

Living in an Age of HIV and AIDS: Implications for Families in South Africa

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ABSTRACT

South Africa has one of the highest HIV prevalence rates in the world. It is understandable, therefore, that the HIV and AIDS pandemic is considered one of the most important factors that has been impacting social integration in general and family life in particular in South Africa during the past decade. In the attempt to assess what the impact of HIV and AIDS is on family life in South Africa, the focus falls in this article on three issues: (a) The impact on the family and household structure. (b) The impact on the socio-economic and emotional dimensions of family life. (c) The strategies employed by individuals and families in trying to cope with HIV and AIDS related challenges. The discussion is based on the findings of three qualitative studies that aimed to shed light on the perceptions and experiences of both HIV positive persons themselves and those living with an HIV positive family member.

Keywords: HIV; AIDS; family; impact; coping strategies

INTRODUCTION

The AIDS epidemic is without doubt becoming one of the most important factors shaping social existence in South Africa. It stands to reason, therefore, that theorists and laymen alike consider HIV and AIDS and the accompanying demographic and socio-economic consequences to pose significant challenges to the South African society at large and families in particular. It is the family, as the basic social unit of society, which will largely bear the brunt of the possible catastrophic impact of HIV and AIDS in the decade to come.

The family in South Africa has always been viewed as an adaptive and vibrant institution. It is this resilient nature of the family that made it possible for this institution to respond creatively to challenges in the past such as colonialism, apartheid policies, political turmoil, large-scale urbanisation, and economic difficulty (Patel 1995: 1). However, in the face of the detrimental impact of HIV and AIDS, the question arises as to whether the family, as a network of care and integral social resource in society, will be able to live up to this challenge. Although HIV and AIDS may impact on individual and family life indiscriminately, regardless of race, class, gender and age, the epidemic has, however, been spreading with rapacious speed among black heterosexuals of both sexes (Patel 1995: 1, Crothers 2001: 14), and thus effecting African family life extensively.

In this article, an overview is given of the major foci regarding HIV and AIDS and its impact on family life in South Africa. By way of introduction, a brief picture of HIV and AIDS in the African (and South African) context will be sketched. Thereafter, the focus will fall on the way AIDS has brought about major social changes in South Africa, with special reference to its consequences for society in general and families in particular. In this discussion light will be shed upon questions such as: What implications do HIV and AIDS hold for family structure and family relations? What are the strategies families are employing in trying to cope with the enormous challenge of having family members living with and dieing of AIDS?

1. THE REALITY OF HIV AND AIDS: FROM THE GLOBAL TO THE LOCAL SOUTH AFRICAN CONTEXT

The World Health Organisation (WHO) reported that an estimated 39.5 million people worldwide were HIV positive by the end of 2006 (UNAIDS 2006a). On no other continent has the HIV and AIDS epidemic been as devastating as in Africa. In sub-Saharan Africa alone 24.7 million people are infected with HIV, with a total of 2.1 million deaths as a result of AIDS in 2006. What is even more alarming, is the fact that more than 60% of the global population infected with HIV live in this region – accounting for 72% of the world's AIDS related deaths (UNAIDS 2006a).

Since the first reported case of HIV in South Africa in 1982 (Marais 2000: 5), the epidemic has spread with alarming speed. Whereas the HIV prevalence in South Africa was estimated at 0.73% in 1990 (Crothers 2001: 8), the Human Science Research Council (HSRC) found that, based on a national household survey, 10.8% of the South African population (two years and older) were HIV positive by the end of 2005 (Shisana et al. 2005). UNAIDS (2006b) reports, however, that the HIV prevalence rate may even be as high as 18.8%. It is estimated that the total number of 5.5 million people, who were HIV positive in South Africa by the end of 2005, may escalate to 6 million by 2015 (Avert 2007a). The demographic impact of HIV and AIDS is undeniable in light of statistics such as those reported by UNAIDS (Avert 2007a), indicating that 320,000 people died of AIDS in South Africa in 2005 alone – compared to the 272,000 AIDS related deaths in 1998.

2. HIV AND AIDS: FROM MACRO SOCIO-ECONOMIC CONSEQUENCES TO FAMILY AND INDIVIDUAL EXPERIENCES - A BRIEF THEORETICAL OVERVIEW

From a macro point of view it is clear that the HIV and AIDS epidemic has become a defining determinant in demographic trends in South Africa. The demographic transition brought about by HIV and AIDS manifests most clearly in the increase in the morbidity and mortality rates. The adult mortality rate in South Africa has increased from 228 per 1,000 in 1990 to an estimated 579 per 1,000 in 2005 (UNAIDS 2005). Due to the fact that women in South Africa have a higher HIV prevalence than men (10.04% and 8.36% for women and men respectively) (Shisana et al. 2005), the female mortality rate has seen an increase of late. According UNAIDS (2006a) the mortality rate of women in South Africa aged 25–34 years has increased five-fold between 1997 and 2004.

Even more alarming is the increase in the child mortality rate from 56.3 per 1,000 in 1990 to 65.5 per 1,000 in 2005 (UNAIDS 2005). Authors such as Barnett and Whiteside (2002: 169) are of the opinion that mother-to-child transmission of HIV plays a major role in the increase in child mortality. Although not all babies born to HIV infected women contract the virus, statistics show that between 24 and 40 per cent of HIV positive mothers do, however, transmit the virus through pregnancy, birth or breast-feeding (Evian 2000: 16).

Prior to the onslaught of HIV and AIDS, South Africa had the benefit of a steadily decreasing mortality rate and an increase in life expectancy. This situation has, however, changed with a visible decline in the life expectancy of the South African population, from 63 years in 1990 to 48 years in 2006 (UNAIDS 2006b).

Apart from the demographic transition brought about by HIV and AIDS, the epidemic also has major long-term macro socio-economic consequences, which in turn will have repercussions for families in society. Some of the socio-economic costs of the high HIV infection rate and adult mortality include the grave burden placed on the welfare and health care systems. It is for example estimated that one out of every two to three patients who are admitted to public hospitals are HIV positive (Crothers 2001: 20, Smit 2003: 25). Some authors, such as Crothers (2001: 20) and the Bureau of Market Research (2004: 1), are even more concerned about the negative effect HIV and AIDS may have on economic development and growth on regional and national level. Shell (2000: 35) mentions for example issues such as (a) a decline in labour productivity due to employee disability and absenteeism, (b) a decrease in overall economic production, and (c) increased expenditure for companies as a result of benefit payments and costs associated with labour replacement. The high mortality rate among people between the ages of 20 and 40 years brings, for example, into play the alarming reality of the loss of skilled, active labour market participants. The loss of social capital, as one of the more subtle large-scale social

consequences of HIV and AIDS, may even have more far-reaching consequences for generations to come (Crothers 2001: 20).

Although the macro level consequences of HIV and AIDS may have a detrimental impact on society at large, it is, however, the micro level impact of AIDS - as experienced by the individual and the family - that has become a source of major concern. Barnett and Whiteside (2002: 182) are for example of the opinion that “[t]his is where the impact is felt first and worst. But it is also here, beyond the obvious clinical and medical consequences, that it is hardest to measure.”

Theorists such as Cross (2001: 133) and Bachmann and Booyesen (2004: 817) stress the economic impact of HIV and AIDS on individuals and families/households whose lives are intertwined with the disease. Apart from economic dilemmas such as reduced household income, HIV positive individuals and their families are also confronted with the reality of the stigma attached to HIV and AIDS (Tomaszeski 2001, Carr & Gramling 2004: 39). They may also need to deal with socio-emotional challenges such as feelings of anxiety, anger, depression, despondence and the experience of inter-personal relationship problems within the family (Patel 1995: 17, Barolsky 2003: 7).

In the subsequent discussion, particular attention will be given to the impact of HIV and AIDS on families from a micro point of view, by focussing on three qualitative studies done in South Africa.

3. HIV AND AIDS AND THE IMPACT ON THE FAMILY. A QUALITATIVE APPROACH.

“There are only two kinds of people in society: those *infected* by HIV and those *affected* by HIV. That means no-one can ignore it – it’s part of our lives.” (AIDS caregiver)

Although there may be differences among families with regard to their perceptions and experiences of the impact of HIV and AIDS, it is, however, clear that both the high HIV infection rate and the increase in mortality place a tremendous burden on the family in terms of its capability to nurture its members, provide economic and emotional support, and function as an agent of socialisation and care (Barolsky 2003: 14).

The subsequent discussion of the impact of HIV and AIDS is based, on the one hand, on the results of research initiated and documented of late in South Africa, and, on the other hand, the findings of three qualitative studies that aimed to shed light on *inter alia* the perceptions and experiences of HIV positive individuals themselves, their caregivers and those living with an HIV positive family member.

- The first of these studies was done in 2004 in South Africa's North West Province. In this study, in-depth interviews¹ were conducted with 25 respondents from the Rustenburg and Phokeng areas and who were platinum mineworkers. These respondents, whose ages ranged between 26 and 51, were all HIV positive².
- The second study was done at a large Johannesburg public hospital in Gauteng province in 2003/2004. Thirty-five in-depth interviews were conducted with patients who were HIV positive, their family members and nursing staff involved in AIDS related care³.
- The third study was done in 2004/2005 and focused on households which have at least one HIV positive member. Twelve interviews were conducted with heads of households in the urban eastern region of Gauteng, who were either HIV positive themselves or who were responsible for the care of an HIV positive family member⁴.

The data from the above-mentioned 72 in-depth interviews, constitute some views and experiences of people whose lives are intertwined with HIV and AIDS and who live in regions in South Africa which are under-researched when it comes to matters related to AIDS and family life⁵. For the purposes of this article, the results pertaining to the impact of HIV and AIDS on family life in particular will be discussed⁶. In the attempt to assess what the impact of HIV and AIDS is on family life in South Africa, the focus fell on three issues, i.e. (a) the impact on the family and household structure, (b) the impact on the socio-economic and emotional dimensions of family life, and (c) the strategies employed by individuals and families in trying to cope with HIV and AIDS related challenges.

¹ These in-depth interviews were conducted in the preferred language of the respondents, i.e. Setswana, Sesotho and Sepedi, and thereafter transcribed and translated into English.

² I would like to express my gratitude towards P. Makhura for involving me in this interesting study, as well as allowing me to use some of the research data in writing this article.

³ These interviews were primarily conducted in English. Only six interviewees preferred to use Afrikaans.

⁴ I would like to thank N. Mashigo for involving me in this study, as well as allowing me to refer to the data in writing this article.

⁵ The quoted material in the subsequent discussion is taken from verbatim transcripts of which all the respondents' names have been changed to protect their anonymity.

⁶ Due to the qualitative and explorative nature of the research and the relative small number of cases, representative sampling was not attempted.

3.1 THE IMPACT ON THE FAMILY AND HOUSEHOLD STRUCTURE

The HIV and AIDS epidemic and the shift in the patterns of, especially, adult mortality have clear implications for the structure of families and households in South Africa. As is indicated in the subsequent discussion, these implications for the family and household structure may place additional pressure on family members confronted with the reality of HIV and AIDS.

3.1.1 Single parent families

HIV and AIDS may contribute to an increase in the number of single parent families in two ways. This happens, in the first place, when spouses desert their families after learning that their partners have become infected with HIV. In the second place, as a result of the high adult mortality rate due to AIDS, many families may be left with only one parent to fend for their children. Sophie, a twenty-one-year-old widow from Gauteng whose husband has died of AIDS, gave the following account of being a single parent:

My husband became very ill...His employer said that he was not fit to work anymore, so he lost his job. He was also in and out of hospital and then he died. Now I'm left behind with my two little ones. I don't have a job...and I would've gone mad with worry if it wasn't for the lump sum payment my husband's boss gave to us after Jacob [husband] was buried.

3.1.2 Grandparent-headed households

AIDS has also brought about, what Crothers (2001: 19) refers to as, "household demographic structures" which have become "hollowed out with only grandparents and children present." Grandparents are often compelled to take on the responsibility of taking care of their grandchildren whose parents (the middle generation) have died of AIDS.

It is a traditional custom in African families in South Africa for grandparents to take part in the socialisation of children. The HIV and AIDS epidemic has, however, added a new dimension to this tradition. As the parents of some of these children pass away, many grandparents, who were previously only part of, what Barolsky (2003: 30) refers to as, "the web of complementary socialising agents within communities", are now faced with the full responsibility of raising and supporting their grandchildren. Not only does this guardianship place even more economic pressure on grandparents who, in many cases, depend primarily on state-funded old-age pensions, but it may also have an impact on the intergenerational relationship between grandparents and grandchildren. Mary, a 62-year-old pensioner, spoke about the challenges of being a member of a grandparent-headed household:

My husband and I had to bring our daughter's children to come and live with us, after she died. You see, we don't know where their father is... We love them, but it's expensive to have three young children in the home. Now we need to feed three more mouths and pay school fees... The oldest boy is sometimes so disrespectful and doesn't what to listen to us. Then I say to my husband: 'We have to be patient, his heart is still crying for his dead mother.'... It's sometimes so difficult. I'm a 'gogo' [grandmother] and now I have to be a mother again.

3.1.3 Child-headed households

According to Barolsky (2003: 55,56) an escalating number of under-aged children are compelled to take on the role of caregivers, both in terms of nursing their ill parents and looking after younger siblings. In many cases, these children drop out of school and are prematurely propelled into income generating activities, such as street vending and hawking. These activities may also include so-called informal criminal activities such as petty theft and begging.

In cases where parents have died of AIDS and children are left destitute without being taken care of by adult kin or state funded organisations, children (some even as young as 12 years old) become responsible for sustaining the household and raising their younger siblings (Van Dyk 2001: 337). Although these adolescents take care of their brothers and/or sisters, they are unable to access welfare grants due to the fact that they are under the age of 21 and can thus not become foster parents. An additional source of stress is the fact that these older children often struggle to establish a sense of authority that is essential in keeping the household together. Younger siblings frequently view an older sibling as their peer, rather than their guardian.

These child-headed households are seen as one of the most worrying consequences of the high mortality rate of adults in the child-bearing age-group (Kamali et al. 1998: 221, Barnett & Whiteside 2002: 189). Of the 15 million children worldwide who have lost one or both their parents to AIDS by 2005, approximately 1.2 million lived in South Africa (Avert 2007b). This number may increase to 1.5 million AIDS orphans in South Africa by 2010 (Barolsky 2003: 54). Although not all of these orphans are destined to become members of child-headed households, many of them may find themselves at some point in time in a situation where they have to fend for themselves and their siblings.

3.1.4 Extended families

The African family in South Africa has drawn traditionally on the strengths of the extended family. Barolsky (2003: 16) is for example of the opinion that qualities associated with the extended family such as strong kinship network relationships, economic and emotional support, and a set of obligations that reaches beyond the nuclear family unit, have made it possible for many families

in South Africa to survive in a milieu characterised by poverty and socio-political difficulty. From the qualitative data it is clear that many individuals rely on the support of the extended family. This is especially the case where members of the extended family, on the one hand, take care of both family members suffering from AIDS and their dependents, and on the other hand, become responsible for raising the orphans of family members who have died of AIDS.

Although the extended family, as a network of care, may undoubtedly be an invaluable source of support to many a family member whose life is intertwined with HIV and AIDS, a number of theorists are, however, of the opinion that the extended family has become “over-extended” (Crewe 2002: 451, Barolsky 2003: 19). As a result of AIDS, continuously, more individuals become dependent on fewer income generating family members, thus increasing the already heavy economic burden experienced by families in a country where the unemployment rate was estimated at 25.6% in 2006 (Statistics South Africa 2006). Herminah, who has been taking care of her sister since she has developed full-blown AIDS, mentioned the following when she spoke about how strenuous it was taking care of her kin:

I’m a domestic worker and I don’t earn a lot of money. But when Precious became too ill to work, I said that she and her baby must come and live with us. Now I lie awake at night, worrying about where I’m going to get more money to buy food and clothes for my two children and my sister’s baby.

In general, based on the research data, it is clear that household fluidity has become a reality to many families affected by HIV and AIDS. A household’s structure may for example change from being a nuclear household to an extended household when parents become responsible for taking care of their adult children (who are HIV positive) and their grandchildren. In cases where the adult child dies of AIDS, the grandparents may continue to act as guardians for the grandchildren and thus forming a grandparent-headed household. Booysen and Arntz (2002: 170) mention for example the increase in household fluidity as a result of AIDS orphans “being passed from one household to another.”

Apart from having an impact on the family and household structure, HIV and AIDS may also hold implications for the socio-economic and emotional dimensions of family life.

3.2 THE IMPACT ON THE SOCIO-ECONOMIC AND EMOTIONAL DIMENSIONS OF FAMILY LIFE

HIV and AIDS may have implications for the access to social and economic resources, which may intensify the vulnerability of both individual family

members and the family as a social unit. The financial position of the family is probably the most manifest of the dimensions of family life being impacted by HIV and AIDS.

3.2.1 The economic income predicament

In asking what effect AIDS has on the household's financial position, it is unmistakable that it dramatically reduces the financial income and increases the household expenditure of the family. The family's ability to participate in the labour market is diminished, insofar as, on the one hand, an individual suffering from AIDS may be too ill to work, and on the other hand, caregivers in the family may need to divert their time away from income generating activities to that of taking care of the sick. This increased financial burden may become even more profound when the person who suffers from and eventually dies of AIDS, was previously a primary breadwinner in the family. This concern is reflected in the words of the following respondent who was diagnosed with HIV in 2005:

I'm okay now. I sell fruit and vegetables at the train station in town. But what if I become ill and can't work anymore? And what will happen to my children when I die?

The financial toll which AIDS is taking of the family is furthermore evident in the additional expenses associated with illness and death. Families are confronted with increased household expenditure with regard to medical related costs such as buying pain medication, expensive anti-retroviral drugs and expenses incurred in visiting health care professionals. A 37-year-old HIV positive mother of two mentioned for example the following:

I can't provide my children with what they need. A big chunk of our income goes towards paying for my health care. The available funds from my medical aid for this year, is also nearly depleted, and that means that I'll have to pay cash for my medicine.

The diet of ill family members also needs to be supplemented with nutritious food which may add to household expenses. In light of the increased risk of mother-to-child HIV transmission during breastfeeding⁷, HIV positive mothers may need to incur expenses by buying milk-formulae to substitute breast milk. Although state disability grants are available to people with AIDS who are too ill to work, most respondents were unaware of these grants until a third party, such as a nurse or a social worker, assisted them in applying for these relevant funds. In addition, some of the respondents did, however, not qualify for these social grants due to the fact that their CD4 cell counts, although being low, were still more than 200.

⁷ According to Evian (2000) breastfeeding increases the risk of mother-to-child HIV transmission by between 12% and 43%.

The increase in the AIDS related mortality rate has forced the reality of high funeral costs on many families. Whereas medical expenses and health care may be subsidised by the state, funeral costs are the sole responsibility of the family. Death has thus become a major expense for many families.

3.2.2 Dependency

The number of adults suffering from HIV and AIDS may have also brought about an increase in the dependency ratio in the South African society. This so-called increased dependency burden on families, does not only refer to the economic dependency of people living with HIV and AIDS (PLWHA) but may also include their dependency on the emotional support provided by the family. For Nomsa, a 32-year-old HIV positive woman, being dependent on others has become a bitter pill for her to swallow:

I've lost my job, so now my family supports me financially. I hate being a dependant and I don't want to feel like a beggar or a baby.

3.2.3 Stigmatisation

The majority of the families interviewed, who were supporting PLWHA, expressed the experience of added strain as a result of social isolation and ostracism due to the stigma attached to HIV and AIDS. This relates to Barolsky's (2003: 25) view that "one of the key obstacles to communities' capacity to care has been the stigmatisation of the infected...which can lead to the social quarantine of the potential contaminant." The following respondents gave their accounts of being emotionally exiled for being HIV positive:

Oh, come on! Don't tell me that you haven't realised that HIV is a taboo disease. It's full of disgust. I haven't told anyone at home that I'm HIV positive. I'll live the lie rather than having my family go through humiliation. [Kanyiso, a 40-year-old male migrant labourer]

People will never stop talking – they will always gossip. So, why try to run away from them...with AIDS there is nowhere to hide. [Mike, a 36-year-old married man]

If people suspect that you are HIV positive, they don't want to sit next to you in the taxi, or they will wipe the seat on which you have sat or wash things you have touched such as a door handle. It feels terrible being treated like a leper. [Maggie, a 20-year-old HIV positive woman from urban Gauteng]

In some of the interviews, respondents mentioned HIV and AIDS as being linked to witchcraft. One respondent said, for example, that when it becomes known that a person is HIV positive, the family of that individual is said to be

bewitched. Contact with that family must therefore be avoided. It thus seems that the possible experience of social isolation, as a result of the stigma attached to HIV and AIDS, may intensify in cases where the community suspects that the family experiences misfortune as a result of witchcraft.

HIV positive individuals and their families are not the only ones being confronted with the stigma attached to HIV and AIDS. From the findings it was clear that for some of the nurses and other caregivers a feeling of anger and frustration was linked to the experience of being stigmatised as a result of being in close and constant contact with PLWHA. A nurse in the public hospital in Johannesburg said for example:

People think because we work with HIV positive people, that we are contaminated or something. The children at my child's school don't even want to play with him because his mommy 'works with AIDS people'.

Although the stigmatisation of PLWHA and those providing care to them remains to be in evidence, a few respondents did not experience social isolation as intense. This relates to the views of theorists, such as Barolsky (2003: 26), who conclude that, due to intense HIV and AIDS awareness campaigns, the community at large are beginning to change their attitudes. The so-called 'softening' of stigma are more perceptible within the family itself where lives have been touched more directly by HIV and AIDS.

3.2.4 Emotional well-being

As was found in studies by Patel (1995: 17) and Lyell (1995: 80), it became apparent from the interviews that many of the respondents who were HIV positive reported emotional experiences such as denial, anxiety, despondence, anger, and guilt as well as varying levels of depression and low self-esteem. One male respondent expressed a sense of helplessness and despair:

I am really trying to cope with my situation, but this AIDS illness will get the better of me one day. It has become my master.

The experience of lower levels of emotional well-being was also voiced by some family members of PLWHA, and more specifically those who act as caregivers. Moreover, many caregivers experience physical, emotional and mental fatigue which could be attributed to the fact that providing care for PLWHA is taxing and demanding in nature. What may be of particular concern is the fact that it is primarily women, in their traditional roles as nurturers and providers of care, who are shouldering the burden when it comes to AIDS related care. Tutu, a professional nursing sister, not only nurses AIDS patients in hospital but also provides nursing care to her own relatives at home who are HIV positive:

When I get to work, I'm tired and when I leave work, I'm tired. People with AIDS demand more time-consuming care. They have skin conditions, all kinds of infection and diarrhoea. We have to brush their

teeth, wash them, feed them and change their nappies. I do it at work, and I do it at home – night and day. Sometimes I just want to cry...it leaves me feeling empty inside.

The emotional well-being of the family may also be influenced by the high AIDS related mortality rate. It is not uncommon to find families where more than one family member has died of AIDS. Siegel and Gorey (1998: 264) relate multiple losses, as a result of AIDS, to family members' experience of 'bereavement overload'. This feeling may even intensify in light of the fact that it is particularly young adults and children who are dying of AIDS in South Africa.

3.3 COPING STRATEGIES: POSITIVE REACTIONS IN THE FACE OF NEGATIVE IMPACTS

Owing to the potential destructive impact of HIV and AIDS, it is imperative that a better understanding must be developed of families' coping strategies and positive reactions to the challenges they face. The first of these positive reactions is that of the family being a support system.

3.3.1 The family as centre of support and care

Patel (1995: 25) defines *social support* as "the subjective feelings, attitudes...and perceptions of being loved, esteemed, cared for..., and being trusted and trusting others". It is within this milieu of care and nurturance that many of the HIV positive respondents wanted to spend their time:

I want to be around those who love me and care for me. And when my time comes to say my final 'goodbye', I want to be at home with my family. I don't want to die in hospital, all alone. [Sipho, a 51-year-old man]

Although many family members may at first react with shock, horror and/or rejection of the person infected with HIV, many do, however, become supportive and a source of care. Matima, a 36-year-old married man, gave the following account of his supportive family:

My family was very shocked when I told them the news. At first they didn't treat me very well, but they eventually accepted my status and now they give me a lot of love and encouragement. My wife also tries to understand. Good families take care of their own people, and mine is one of those families.

Although theorists such as May (1998: 85) are of a mind that much of the celebrated African value of *ubuntu*, that signifies authentic caring, sharing and

acceptance, has been eroded by poverty, it seems that many African families continue to manifest this principle. The spirit of *ubuntu* not only comes into practice when support is given to those who are HIV infected but it also manifests in the fostering of AIDS orphans. The traditional notion of ‘every child is my child’ and a sense of responsibility regarding the collective rearing of children may therefore be a powerful ‘resource’ in dealing with the orphan situation in South Africa. The principle of *ubuntu*, in combination with other innovative strategies, may thus contribute to the survival of families who are faced with negative HIV and AIDS related challenges.

One of the most distinct examples of the family as centre of support is the system of home-based care. Barolsky (2003: 24) refers to the World Health Organisation’s definition of home-based care as “the provision of services by formal and informal caregivers in the home in order to promote, restore and maintain a person’s maximal level of comfort, function and health including care towards a dignified death.” In most cases it is the family members themselves who take care of the ill. Both the Department of Health (DOH) and non-governmental organisations (NGOs) such as CARE and the Society for AIDS Families and Orphans (SAFO) provide training and support to family members to enable them to render basic nursing care and address the social and emotional needs of PLWHA within the home-based care context.

3.3.2 Community involvement: creating a support network for the family

Despite reports on communities that marginalise and ostracise individuals and families affected by HIV and AIDS, and notwithstanding the fact that this epidemic may sow dissension within a community, community involvement in the ‘fight against HIV and AIDS’ may assume a more positive approach through supporting PLWHA and their families. Bongani, a 54-year-old woman whose 21-year-old daughter, Rejoice, is HIV positive, expressed how grateful she was to have supportive neighbours:

They [the neighbours] help me so much in taking care of my daughter. When I’m at work Dolly [the next-door neighbour] will make sure that Rejoice is comfortable and helps her when she needs something. My neighbours have really become part of my family, not only helping me to help my child, but loving my daughter for who she is.

Through a network of home/community-based care programmes, NGOs and community based organisations (CBOs) train volunteers from the community to assist in the nursing of PLWHA in both the hospice and home-based care environments (Tshabalala-Msimang 2003). The Department of Health reported in 2003 that a total of 466 home/community-based care programmes were in place, that 9 553 volunteers were involved in these programmes and that more than 370,000 individuals were utilising these services (DOH 2003).

3.3.3 Religion and spirituality

Religion and spirituality played an important role in the lives of some individuals and families, in making sense of and coping with a life directly affected by HIV and AIDS. A few respondents had spiritual concerns in the sense of believing that their lives became intertwined with HIV and AIDS because their ancestors were punishing them for some or other reason. Others, from a more Christian point of view, mentioned heightened feelings of alienation from God. In contrast to these negative experiences, other respondents found refuge in their spiritual beliefs.

I believe that we as a family get our strength and help from both God and our ancestors. It is not our bodies - with or without AIDS - that are important. It is our souls that are important. That is why I pray and that is why I slaughter for my ancestors. [25-year-old male mineworker]

Religion and spirituality therefore seems to be a strategy for some individuals in coping with the reality of AIDS and making sense of the meaning of life and death.

3.3.4 A positive outlook on life and death

When listening to the voices of PLWHA and those of their families, it becomes clear that one of the major strategies employed in the context of the high AIDS mortality rate, is having a positive outlook on life *and* death. Evian (2000: 92) emphasises the importance of having a positive mental attitude in promoting health and well-being as part of a self-care wellness programme for PLWHA. Yet, wellness is not exclusively based on the way one looks at *life*, but needs to incorporate one's contemplation of *death* as well. Examples of some of the remarks uttered by respondents, expressing this notion, are:

It's inevitable - we all have to die. So, when you ask me about my future, I can tell you, today is my future. I take it one day at a time.

I still have dreams and goals and things that I want to do, and I have decided that having HIV is not going to change that.

Remember, being HIV positive doesn't mean your life is over. I've realised how precious life is...Like others, I too can say: 'I'm not dying of AIDS, I'm living with AIDS'.

3.3.5 Social involvement and activism

Apart from having a positive outlook on life and death, a few respondents went further insofar as becoming positively preoccupied with HIV and AIDS, by becoming involved in community-based care programmes and volunteering at

hospices. For some respondents social involvement became social activism – by involving themselves in AIDS awareness programmes and AIDS related NGO driven campaigns. One respondent explained why she became a social activist in the fight against HIV and AIDS:

I want people to hear my story and teach them to fight HIV and not to fight me as someone who has HIV.

4. CONCLUSION

In this article a panoramic view was given of the possible impact of the AIDS epidemic on family life in South Africa. In listening to the array of voices of family members and caregivers whose lives have become enmeshed with the reality of HIV and AIDS, it is evident that the epidemic has the potential to tear at the heart of families and communities. Although not all families may necessarily respond to the challenges of HIV and AIDS in a similar way, the research shows, nonetheless, that many families do endure a lot of strain as a result of the impact of HIV and AIDS on the family and household structure as well as the socio-economic and emotional dimensions of family life.

In order for researchers to contribute to a better understanding of the AIDS and family life debate as well as to inform social policy, it is imperative that, instead of only overemphasising the destructive impact of HIV and AIDS, the focus must also fall on the strategies families are employing in the attempt to cope with the mammoth challenge of having family members living with and dying of AIDS. In order for the South African government to reach the overall goals of its comprehensive HIV and AIDS strategic plan, i.e. to (a) reduce the number of new HIV infections and (b) reduce the impact of HIV and AIDS on individuals, families and communities (DOH 2006), government, in partnership with the community and other organisations, need to draw on the already existing strengths of the family. This can only be done when support is given to families, by *inter alia* streamlining the process for accessing social grants and making existing community-based support mechanisms more assessable. It thus seems that the extent to which the family will remain resilient in the midst of the AIDS epidemic depends largely on the attitudes and behaviour of organisations and individuals in society towards PLWHA. It is clear from the studies referred to in this article that many families, living with the reality of HIV and AIDS, express the need for a compassionate society and long for a sense of belonging, inclusion, nurturance and support.

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