTHERS  
VALUE EDUCATION?**

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# **“There is no other way out”: Educational decision-making in an era of AIDS: how do HIV-positive mothers value education?**

## **Abstract**

*This paper examines the logic behind some of the hypotheses found in influential studies and literature on the potential impact of HIV/AIDS on affected people's values in life, and more specifically, on the value they attach to education. It has been suggested that caregivers or children, faced with illness, death and a decreased life expectancy as a consequence of AIDS, might no longer be interested in investing in education. However, there does not appear to be any detailed empirical research on how AIDS does make an impact on people's values in life, their views on the future or the value attached to education. This paper begins to investigate how affected caregivers value education for both themselves and their children. The sample comprised ten HIV-positive mothers, nine of whom have at least one child of school-going age. One group discussion and five in-depth interviews were conducted, using semi-structured questionnaires. This research suggests that HIV-positive mothers are, in fact, strongly inclined to invest in their own education and especially their children's education. As caregivers, they have an increased sense of the importance of independence for both themselves and their children, and they regard education as the means to achieve that independence. Hence, providing schooling for their children is an intrinsic part of their caregiving.*

## **Background and introduction**

Various studies have indicated the already visible, devastating effects of HIV/AIDS for the children in heavily affected regions. One of the ways in which the AIDS pandemic already does and will almost certainly continue to

influence these children's lives, is through its impact on both the demand and supply sides of education<sup>1</sup>.

On the demand side, the educational system faces a potential *decline in enrolment* due to a declining birth rate as well as a rising *drop-out rate*, among children orphaned and vulnerable due to HIV/AIDS. *Attendance rates* are also influenced, as children from households affected by HIV/AIDS are often, for shorter or longer periods, taken out of school to care for the ill in the family, to take on household chores previously done by those that are ill or dying, or to take on income generating activities, in order to replace the lost income of a sick or deceased household member (Ainsworth *et al.*, 2002; Booysen *et al.*, 2003; Children's Institute, 2001; Steinberg *et al.*, 2002). Research has furthermore shown that children confronted with frequent illness and death, find it difficult to concentrate in school. Lack of psychosocial and physical support makes it difficult for the children to keep up their *school performance* (Booyesen *et al.*, 2003; Children's Institute, 2001; Germann *et al.*, 2001; Steinberg *et al.*, 2002; Unicef, World Bank, 2002).

It is generally assumed that the supply side of the system is, at the same time, affected by *increasing teacher morbidity and mortality* and *AIDS-related absenteeism*. It is further expected that the supply side will suffer from *resource dilution at both the institutional and state level*, when more resources will have to be shifted towards health care and thus possibly away from other services as education. All of this eventually leads to a decrease in the *quality of education* offered (Badcock-Walters *et al.*, 2003; Barnett, Whiteside, 2002; Hickey, 2002; Jansen and Taylor, 2003; Mobile Task Team, 2005; Shisana *et al.*, 2005; UNICEF and World Bank, 2002).

This paper is concerned with the impact on the system's demand side. Researchers, when trying to explain noticeable changes in enrolment, attendance and absenteeism in heavily affected areas, have placed a lot of emphasis on poverty-related issues (Booyesen *et al.*, 2003; Children's Institute, 2001; Giese *et al.*, 2003; Steinberg *et al.*, 2002; World Bank, 2002). However, some hypothesise also that people, once faced with the decreased life expectancy following the AIDS pandemic, might no longer be willing to invest in their or their children's education. As a matter of comparison: UNDP indicates that in South Africa, life expectancy at birth for the period 1970-1975 was at 53.7, then steadily increased and was well on its way to reaching approximately 70, but has

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<sup>1</sup> On the impact of HIV/AIDS on children, and on education, see e.g. Bennell *et al.* 2002; Booysen *et al.* 2003; Stein 2003; UNAIDS, UNICEF, USAID 2002; UNAIDS, WHO 2004; UNICEF 2003; UNICEF, World Bank 2002.

in recent years dropped dramatically again to now approximately 47.7 years (UNDP, 2003: 264; UNDP, 2004: 170).

Barnett and Whiteside argue that “sick adults may have reduced expectations of the returns of investing in children’s education, as they do not expect to live long enough to recoup the investment.” Also: “The shorter the time frame that people have, the more short-term risks they take with their health and the less willing they are to risk their limited assets which must be used for short-term survival. They are unwilling to invest in the future. A Zimbabwean who believes he or she will live only 40 years will not invest in education” (Barnett and Whiteside, 2002: 202; 273). Similarly, De Waal suggests (as reported by Mattes) that “when adult life span becomes highly uncertain, individuals’ rationale to invest time and resources in their education or training, or to save and invest is less rational” (Mattes, 2003: 3). The same logic is found in the work of some economists. In their attempt to model the effects of the AIDS pandemic, Bell *et al.*, for example, assume that parents’ expectations “concerning their children’s future are so bleak as to induce them to roll back investment in schooling to levels not seen since the middle of the twentieth century...” (Bell *et al.*, 2004).

However, whereas the negative impact of HIV/AIDS on household economics, and thereby on households’ possibilities to send children to school, has been shown in several studies (e.g. Booyesen *et al.* 2003; Steinberg *et al.*, 2003; Children’s Institute, 2001), the impact of HIV/AIDS on people’s view on the future, their aspirations and values, and more specifically values attached to education, have, to the best of the researcher’s knowledge, not yet been studied. Some studies have commented implicitly on the value attached to education, and these comments do not support the view of Barnett, Whiteside and others. Booyesen *et al.* found that one of the first reasons why HIV-affected households sell assets was their willingness to continue to pay school fees (Booyesen *et al.*, 2003: 91). Steinberg *et al.* found that many of the affected families in their sample hesitated to turn back on the payment of school fees, even though they could actually no longer afford the expenditure (Steinberg *et al.*, 2003: 25). In addition, research by the Children’s Institute indicated that affected children did not lose their motivation to continue to go to school (Children’s Institute, 2001: 22).

Although these findings thus certainly do not testify to a decreased value of education, the negative hypotheses persist and are often mentioned in the same breath as the doom scenarios around the negative impact of HIV/AIDS on the social fabric of heavily affected societies, and even the threat posed by the disease to the survival of the democratic state form (see e.g. Barnett and Whiteside, 2002; Hunter, 1990). The consequences of such negativist theorising are the dangers of overlooking affected people’s strengths and strategies to cope

with the challenges AIDS poses to their daily lives, and of neglecting the needs of these caregivers and children who do continue to build their future, perhaps also by continuing to believe in education. By taking an over-simplified, generalising attitude vis-à-vis affected people, one furthermore strongly runs the risk of contributing only to those people's stigmatisation in a context that is already heavily influenced by fear for the disease and its consequences.

This paper presents the findings of a small, qualitative study conducted in Khayelitsha, a black African, resource-poor settlement within the Cape Town Metropolitan Area. The study focused explicitly on the way in which affected caregivers value education, and to what extent these caregivers' (perceived) life expectancy could potentially impact on this value. This preliminary qualitative work is part of a larger study that combines qualitative and quantitative research methods and aims at providing a comprehensive view on the factors that influence caregivers', young adults' and children's educational decision-making, and the way in which HIV/AIDS impacts on that decision-making.

## **Breaking down the hypotheses: what are the assumptions?**

A common assumption in the negative hypotheses about AIDS and schooling is that:

- Deciding to invest in a child's education is merely a selfish cost-benefit analysis of caregivers, weighing the direct costs of education – such as the cost of school fees and books – against the expected future earnings of the child, which would then not only benefit the child, but also the caregivers.

Secondly, it is assumed that:

- Because HIV/AIDS lowers people's life expectancy, affected people will make decisions with a view to the short term, not the long term, also within their role as caregiver (i.e., also as provider of education to their children).

Both of the above assumptions, to us, seem to take a fairly narrow stance on caregiving as a starting point: is the relationship between a caregiver and a child based on nothing but a cost-benefit analysis in which caregivers or parents are interested only in "recouping" the investment? Would affected parents, in view of their own shortened life expectancy, truly define their caregiving role based solely on short term thinking? While it may certainly be the case that HIV-affected caregivers may seek ways to redefine themselves in order to cope with

the dual role of being e.g. HIV-positive and a caregiver, research has also shown that “HIV positive women ... have a particularly strong need to maintain their parental status, and that many will continue in their role as mother and caregiver, even at the expense of their own physical and emotional well-being” (Brandt, 2005: 3). Should one not, perhaps, first look into the broader context of care, and how caregiving arrangements have been, and are being shaped within a specific setting, before drawing conclusions on the impact of HIV/AIDS?

Secondly, should one not explore the nuances of the factors that possibly influence people’s or caregivers’ educational decision-making? Although purely economic models would generally indeed look upon decisions with regards to education as based on a cost-benefit analysis, other theories believe that people’s “values, preferences and behaviours are generally a function of their material, demographic or other life circumstances” (Mattes and Bratton, 2003), and therefore take into account also the impact of e.g. household structure, significant others, quality of schooling offered, etc. Still others would also take the impact of cultural elements, traditional norms and values into account (for detailed studies on the determinants of educational decision-making in African countries, see e.g. Ainsworth *et al.*, 2002; Buchmann, 2000; Cosser and DuToit, 2002; Gould and Huber, 2002; Glick and Sahn, 2000; Lloyd and Blanc, 1996).

It is beyond the scope of this paper to provide full answers to the questions that deal with, on the one hand, the definition and context of care, and, on the other hand, educational decision-making. However, as the paper will provide findings that clearly link to both these aspects, I find it important to first consider in somewhat more detail the social and educational context in which my research is taking place.

## **The context of care and education in South Africa**

Barnett and Whiteside’s hypothesis implies that parents would only invest in their children’s education if their economic cost-benefit analysis of that investment would have a positive outcome. Such a stance raises the question of how exactly care can be defined and how it should be regarded within a specific context. Ethnographic researchers looking into care and child rearing have pointed out that care is “a multidimensional experience that goes far beyond the provision of physical needs.” (Bray, 2004: 9; see also Dawes, 2004; Swartz *et al.*, 2005). Care is a complex concept that embraces “various physical, social, emotional and developmental aspects of need, bound up together” (*ibid.*). In their theory, however, Barnett and Whiteside single out only a possible reciprocal dimension of care. While the expectation of reciprocity in care may certainly be

present among the Xhosa women in the sample (Bray, 2004), the provision of education as an element of care, might also be a caregiver's response to different aspects of his or her children's needs. Offering a child the chance to receive education so that he or she could gain more knowledge, would, for example, meet the child's developmental aspects of needs; providing the child with the opportunity to go to school and hence share time with friends and peers, would respond to the child's social aspects of need.

Not only is care multi-dimensional but also different standards of care are socio-economically, culturally, and historically determined. "In this way, living conditions ... and family arrangements ... influence the way children are raised..." (Dawes, 2004: 5). Apart from these, the caregivers' (psychological) well being will also have its influence on the care provided to children (ibid). Through its negative impact on a household's economic status, its possible consequences for the extended family structures, its effect on a caregiver's physical and emotional well being, etc., HIV/AIDS can evidently have a significant impact on the way in which children are cared for. However, the disease is clearly also "only one" of the contextual factors influencing care. In their roles as providers of education, caregivers will inevitably also be influenced by other circumstances, such as family arrangements, living conditions, the historical context of education, and the current context of unemployment and affirmative action in South Africa – most of which, I believe, might be motivating (Black) South Africans in general to invest in education, and might in fact be pushing HIV-affected mothers to value education even more than non-affected women.

## **Family Arrangements**

Surveys and ethnographic work have indicated that multiple and "fluid" family forms with different caring responsibilities co-exist "and have been prevalent in South Africa before AIDS-related pressures entered the dynamic of care arrangements for children" (Bray, 2004: 2). This finding holds, more specifically, also within the Cape Town Metropolitan Area: data from the Cape Area Panel Study (CAPS)<sup>2</sup> reveal a great diversity of household types. Household size is generally not large, with the average being 4.2 people per

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<sup>2</sup> CAPS comprises various survey waves whereby an original panel of almost 5000 adolescents (aged 14-22 in 2002, the start of the study) is being interviewed several times over a period of at least 5 years. CAPS has been designed with the aim of gathering more specific information on the youth in the Cape Metropolitan Area, especially looking for determinants of schooling, unemployment and earnings of young adults. In doing so, CAPS means to supplement data collected through the Census, The October Household Survey and the Labour Force Survey.

household (Cape Area Panel Study, 2005). This rather small household size does, however, not imply that the majority of households would be nuclear. Whereas such nuclear households are indeed the norm among White and Coloured young adults, one in four African young adults were found to live in “the extended two-generation household”: a household which consists of the young adult, his or her parent(s), perhaps (a) sibling(s), and a more distant relative (Cape Area Panel Study, 2005). In Khayelitsha, the area of this study, the average household size is 5.45, slightly larger thus than that of the complete CAPS sample, but again the most common household type is the extended two-generation household (author’s own calculations of CAPS data).

Furthermore, a large number of South African children do not live under (double) parental care. Considerable numbers of children grow up without fathers present, with figures on the Cape Town Metropolitan Area as high as 39%, data from the Khayelitsha Mitchell’s Plain survey indicating 36% (Bray, 2004). Figures for Khayelitsha paint an even more dramatic picture, with 56% of children under the age of 18 living without a father (author’s own calculations with CAPS data). A smaller, but still significant proportion of children live without a mother: Bray mentions between 5.2% - 12.9% (Bray, 2004), but CAPS figures show 26% for children under 18 in Khayelitsha (author’s own calculations with CAPS data). Other surveys found that half to three quarters of South African households are female-headed and that no more than 12.5% of these women have a co-resident partner (Brandt, 2005; See also Russell, 2003). Census 2001 data for Khayelitsha show that more than 50% of the women are unmarried (Census 2001, author’s own calculations). It might seem then, that caregiving is very much a female responsibility, with only a small number of women being able to rely on a partner to share that responsibility.

Moreover, research has indicated that the majority of maternal orphans do not live with their biological fathers, and that most children who become orphaned as a result of HIV/AIDS, are cared for by members of the extended family (Case and Ardington, 2004; Bray, 2004). Current analysis of extended household size, however, indicates a substantial and persistent decline in that size (Wittenberg and Collinson, 2005), which might indicate that these networks of care might themselves be weakening. Furthermore, stories of orphaned children being abused, neglected or economically exploited by their kin (see e.g. Giese *et al.*, 2003), might make the extended family network an unattractive future option of care to an HIV-positive mother.

Thus, it seems that a fair number of HIV-positive mothers might not be able to rely on their children’s biological fathers to take on the care of their child(ren) after their death, nor is it clear whether the extended family will - in a reliable way - be there to take in the children.

It remains largely unclear what these changing dynamics mean for caregivers' decisions on how to prepare their children for a future without them. In the context of poverty, LeVine hypothesised that "parents ... possess the "universal" intent of optimising their children's survival and adaptation, tuned to local conditions in which they live" (LeVine, 1998, in Durbrow *et al.* 2001).

Thus, rather than assuming that caregivers would no longer be interested in investing in their children's future, I believe they might just as well look for opportunities to "optimise their children's survival", and to make them more independent of care by their partners, or by extended family members. Offering children education might, in fact, be one such opportunity the mothers would grasp.

## **Education in post-apartheid South Africa: some facts**

Education-related research in South Africa cannot overlook the historical context within which e.g. values around education have been shaped. Under the previous apartheid regime, racial segregation (into "Black", "Coloured", "Indian" or "White") was reflected also in the educational system, with far fewer resources flowing to 'Black' schools than to 'White' schools e.g., and black pupils being allowed only a certain, lower level of education than their White or Indian peers (Jansen and Taylor, 2003).

In abandoning its apartheid past, South Africa chose to install basic education as a right for all citizens. Racially defined departments of education were abolished and a single educational system<sup>3</sup> was installed. It included compulsory education for all children from the age of 7 till the age of 15 (or till the learner reaches grade 9, whichever occurs first), thereby for the first time making education compulsory also for the black African majority. One of the tools used to materialise the redistribution of education has been the development of a system of democratic, united and non-racial public schools<sup>4</sup> that must "admit learners and serve their educational requirements without unfairly discriminating in any way" (South African Schools Act, 1996, 5(1)). School choice is not necessarily

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<sup>3</sup> There are four years of elementary school, followed by four years each of middle and high school. In order to gain access to higher education, students must pass the Matric exams at the end of grade twelve. Once students have passed these exams with the required average, they are eligible to apply to either a university or a technikon. Students generally enter higher education between the ages of 18 and 20.

<sup>4</sup> The only other types of schools are the independent, or private, schools that can be established or maintained by any person at his or her own costs (South African Schools Act, 1996).

bound to zoning: parents can now decide to try and send their children to school, also outside their own area of living<sup>5</sup>.

However, despite all good intentions, high public expenditures on education<sup>6</sup>, and fairly high enrollment rates<sup>7</sup>, many inequalities within the South African schooling system remain. The school funding system is such that government investments in public schools have to be supplemented by school fees and other (private) sources for schools to be able to operate (Cassiem and Streak, 2001). Thus, schools rely on the additional incomes provided by school fees, especially to cover costs incurred by “maintain(ing) school buildings and services, pay(ing) electricity, water and telephone accounts and purchas(ing) equipment such as blackboards, chalk and paper.” (Giese *et al.*, 2003: 188). Evidently, schools in poorer, black areas will find it difficult to maintain the same standards of quality as those in richer, white ones.

Consequently, in their search for the best possible opportunities for their children, some parents attempt to send their children to school outside the townships. In her ethnographic work on youth in New Crossroads, a black African township near Cape Town, Ramphele states: “increasingly parents living in New Crossroads were giving up on the township school system and sending their children to schools outside the township. They clearly felt unable to do anything about the nearby schools and saw the opening as an opportunity”. Parents were found to send their children to former coloured schools: “under the apartheid dispensation these schools had better resources, and better matric performance records. ... The best option, however, was access to former white schools” (Ramphele, 2002: 94). Coloured and white schools are also more expensive, however, and some schools – whilst acting unlawfully – have been found to refuse children whose school fees cannot be paid.

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<sup>5</sup> Schooling is, however, not completely free of zoning. According to the National Education Policy Act (1996), “feeder zones” may be established by the Head of Department, and “after consultation with representatives of governing bodies... in order to control the learner numbers of schools and co-ordinate parental preferences”. A learner who lives outside the feeder zone may nevertheless seek admission at whichever school he or she chooses (South African Schools Act, 1996).

<sup>6</sup> According to the Human Development Report of 2004, South Africa spent 5.6% of its GDP on education in the period between 1999 and 2001. As a matter of comparison: the United States spent 5.6% of its GDP on education, the United Kingdom 4.6%, for that same period (UNDP 2004).

<sup>7</sup> It is estimated that approximately 12 million children are currently in school (Jansen, Taylor, 2003: 7), and according to UNDP data, the net primary enrolment ratio for the year 2001-2002 was 90 %; the net secondary enrolment ratio for the same period was at 62 %. The ratio of girls over boys in primary education is an estimated 0.94, one of Africa’s lowest gender disparities in education (UNDP, 2003: 198-227; Cf. also Jansen, Taylor, 2003).

Inequality thus continues to exist between schools, but also among students from the different racial groups. Analyses of the first wave of data collected by the Cape Area Panel Study have indicated that grade attainment differs greatly between African children and their white or coloured peers. At the age of six, almost all children from the different racial groups that are in school, are in the same grade. African children, however, have been found to fall behind white and coloured pupils almost immediately. By the age of fourteen, white and coloured children are one grade ahead of their African peers. By the age of nineteen, white adolescents have completed an average of twelve grades, whereas coloured adolescents have then completed just over ten grades. Importantly, African adolescents do fall behind, but are also seen to stay in school longer, and at the age of twenty-two reach the same average grade attainment as coloured adolescents (Cape Area Panel Study, 2005). However, at the age of twenty-two, approximately 50% of African adolescents are out of school, without having completed their matric exams.

Educational attainment thus still differs greatly in the new South Africa. Various factors may be at the basis of that difference: research has shown that parents' schooling has a significant effect on the way in which children progress through school, as does a father's earnings, and community and neighbourhood characteristics, albeit to a smaller extent (Lam, 1999). Another possible factor of influence might be the value attached to education by both the pupils and their caregivers (as that value would e.g. influence financial and academic efforts one is willing to put into education). However, research looking into the educational expectations of adolescents and their households in the Cape Town Metropolitan Area found that expectations in the black African population group were, in fact, very high: 93% of black adolescents expected to complete matric, 87% of the households expected the young adults to pass matric. The researchers concluded that these findings might "reflect (at least in part) positive values regarding education" (Beutel and Anderson 2004: 27).

## **(Un)employment and affirmative action**

In its attempt to rectify the racial inequalities created under the Apartheid regime, the new South African government did not only implement changes in the educational system. Among other measures, the ANC government also installed policies of affirmative action and Black Economic Empowerment, which were designed to promote employment of especially Black African people, and the growth of businesses owned and led by Black South Africans. The idea behind these policies was clearly that they would benefit all those people who had previously been disadvantaged: the intention to provide better opportunities and upward mobility for *all* black people was also voiced as such,

thereby undoubtedly creating the belief among many of the public that their (and their children's) lives would only change for the better in future, regardless of them being HIV-affected or not.

However, contrary to the intentions, the result of the above mentioned policies has been “an accelerating growth of the African elite and middle classes”, but little or no changes in the situation of the poor, unskilled black labour force (Seekings, 2004). In fact, formal employment of unskilled labourers has dropped significantly since the end of Apartheid, and unemployment in the country has only continued to increase since 1994, now standing at 30 to 40% (*ibid*). The value people attach to education in this country may thus also be driven by the reality that unemployment is mostly found among the unskilled, those with no, or relatively low levels of education. In this respect, and linking back to the economic theory that is built on by Barnett and Whiteside, it should also be mentioned that studies of the returns to education in South Africa have indicated that the “rates of economic return to schooling increase with the level of education attained” (Keswell and Poswell, 2002).

From all of the above, it is clear that no simple hypotheses can be formed regarding educational decision-making among HIV-affected caregivers. It is obvious that various contextual factors will have their role to play in that decision-making process, and in the way in which caregivers value education. The following findings are the result of a micro study on what exactly that value entails, and how being HIV-positive may or may not have an impact on that.

## **In-depth research: aims and methodology**

### **Aims**

The broader aim of the overall study into educational decision-making and the role of values within that decision-making, in fact, started off with several aims, the most relevant of which for this paper were:

- To explore the way in which South African children and caregivers make decisions about their education, or their children's education;
- To investigate how, and to what extent HIV/AIDS influences children's and caregivers' values and attitudes in life, and more specifically, towards education;

- To gain insight into the way in which affected caregivers view their future and their children's future, the importance of education within that perceived future, and the values affected caregivers wish to pass on to their children.

For this first qualitative part of the study, however, I limited myself to the following two specific research questions:

- What value do HIV-positive mothers attach to education?
- How does life-expectancy affect that value?

## Sampling

The study sample comprised ten HIV positive caregivers, the majority of them living in Khayelitsha, a low income settlement in the Cape Town Metropolitan Area. Khayelitsha has a relatively high HIV prevalence, but at the same time, a considerable range of HIV-related services. One such service is the Wola Nani Support Group, through which five of the women were sampled. Wola Nani is a Cape Town based, non-governmental organisation (NGO) established in 1994, which sets up programmes “to help HIV+ people in the local community cope with the emotional and financial strains brought about by HIV and AIDS” (Wola Nani, 2005). Activities organised by the NGO include support groups, income generating activities for some – but not all – of the people in those support groups, distribution of food parcels, etc. (Wola Nani, 2005).

The study was introduced to participants of the Wola Nani support group, by the researcher and an isiXhosa speaking researcher at the Wola Nani offices in Khayelitsha. Information letters were handed out in both English and isiXhosa, and consent forms were handed to and signed by those women who were interested in taking part in the study. Those women who were later interviewed, were asked whether they agreed with their children participating and, if so, signed a consent form as a child guardian, allowing us to contact the child to also ask his or her consent to take part in later phases of the study.

The other five women in the study sample were selected out of the Bambanani Women's Group, a group of HIV-positive women who have been working with the University of Cape Town (UCT) since 2001. Originally, the group was central to another AIDS-related intervention: The *Longlife* AIDS-Art advocacy programme. This intervention was initiated by the AIDS and Society Research Unit (ASRU) at UCT and Medicins Sans frontiers (MSF) in 2001 and was aimed “to support the AIDS treatment agenda by publicising the life narratives and art of HIV-positive people” (Almeleh, 2004: 1). The programme resulted in a book, *Longlife: Positive HIV Stories*, launched in 2003; the Bambanani

Women's Group has since then been presenting their works of art (i.e. life size bodymaps) "at lectures, conferences, on radio, in the print media, universities and exhibitions." (Almeleh, 2004:6). Of the Bambanani Women's Group, those women who took part in the study again received information about the research and were asked consent before starting the study.

I aimed at selecting caregivers, independent of gender, of either their own biological children, or children under their care, living in their households. However, in practise, I selected mothers of children of school going age, all of whom were HIV-positive. Within the sample of women who were individually interviewed, two of the mothers were on antiretroviral treatment, three were not. However, given the intrinsic nature of the sample, i.e. HIV positive caregivers who were all to some extent involved in support groups, all women obviously had a good knowledge of the disease, and of the existence and accessibility of antiretroviral treatment. As a result of their participation in support groups, they were also more used to talk about their feelings than other HIV positive caregivers may perhaps be. I am aware of the fact that this has undoubtedly created a bias in my sample, but I nevertheless believe the findings of this study can shed valuable light on the research questions mentioned and can be of help in further hypothesis development.

## **Interview techniques**

The five women selected from the Bambanani Group were interviewed during a two-hour group discussion, using a semi-structured questionnaire. The aim of this first group discussion was to gain some understanding of the value of education held by HIV-affected caregivers – in this case all HIV-positive mothers. A number of different leads were later explored in the individual interviews with the caregivers selected through Wola Nani. They were interviewed in-depth, during approximately an hour and half, again making use of semi-structured questionnaires. Probing questions were used to allow gaining deeper insight into topics including childhood, history of care, their own schooling and that of their children, and the experience of living with HIV/AIDS. Story-telling techniques were used to elaborate on the value of education. Examples of such exercises were telling a story about: a girl or boy of school-going age who was not in school; a world without education; etc.

All interviews were conducted in an informal, conversational approach. At all times, special care was taken not to ask too sensitive or threatening questions of the respondent. The women also knew they could always refuse to answer a question. In order to allow them to express themselves as freely and openly as possible, an isixhosa speaking researcher joined the interviews when the women asked for it.

## **Data analysis**

All interviews were tape recorded and later transcribed. Field notes were kept by the researcher after each interview, and used as complementary material during the analysis. All information was thematically analysed. The record of the focus group was analysed, looking at the contributions of each individual respondent, yet never losing sight of the context and dynamics of the group as a whole. The results presented in this paper are based mainly on the individual work, but supplemented as appropriate with findings from the focus group.

## **Research setting**

At the time of the study, all participating women lived in Khayelitsha, a resource-poor township approximately 26 kilometers from Cape Town, one of the largest cities in South Africa. Census 2001 data indicate a population of approximately 329,000, the majority of which (67%) was below the age of 30. According to the Census data, the unemployment rate was approximately 35%. Earnings were low: a majority of those people who did earn an income, earned less than R1,600 per month. The majority of households in the township lived in an informal dwelling. Most (94%) of children of compulsory school going age (i.e. aged between seven and fifteen) were enrolled in school. Many (79%) of adolescents aged between fifteen and eighteen were also in school. Among young adults between fifteen and twenty-four, only 22% had a matric or post-matric qualification. With an HIV-infection rate of 22% among women who attend antenatal clinics, Khayelitsha is believed to have the highest prevalence rate within the Cape Town Metropolitan Area (Development Action Group, 2003).

# Research findings

## *Relevant details of participants in the individual interviews*

		Nobahle	Nosipho	Lungelwa	Nokutheta	Xoliswa
<b>Demographics</b>	Age	31	35	31	33	23
	Gender	Female	Female	Female	Female	Female
	Relationship	Single	Married	Single	Married	Single
	Children	2	2	2	2	2
	Employment	Unemployed	Unemployed	Unemployed	Unemployed	Unemployed
<b>Household structure and resources</b>	Size	3	3	8	4	3
	# adults	1	2	5	2	1
	# children	2	1	3	2	2
	Resources	Child support grant Food Parcels Wola Nani	Husband's income Grants Wola Nani parcel	Brother's income Mother's income Child support grants Disability grant Food parcels Wola Nani	Husband's income Child support Grant Food Parcels Wola Nani	Child support grant Food parcels Wola Nani Sister's support
<b>HIV status and treatment</b>	Diagnosis	2002	2000	2002	1994	2002
	ARV	No	Yes	No	Yes	No
<b>Education</b>	Highest level	Standard 6	Grade 12	Grade 12	Standard 8	Sub-B
	Currently studying	Yes	No	Yes	No	No
	Children in school	Yes	Yes	Yes	Yes	Yes

## Life stories<sup>8</sup>

By providing a brief description of each of the women who participated in the individual interviews, I want to offer a number of interesting elements out of these mothers' own family and educational backgrounds which may prove useful when reading through the analysis. It is not my intention to offer a conclusive summary of everything that was said by the women, rather to provide the reader with some understanding of their past and present life contexts, which may have influenced the value they attach to education.

### Nobahle

Nobahle is a 31 year-old, single mother of two boys. She was born in the Eastern Cape where she spent most of her childhood years in her grandmother's home, together with her two brothers and sister. Her mother was absent most of the time, but returned to the house and the children when Nobahle was about 17.

<sup>8</sup> Throughout the paper, pseudonyms are used to refer to the women who took part in the study, in order to protect their identity and insure confidentiality.

Just before that, Nobahle and the other children had been through a period of moving from one aunt to another, trying to get used to the different sets of rules maintained in each of the families. Nobahle described the bond between her and her mother as weak, and as uncaring. More than once, her mother claimed she did not understand the necessity of Nobahle going to school. At the age of 19, Nobahle finished Grade 9, but was not allowed to continue her education, despite attempts by her school principal and teachers to convince her mother of the necessity to do so, and even to look for alternative ways to fund Nobahle's schooling.

Nobahle left the Eastern Cape in 1999, together with her youngest son, to come and look for a job in Cape Town, leaving the oldest boy under the care of her mother. Four years later, in 2003, she went to fetch her firstborn and now lives with the two children in a shack in Khayelitsha. Nobahle says the relationship with her oldest boy has been a bit problematic, as she had to forge ties with him again after four years of absence. She tries to (re-)build a bond by talking and interacting with him a lot, and frequently seeks advice from counselors and from school on how to interact with him, as, she says: "This is new to our culture..".

The two boys are in school, both in Khayelitsha, and there appears to be a lot of interaction between the school and the parents, and between Nobahle and her children when she tries to stimulate them to do well in school.

On how HIV/AIDS may have changed her relationship with her children, she says: "it has brought us closer.. Me as a parent, I want to embrace my children as much as possible, just to reassure them that whatever happens, I love them. ... To always spend as much time as possible with each other. .. I'm trying to prepare them for when I'm not here."

Education, for Nobahle, is something that she has been deprived of, just as she has been deprived of a strong bond with her mother, or another caring and truly understanding, motivating parent or carer. She is determined now to be another sort of parent to her own sons. She wants to learn as much as possible about being a parent and when things are not clear to her – e.g. how to bond with a son she has not seen for four years – she seeks professional advice from counseling organisations in the community or at school. Before disclosing her status to her son, she also sought advice within the support group. Although Nobahle is a very outspoken and seemingly very confident woman, she frequently expressed concerns about the future and who would be taking care of her children when she would no longer be there. She says she avoids thinking about the future too much, as it is such an uncertainty and in the time left simply tries to be as much of a caregiver as possible to her children. She has therefore started a home management course that would allow her to earn some more money and to take better care of "all the needs of her children", especially food, clothes and

education. Because she is so worried about the future and about who will look after the children, she pushes especially the eldest one as much as possible to do well in school so that at least when she dies, he will be able to take care of himself and the youngest one. Similar to that, in the house, she teaches them especially those things that will help them to be independent, reassuring herself that way that they will be able to care for themselves and each other.

## **Nosipho**

Nosipho is a 35-year old, married woman who lives in a shack in Khayelitsha, together with her husband and her six-year old son, the youngest one of her two children. The other child, a daughter of thirteen, is staying with Nosipho's aunt in the Eastern Cape. Nosipho was herself raised by that aunt in the Eastern Cape, and from her story, it seems Nosipho had very little emotional care and support available to her. Her aunt looked after her materially, but had emotional problems, Nosipho would go to her grandmother, who was not always available. She fell pregnant with her first child at the age of 22, when she was doing her matric year, yet managed to finish and pass her matric exams. After having stayed home for a year to look after the child, Nosipho attempted a number of times to go back to school, but did not manage to get through any further years of education.

At the age of 23, Nosipho was abused by a family friend and, as she says herself, she started to "act out, badly". Nosipho believes her aunt wanted to prevent her from getting drawn into a negative spiral, and therefore persuaded her to go to Cape Town and look for work. Her aunt insisted Nosipho's child stayed with her, so that she could take care of her and provide her with education.

Although her daughter lives in the Eastern Cape, quite a lot of interaction seems to be going on between Nosipho and the child. They make regular telephone calls and then discuss personal matters including HIV. Since Nosipho disclosed her status to her daughter, the latter seems to be keeping an eye out on her from a distance, e.g. asking how she is feeling. When she is visiting, she checks whether Nosipho takes her medicine. Education and schooling also regularly seem to be discussed. The daughter goes to a multi-racial school and Nosipho, "encourages her that she must not play, she must read, because I want her to pass, ... I want her to be something I failed to be...". Within that discourse of reaching a "better future", there is also the necessity to do well, as well as possible in a short frame of time, so that the child will eventually be able to look after herself, and her little brother: " even if I die, I'll know you that are somebody, you can take care of your brother...".

Nosipho's youngest child goes to a non-mixed school in Macassar, an area of Khayelitsha, but Nosipho's ambitions are to send him to a multi-racial school as well. Nosipho's care for the boy seems to take a predominantly emotional and materialistic form. There is less motivational interaction, perhaps simply because she considers him too young for that (he is not yet seven): "With him I don't have much time, because he is too playful. ... I have to prepare food, and he'll go to bed". When talking more generally, however, it is clear that for this child too, she wants him "to take school seriously, .. to respect elders, .. and to take care of (him)self(s)."

Interestingly, in her "story about a boy who is not in school"<sup>9</sup>, Nosipho referred to a child who was part of a newly formed household, but not recognised by the husband as his own and therefore treated less favourably by both his mother and his new father. His lack of feeling of belonging – both in school, due to lack of material, clothes, .. and at home - , is what eventually leads him to leave school and move to a friend's home where "he will get care". When that care disappears after a while as well, he will take to the streets and "meet other kids". It is not clear whether she is here projecting her own feelings and fears about her current husband possibly rejecting or not supporting her firstborn and thereby undermining that child's chances to a better future. What is a striking element in this story, however, is the feeling of belonging that this imaginary child would look for, outside the family. Perhaps by deciding to keep her daughter in the Eastern Cape, Nosipho is able to ensure the child with a stronger bond to the family than when she would have her move in with her and a man who is not the child's father.

## **Nokutheta**

Nokutheta is a 33-year old, married mother of two boys. She spent most of her childhood in the Eastern Cape with her grandmother, but dropped out of school at the age of thirteen due to a lack of money to pay for the fees. Although her grandmother tried, she was far from able to satisfy the (basic) needs of all of the children that were under her care. Nokutheta decided to go to Johannesburg together with a friend, to find a job and thus help support the family in the Eastern Cape. She failed to find a permanent job, but did find boyfriends who could support her. All or part of the money that she got from the boyfriends or a temporary job, she sent to her grandmother, mother and sisters in the Eastern

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<sup>9</sup> One of the projective questions in the individual interviews asked the women to tell a story about a girl or a boy of approximately 13 years old, who was not in school. The women were asked to describe this child: who is he or she, what would be the reason the child is not in school, how he or she feels about that, what would his or her future life look like, etc. This question was not asked of all respondents, but only of those with whom time permitted and who felt confident enough to work through the exercise.

Cape, where the money was, amongst others, used for food and to send younger siblings to school. She returned to the Eastern Cape after two years and decided to use some of the money that she had kept to go back to school, because, as she says herself: “ I needed so much to go to school, because I was very clever, but the thing was money, there was no money at all...” Nokutheta eventually managed to finish grade 10, but then fell pregnant and dropped out: “That was it, I couldn’t move, I went back to suffer again.”

At the age of 18, she left for Cape Town to look for a job, leaving her son with her mother and posting money whenever possible: “ My younger sister was still at school and then I would send her money until she’s... she’s finished now.” Four years after she came to Cape Town, her mother came as well, bringing Nokutheta’s child with her. Today, Nokutheta is married and has just become mother of a second child. She describes a strong and intimate interaction with her children, also with her eldest boy. They talk about “personal things”, they tell stories, etc. Nokutheta has disclosed her status to her eldest son and the boy now takes a caring role towards her mother by asking her regularly how she is feeling, whether she is not ill, and so on. Of her husband she explicitly says: “he loves my child like he was his own”, and it is clear that both adults in the house will go to great lengths to satisfy the children’s needs.

Nomthetho seems to focus on the intrinsic value of education. There is the instrumental side (“you can get work easily if you are educated”), but also, repeatedly: “you can read and do things, ... you read and write.” For her children, she values education highly, and, to a certain extent leaves the schooling-decisions up to the child. For example, her oldest son indicated that he no longer wanted to go to a school in Khayelitsha, as he felt “education is poor” there. Nokutheta leaves the school choice up to the boy: “My child go to Salt River, and he came back and he said that he found the school”, but worries about where she is going to get the necessary funds for him to keep going there. He does go there now, but has already asked to move to a white school, as he finds there is too much crime, dagga smoking etc in his current school. Although she has been very ill the last few years, Nokutheta is adamant that she will go to lengths to ensure her child’s education: “I like him to have what he wants, no matter I have nothing, but I’m trying my best... my head is like bursting... My CD4 count, now it goes up, now it’s 400, so I think I will look for a job now ...”. Nomthetho’s support for her children seems very emotional – interaction is high, reading stories, etc.. – but again the instrumental dimension of care becomes quite clear when she is talking about her and her children’s future: “ Every day I’m praying for God to give me more years, for me to survive, at least for one of my children to achieve, mainly him, then this one will (care for ) that one.”

## **Xoliswa**

Xoliswa is a 23 year old mother of twins: a boy and a girl of ten. She lives in a shack with her two children, in Khayelitsha. She is unemployed, looking for a job, but as she says: “she can’t find a job, because she’s not educated. And her heart is very sore about that. When she wants to ... go to look for a job, she can’t go because she can’t say anything in English to anybody” (Xoliswa, translated by Viktoria).

Xoliswa grew up in the Eastern Cape, her father worked in Johannesburg, her mother left her and her siblings (one brother and two sisters) when she was ten. The children were taken care of by an uncle (“father’s brother”) who moved in to look after them, but had himself very little money. He could provide them with food and clothes, but not with school fees; Xoliswa dropped out of school when she had completed grade 2, at the age of nine. She stayed at home, feeling excluded from friends and very trapped: “because when the other friends go to school, they’re always at home, ... just staying at home doing nothing, don’t know how to write, don’t know how to do anything.. Their friends were educated and go to school each and every day, but them, they are just staying at home doing nothing ...”

Xoliswa fell pregnant at the age of thirteen, shortly after which her elder sister – who earlier already migrated to Cape Town – decided to have both Xoliswa and a younger brother come to Cape Town and to support them. In a very abusive environment, the sister stole from her own husband to be able to provide Xoliswa and her brother with food and clothes. Until today, the care and support bond between Xoliswa and her elder sister is very strong, and appears reciprocal, although financial support flows mostly from her sister to herself than vice versa. The only other support person for the two sisters that was frequently mentioned by Xoliswa, is an older woman in the neighborhood who looks after the children and offers practical advice when necessary.

Xoliswa described the relationship with her children as very close and caring, with a lot of interaction, also about their education. For Xoliswa especially, education is a very important instrument to “a better life”, to employment, and to care: “she wants them to be educated, they can work after that, after that, if one of them needs help, they can help each other...”. In her mind, it is an absolute necessity for the children to be able to get an education. Getting especially that which she has been deprived of: learning to read and write, being able to communicate and thus also to ask for help, look for a job, and especially also: to help other people. The impact of her illness on these aspirations for her children seems to be a hastening in her wish to be able to help them achieve

exactly that: “she don’t want to get sick while her children are still at school.. maybe they can drop at school..”

Asked how she would describe a “good carer”, Xoliswa replied that that is someone who stays together with the children and “tells them what is wrong and right... sit down and talk to your children.” Next to that, a caregiver must provide especially material care, on the most basic level, that is: “you must try by all means to give your child ... everything ... that he or she needs.” She talks about food, clothes and schooling, so that a child doesn’t have to go out on the street and ask other people for it.

## **Lungelwa**

Lungelwa is a 31-year old mother of two sons. She spent a happy childhood with her grandparents in the Eastern Cape, until her grandfather died. Aged eleven, she moved to Cape Town, to come and live with her mother, stepfather and aunt. The family moved several times, from Gugulethu, Langa and later to Khayelitsha, where she finished grade 12, after which she “couldn’t find a bursary ... so decided to go and help her mother”, who was a domestic worker. Lungelwa herself has very nice memories of her time at school. Her motivation to always try and continue school as a child seems to have come mostly out of an ambition to do better and reach a better standard of living, higher levels of luxury.

Today, Lungelwa lives in a large, complex family structure, with her brother and his wife, her sister, her cousin, children of the sister, etc. It is a situation of which she says it causes her so much stress, as “she has to be mother to all of them”. She is very consciously considering moving out of the house into a small shack with just her two children – a possible decision which comes across as a coping strategy to deal with that stress. She is also adamant that she does not want a husband: she wants to make it on her own, just her and her children.

She describes her care for her children as wanting them to “get each and everything that they want”. She aims to satisfy all their needs “like clothing, eating, and when they are sick”. She seems especially sensitive to the fact that they might be deprived of things that other children who live with both parents, would get.

Her oldest son is in school, the youngest one – who is three – stays at home, but “when there is money”, she wants to send him to crèche. Interestingly, Lungelwa herself is back in school – which might indicate that she values education for herself and her child of compulsory school going age more than that for the younger child. With regards to her own education, she focuses

especially on the fact that it will allow her to be a better caregiver: “I am doing this for my children and for my own sake, you know, to give them a better future.” ... “so that they mustn’t be poor like me when they grow up”.

Her illness seems to have made all aspects of caregiving more important: “ I always pray to God that he can keep me long to raise my children... I want to do everything that they want, like school, ...”.

## **Summary of the key findings**

### **The value of education**

In the interviews, it was my intention to get an understanding of the value caregivers attached to education: did they believe education was important, and why, or why not? I wanted to get a feeling of the different dimensions education had for the women. To that end, they were probed to describe school during their own childhood, what kind of places their schools were, how they felt at school, what was nice, and not so nice, and exactly why that was. Not only for themselves, but also in their roles of mothers, were they asked to describe whether or not they believed education to be important, and exactly why that was the case.

From the above, it has already become clear that, without any difference, all of the women defined education as “very important”. They identified several different dimensions of education, many of which, especially the instrumental ones, seem to form very intrinsic parts of the way in which they view themselves as caregivers. Other dimensions, such as “social space” were, to a large extent, related to the background of poverty and inequality, and the ability to - just for part of the day - escape the hardships of every day life at home.

### **Education and school as a social space**

Although many women talked about the hardships of their time at school – physical abuse by teachers was brought up regularly, e.g. when coming late to school, not wearing proper clothes, etc. – school to them was nevertheless often a happy place. It was a social place, where they as children were familiarised with feelings of equality and belonging. School was often a place where they could forget about the demands that were placed on them at home, or the way in which they were (mal) treated at home.

- “It was nice, we were all from the same background, there was no rich or poor...” (Nobahle)
- “I met friends. We shared food, but also stories. ... I forget how I am treated at home...” (Nosipho)
- “It was nice there... “(Lungelwa)

When they, for whatever reason, were no longer able to go to school, they felt lost and excluded from that social network that was so important to them.

This is not an uncommon view on schooling to be found. Other, school-based research has found that school is to many children what it has been to the mothers in my sample: a social place to be among friends, regardless of the fact that many schools – certainly also in South Africa – are often described as “unsafe places” for children (see Brookes *et al.*, 2004; Giese *et al.*, 2003; Bennell *et al.*, 2002; Coombe, 2001; Human Rights Watch, 2001).

## **Education as the only way to a better future**

Apart from the social dimension, education clearly has a very strong instrumental value. When asked why exactly the women thought that education was “very important”, strikingly, all of them in one or other way referred to the fact that education was “the only way to gain a better life”, a better future – an element which also very strongly came out of the focus group discussion.

Reflecting on their children’s education out of their own previously and presently deprived situation, the carers rigorously urge their children to do well in school, to take all the opportunities they can, so that the children could succeed where they failed:

- “Without education, you can go nowhere... You need to be educated to have a better life, there is no way out..” (Nobahle)
- “There is no future without education” (Nokutheta)
- “I want her to be something I failed to be”(Nosipho)
- “I want him to go where I couldn’t reach” (Nokutheta)

Some of the mothers have even further pursued this notion of “a better future through education”, by themselves starting school again. Both Nobahle and Lungelwa recently decided to go back to school. As will become clear below, schooling is also for them an instrument that will enable them to reach a better life, i.e. by providing them with a better chance of finding a job. Interestingly, however, in their explanations about their decision, it is clear that even their own education to a large extent remains instrumental for their children’s future:

- “I am doing this for my children and for my own sake... to give them a better future. The future I didn’t have when I was at their age.” (Lungelwa)

## **Education and schooling as the road to employment and independence**

Within that same instrumental dimension of education, perhaps at a more concrete level, is the fact that education, doing well in school, and getting as high an education as possible, is the only way to find at least “a job”, but especially a “good job”. Again, this evaluation of education seems to a large extent based on the caregivers’ own context of unemployment: it is due to the fact that they themselves dropped out of school, or never completed higher levels of education, that they are now unemployed. They now desperately want their children to do so much better than they have done and do now:

- “I want them to be educated so that they can work after that” (Xoliswa)
- ‘My children must have better education, so that they can have better jobs’ (Nosipho)

This dimension is also again one of the reasons why two of the women have started some form of education for themselves. As Nobahle states:

- “I started home management courses so that I have better chances of finding a job” (Nobahle)

The above mentioned dimensions of education should not come as a surprise. They are acknowledged by other studies looking into e.g. parenting in poverty and African families’ expectations for their children’s future, their employment etc. (Watson-Gegeo, 1992; Corsaro-Rosier, 1992)

There is, however, one more, frequently mentioned aspect of education that may be somewhat more surprising: education as means to care.

## **Education creates the ability to care**

The fact that getting and completing (a high level of) education would create the ability to care came up several times in the conversations, not only in the sense that one child would be able to care for his or her sibling(s), but also for others in need.

- “You’d better study hard, so that... even if I die, I’ll know that you are somebody, you can take care of your brother..” (Nosipho)

- “I want them to be educated so that they can help each other” (Xoliswa)
- “Education is very important. ... I would like them to grow up and ... care about other people, the poorer people.” (Nokutheta)

I will return to this point when discussing the impact of HIV/AIDS on the caregivers’ life expectancy, but I do already want to mention that this dimension of education seems very much related to the caregivers’ need to prepare the children and themselves for the time when they will no longer be able to perform their caregiving tasks. Within the context of HIV/AIDS and the uncertainty about who will be taking on the care for the children after the mother has died, the caregivers wish to prepare their children for an independent life in which they will be able to take care of themselves and each other.

## **The intrinsic value of education: knowledge**

Apart from the several instrumental dimensions of schooling, an important element in the women’s stories was the fact that education has a much more intrinsic nature as well. Getting an education gives you knowledge, which evidently can be used as a tool for something else – without knowledge, there can be no communication e.g., hence no possibility to look for a job - but which also clearly exists as a fact *per se* in the caregivers’ evaluation of schooling. However, whereas the previous instrumental dimensions of education were very clearly used as arguments for which their children should be in school, this more intrinsic element came up mainly in the women’s stories of why they themselves had liked school, and why they would have wanted to stay in school themselves:

- “I like it: you read and write...” (Nokutheta)
- “I have to go to school, I will have more knowledge. ... At school, I meet new ideas..” (Nosipho)

## **Future-orientedness in an era of HIV/AIDS?**

The fact that the sample existed of women who in some way have learned to deal with their uncertainty and questions around their disease through a support group, that they have a fair level of knowledge of the disease and its course, and knowledge of and access to antiretroviral treatment, will undoubtedly have had an impact on my findings regarding their views on the future and their perceived life expectancy. It is, nevertheless, important to point at these women’s remaining uncertainties about the course of their future lives, and the way in which they have come to give their caregiving another, more urgent interpretation than has so far been assumed in hypotheses as the one this paper started out looking at.

In fact, no clear conclusions can be drawn about whether or not the women have consciously come to see – or explicitly accepted – their life expectancy as having decreased. How long they still have to live, is a question that remains unanswered to all of them. Their life-expectancy has become uncertain, the time frame within which they shape their identity as caregivers, more narrow. As Nobahle says:

- “I don’t know how much time I have on this earth. ... I try to avoid thinking about the future, because it’s now frightening, uncertain ...” (Nobahle)

Within that more narrow time frame, the sense of urgency is high. There is the need to achieve more, to give as much as possible, in whatever time they may have left. Within the uncertainty of their future lives, the standards are set very high, for both themselves and their children.

Nobahle, for example, very explicitly communicates this urgency to her children. She tells them:

- “You need to use this time while I am still alive to push ... to try and pass every class, so that by the time I die, at least you are somewhere” (Nobahle)

Strikingly, the emphasis is again often on the need to get as much education as possible, not only for their children, but also for themselves. Nobahle and Lungelwa both situate their decision to get a further training or education within their more narrow time frame: it is because they may have less time left, that they now have to get more education, thereby more easily find a job and hence have a better chance of satisfying all their children’s needs for as long as still possible. The hope to be alive long enough to have provided as much care as possible for at least one of their children, so that he or she could then take further care of the younger sibling(s) resonates in all of the women’s stories:

- “I want to be working ... I pray for a job, so that I can help my kids. My children, they are supposed to be in school, also, I don’t want to get sick while the children are in school” (Xoliswa)
- “If I can at least get a job, just to, to provide for them.. It’s an uphill battle even to keep them in school... So I wish they can get an education.. Even if I’m not around, if only they can find education.. Because I don’t want them to suffer or struggle as I did in life. ... I hope God can give me enough time so that he (her son) can grow up and be independent.” (Nobahle)

- “I’m dreaming about having a job ... I will (be able to) afford to buy food and (satisfy) the needs of my children. ... Everyday I’m praying to God to give me more years, for me to survive, at least for one of my children to achieve.” (Nokutheta)
- “I hope to give them a better education. I always pray to God that he can keep me long (enough) to raise my children, ... I want to do everything they want, like school, ...” (Lungelwa)

Although contrasting with the hypotheses I started from, these findings are corroborated by those of other, ongoing research in South Africa, on care and caregiving in the context of HIV/AIDS. In a study on the psychological experiences of HIV-positive mothers and women caregivers, Brandt found that concern regarding their children was high among HIV-positive mothers and that that was “perhaps the issue which most compelled the women to confront the potential implications of their HIV status.” (Brandt, 2005: 23). Analysis by Bray of ethnographic data found just as well that parents wished to achieve as much as possible for their children while still alive (Bray, Brandt, 2005, forthcoming).

## Concluding comments

This paper has tried to look into the validity of hypotheses around a decreased interest in educational investment, as a result of a lowered life expectancy caused by HIV/AIDS. Contrary to what Barnett and Whiteside hypothesised, findings of this study indicate that HIV-positive mothers are strongly inclined to invest in their and especially their children’s education. Rather than becoming passive people who lose sight of any future possibilities for both themselves and their children, these women seek ways to adapt and cope with the changing realities they are faced with. Providing education to their children, is in their minds one way of doing so.

From the caregivers’ stories, it became clear that the will to educate and to be educated, is, in fact, very much value-based and future-oriented. Expectations about the “return on investment” were present in the sense that caregivers hoped their children would find decent jobs and would be able to provide for themselves and their own households later, but no reference was made to parents expecting to recoup the investment to their own immediate benefit. The multi-dimensionality of care resonates in these mothers’ stories, in that providing their children with education is one way in which they wish to answer all different levels of their children’s needs (i.e. social, emotional and developmental). My findings are supported by those of other ongoing studies that look explicitly into the concept of care, and the impact of HIV/AIDS thereon. Being able to provide

for children's "basic needs ... and education" was frequently mentioned by HIV-positive caregivers when asked what "good care" would imply to them (Bray and Brandt, forthcoming).

From the respondents' stories, it is, however, also clear that the mothers are very much aware of the fact that their HIV positive status will eventually lead to a "changing circle of care" for their children, but that they are not really confident about what exactly that will mean for their children. Whereas the reliance on extended family networks did not seem evident from the mothers' stories, teaching children "to be independent" was clearly an important part of preparing the children to a life after their mother's death. They are trying all they can to provide the children with the necessary intellectual, emotional and social resources, so that they will hopefully be able to cope with these changes and to, if necessary, take care of themselves and one another. Education clearly plays a very important role in all that, and some will go to great lengths to provide their children with the best possible education, for example sending them to multi-racial schools, and schools outside the township system.

The findings indicate the need to refrain from over-generalised hypotheses about the impact of HIV/AIDS on people's values and views on life. Continuously repeating the possibly destructive consequences of the disease does no justice to those people who are daily trying to survive the realities of AIDS. It denies them attention to their needs, and rather heightens the fear and stigmatization that already surrounds the pandemic.

Further research into the impact of HIV/AIDS on educational decision-making should allow me to identify those factors on which the disease can and does impact, and thereby to develop an understanding of how AIDS impacts on children's chances to education in "the new" South Africa.

## **Further research**

This research offers a first insight into the value of education among HIV-positive mothers. It is impossible, however, from these data to draw relative conclusions about this value: no material is available to compare the statements of these women to the value non-affected mothers would attach to schooling, which I believe might be high as well, given the context of education and care in South Africa. This first part of the research does thus not allow me to assess the exact impact of AIDS on this value.

As mentioned, it is my intention to complement these first findings with further research. The broader research project of which this preliminary study is a first

part, combines quantitative and qualitative research with both affected and non-affected caregivers, young adults and children. Working with control groups of non-affected people should allow me to draw further conclusions on the way in which HIV/AIDS influences the value of education. Multivariate quantitative analysis will be performed on data assembled through specific “health, values and education” questionnaires, from both affected and non-affected caregivers and young adults. As such, the larger research project seeks to provide an answer to following research questions:

- What factors are at the basis of educational decision-making for HIV-affected people? (i.e. how do values on the one hand, and material factors on the other, influence educational decision-making? How does life-expectancy, mortality and morbidity influence the decision-making?)
- Do these factors differ from criteria used by non-affected people?
- Does access to antiretroviral treatment change anything in the educational decision-making process of affected caregivers?

One hundred and fifty affected caregivers (75 on ARV, 75 not on treatment) and 100 adolescents from the same, lower end socio-economic background will be recruited through clinics and support groups. Control groups of non-affected people will be found through the existing *Cape Area Study (CAS)* and *Cape Area Panel Study (CAPS)*<sup>10</sup>. The 2005 waves of both studies will contain specific questions on health, values and education.

Supplementary to the survey work, more in-depth qualitative research will be set up to allow probing on affected people’s views on the future, their values in life in general, and the value attached to education for either themselves, their children or their siblings. Apart from caregivers and adolescents, this qualitative component will also include sessions with affected children of school-going age (between seven and fifteen), allowing also the voice of those children who might have to redefine themselves into caregivers for themselves and/or their siblings, to be heard, their views on future and the place of education in that, to be understood.

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<sup>10</sup> CAS contains a representative sample of adults in the Cape Town Metropolitan Area and consists of an ongoing series of surveys on a very broad range of topics, among which social and political attitudes and behaviour. CAPS comprises various survey waves whereby a panel of adolescents is being interviewed several times over a period of at least 5 years. CAPS has been designed with the aim of gathering more specific information on the youth in the Cape Metropolitan Area, especially looking for determinants of schooling, unemployment and earnings of young adults.

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The **Data First Resource Unit** ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The **Democracy in Africa Research Unit** (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

The **Social Surveys Unit** (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. Our core activities include the overlapping Cape Area Study and Cape Area Panel Study. The Cape Area Study comprises a series of surveys of social, economic and political aspects of life in Cape Town. The Cape Area Panel Study is an ongoing study of 4800 young adults in Cape Town as they move from school into the worlds of work, unemployment, adulthood and parenthood.

The **Southern Africa Labour and Development Research Unit** (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. In line with its historical contribution, SALDRU's researchers continue to conduct research detailing changing patterns of well-being in South Africa and assessing the impact of government policy on the poor. Current research work falls into the following research themes: post-apartheid poverty; employment and migration dynamics; family support structures in an era of rapid social change; the financial strategies of the poor; public works and public infrastructure programmes; common property resources and the poor.

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