University of Pretoria

Series Editor: Mary Crewe

(Over) extended

AIDS Review 2003

Vanessa Barolsky

(Over) extended
AIDS Review 2003

Author:

Vanessa Barolsky is a sociologist with wide-ranging research interests and experience. She has conducted research in human rights, political and criminal violence and policing issues. She worked for the Truth and Reconciliation Commission and for the Secretariat for Safety and Security. She is currently completing her PhD in the Sociology Department at the University of the Witwatersrand.

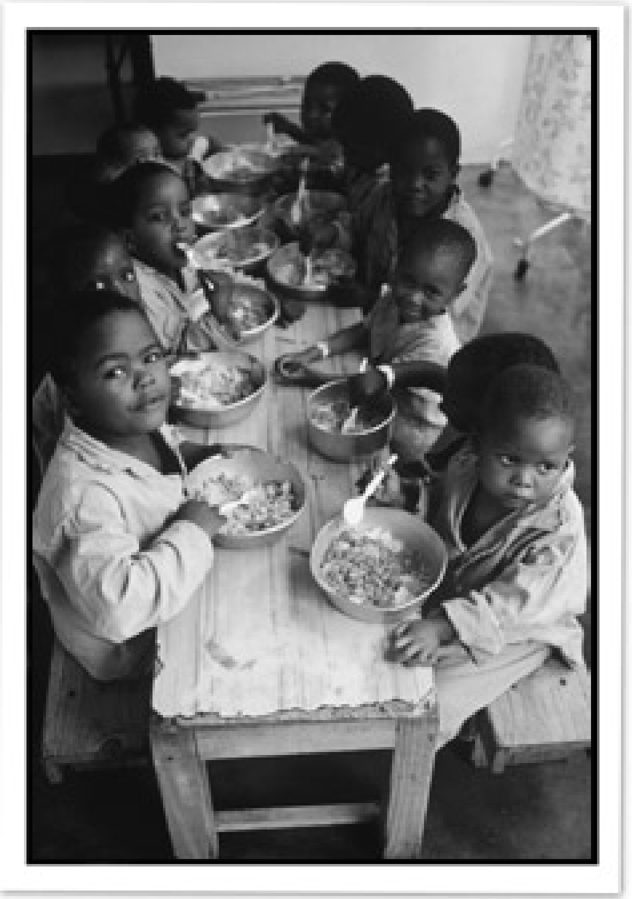
Series editor:
Mary Crewe

Publisher:
Centre for the Study of AIDS, University of Pretoria

Design and production management:
Bluprint Design

Language editing:
Robin Hamilton

ISBN 0-620-314370.



Contents

Foreword

This is the fourth in the series of *AIDS Reviews* published annually by the Centre for the Study of AIDS at the University of Pretoria. Each *Review* seeks to address a particular question and in answering it, broadens our knowledge and understanding of HIV and AIDS as the epidemic unfolds in South Africa. In 2000 we traced the response to HIV and AIDS starting from the National AIDS Plan in 1994. In 2001 we addressed the issue of international, regional and local care and commitment to the epidemic. In 2002 we looked at the relationship between HIV/AIDS and human rights in eight of the SADC countries.

In 2003, we are asking the question: how does the epidemic impact on families and the personal relationships between family members – between partners, between husbands and wives, between parents and their children and between siblings? We ask the question as to how the *(over)extended* family will cope with this epidemic and how social and community structures might be able to find creative new ways to look after families living with HIV and AIDS, as well as people living with HIV and AIDS, and how social and community support can be developed in innovative and creative ways.

AIDS Review 2003 looks at a small microcosm of individual people and families living with HIV and AIDS, and giving care to and taking in family members and friends. It relates the lives and experiences of a small number of people who are dealing with families and who are linked into support groups and other networks. This small sample reflects what many other South African families of all races and classes are experiencing as they find ways of coping and ensuring that family members are supported and cared for. This *Review* looks at the possibility that we can create new families, new communities and a new culture of care and compassion and support, and develop a strong social cohesion and integrity. In this way we will create a new society that will be stronger, having survived this epidemic.

The University of Pretoria remains committed to a comprehensive HIV/AIDS programme, through the Rector, Vice Rectors, Deans, staff and students. All sectors of the university are increasingly involved in the HIV/AIDS programmes at all levels. The Centre has international collaboration with key HIV/AIDS research units and is working closely with regional and national tertiary institutions to increase our knowledge and develop effective responses.

This *Review* was made possible through the sustained support and commitment of the International Development Research Centre, Canada.

The view expressed in this *Review* are solely those of the authors and the Centre for the Study of AIDS.

Mary Crewe
Director, Centre for the Study of AIDS

'My family, my side, they've all gone because of HIV, they died. My sister also, she got five children (between the ages of 2, and 19), I look after them, I've got three, I look after the three, the big one has got two child, so I look after them, it's ten children and I've got also my brother who's living with HIV/AIDS, also he's not working, I must look after him as well, but if I'm here, the little I got I can share, but the problem is if I'm not here…'

- Interview with a PLWA, July 2003

Introduction

One of the ways in which the HIV/AIDS epidemic will be felt most acutely is at the level of families. It is within the family that people living with HIV and AIDS will need to be able to disclose their status and to be cared for and supported. It is within the family that decisions will need to be made about the allocation of resources, which will in turn determine how each family member will be affected. Decisions will need to be made about the ways in which food and essential goods will be acquired, whether young people can remain in school, how access to health care and medications will be possible, and what the future of family members and household integrity is likely to be.

Parents who are living with HIV and AIDS need to come to terms with the fact that they may die and leave young children who need to be cared for by extended family and community networks. Older people will need to accept that they may be responsible for the care and support of young and often traumatised grandchildren, and that their children, upon whom they have expected to rely for support through their old age, will die before them. Inheritance and property ownership need to be secured, wills need to be drawn up and guardianship assured, and the support of the social and welfare services needs to be obtained.

In reality this is very difficult to achieve. The silences and stigma that still surround the epidemic make disclosure, even within families, difficult, and families still respond in dramatic and punitive ways. The economic reality of most South African households means that having to confront reduced earnings and the costs of care is often catastrophic and leads to rejection and resentment of the person needing support and care. The health and welfare systems have not responded to this epidemic as they ought to, making the access of welfare grants difficult and health care patchy and inadequate. There are insufficient counselling and support services, there is a failure to provide home visits, there is no comprehensive continuum of care for home-based care services, and there is a lack of commitment to medication and anti-retroviral drugs.

The position of the elderly in South Africa was already precarious before the HIV/AIDS era. There has been no development in the provision of care and support services for the elderly – especially counselling and particular health needs – and their legal position with regard to inheritance and property remains inadequate.

The lack of a child support network means that many children will not be able to access social grants and support. There has also been a failure to address creative and innovative models of community and institutional care for young people. This means that many children, distressed and traumatised by the death of their parents and the break-up of their families, are being placed in families which may be willing to provide help, but which are already over-extended and so unable to give the children the psychological and physical care and support that they need.

The education system has not adequately trained teachers nor provided a creative response to this epidemic, and so has been unable to give families and young people the support that they need.

On every level families dealing with HIV and AIDS are left on their own to battle against the system and to find ways in which they can support mothers, fathers, grandparents, siblings and young children to cope with the devastating potential threat of HIV and AIDS to their family, community and social structures.

Background

The statistics of HIV prevalence in South Africa and the rates of death due to HIV/AIDS speak for themselves. The raw data reveal a national HIV prevalence rate of 11%, which means that approximately five million people are infected with HIV (*Nelson Mandela, HSRC Study of HIV/AIDS*, 2002). Nearly three million of those infected are women and 250 000 are below the age of 15 years. The estimated number of children who have lost one or both parents to AIDS was 660 000 in 2001 (*South African Epidemiological Fact Sheet*, 2002).

UNAIDS has sketched the development of the epidemic in South Africa over the past decade: "Antenatal HIV prevalence in South Africa increased rapidly from 0.7% in 1990 to 10.5% in 1995 and then 22% in 1998. HIV prevalence in [antenatal clinic (ANC)] attendees was 22.4% and 24.5% in 1999 and 2000 respectively. Age specific analysis shows a modest decline in HIV infection rates among 15-19 year old ANC attendees, from 21% in 1998 to 16.5% in 1999 and continuing to decline in the year 2000. However, ANC attendees in their early 20s still exhibit an HIV prevalence of over 25%. In KwaZulu/Natal, Mpumalanga and Gauteng provinces HIV prevalence is still exhibiting an upward trend" (*South African Epidemiological Fact Sheet*, 2002).

Leclerc-Madlala argues that the pandemic "can be viewed as a result of pre-existing patterns of sexual culture and gender inequalities combining with ongoing experiences of labour migration, urbanisation, civil strife, growing poverty and family disintegration, as well as the more recent influences resulting from increased access to foreign cultural and media programmes and new opportunities for acquiring and demonstrating wealth. Together, these components have interlocked in such a way as to form a lethal context that has propelled the spread of HIV/AIDS [in a way which is] unequalled anywhere else in the world" (Leclerc-Madlala, 2002:14).

As a consequence of these increasing prevalence rates, there has been a significant shift in the pattern of adult mortality during the 1990s. UNAIDS estimates place the number of deaths in 2001 due to HIV/AIDS as 360 000. Most importantly, it is the young, the embodiment of social potential, who are dying in the greatest numbers. The Medical Research Council (MRC) reports a steadily increasing adult mortality during the 1990s, most significantly among young women: "The pattern of mortality from natural causes in South Africa has shifted from the old to the young over the last decade, particularly for young women – this is a unique phenomenon in biology" (*The impact of HIV/AIDS on adult mortality*, 2001:4). The MRC's research concludes that "40% of deaths in the year 2000 among 'adults' between 15 and 49 were the result of HIV/AIDS … The projections show that without treatment to prevent AIDS, the number of AIDS deaths can be expected to grow, within the next 10 years … resulting in 5 to 7 million cumulative AIDS deaths in South Africa by 2010" (*The impact of HIV/AIDS on adult mortality*, 2001:6).

But what do these statistics mean? What do they actually speak about? The meaning of the numbers has been fiercely contested in South African public debate. However, in this debate of numbers, the social processes and the human cost that these statistics signify, remain mute.

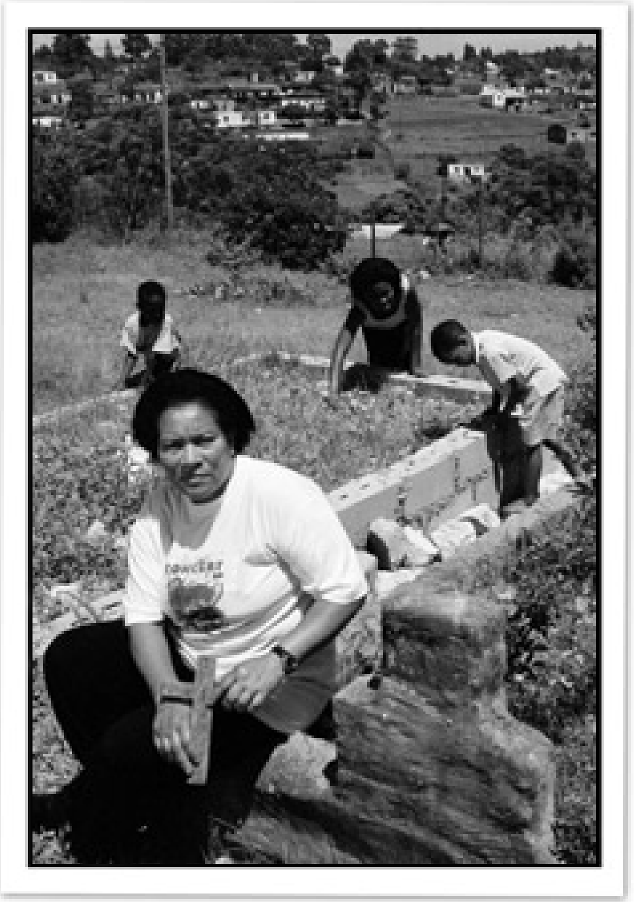
Statistics are also living people

The statistics do not speak of the life which underlies and contests the deaths that these numbers denote. An extraordinary phenomenon is taking place in South Africa, where people living with HIV/AIDS (PLWAs) are involved in a vigorous and creative reconstruction of what it means to live and to die. PLWAs are taking the irrefutable fact of universal human mortality and reframing it as an assertion of life against disease. PLWAs play with meaning and double entendre to assert that they are people *living* with HIV/AIDS, and that they will live *positively*. In a critical affirmation of the capacity for social agency in the face of putative calamity, PLWAs are snatching life back from death, despair and disease.

AIDS activists speak of the link between death and depression. Death here is framed as a failure of spirit rather than a medical inevitability. The ailing of the spirit can be addressed and 'healed' through 'care' and *ubuntu*. Humanity can be affirmed against the cold alienation of medical science which issues 'death sentences', when in fact life and death are infinitely malleable.

The intention of this *AIDS Review 2003: (Over) extended* is to begin to engage with such hidden processes and to make visible the lived reality of HIV/AIDS, which is concurrently tragic, heroic and mundane.

In 2000 the government responded to the escalating problem of HIV/AIDS with the development of a strategic plan. The stated goals of the plan were to: "[r]educe the number of new HIV infections (especially among youth) and reduce the impact of HIV/AIDS on individuals, families and communities" *(HIV/AIDS/STD Strategic Plan,* 2000). The resources allocated by the state to address HIV/AIDS have steadily increased from R30 million in 1994, to R605 million in 2002, divided between the Department of Health (R409 million), the Department of Education (R148 million) and the Department of Social Development (R48 million) (*Tracking progress on the HIV/AIDS and STI Strategic Plan*, 2003). While increasing resource allocation does not guarantee an effective response to HIV/AIDS, it is certainly an indicator of growing social concern as HIV



Even if the rate of HIV infection is significantly reduced over the next few years, the social consequences of illness and death among the millions already infected are going to be substantive. Most research thus far has focused on calculating the potential demographic and economic impact of HIV/AIDS. There has been less analysis of the social implications of HIV/ AIDS, the impact the disease is having on social processes, social structure and social relationships. Perhaps demographic and economic research, which uses models to 'predict' potential outcomes, provides for greater certainty than the more messy and complex topics of human subjectivity and social milieu.

Social problematics lend themselves far less easily to prediction and forecast. We cannot anticipate with certainty how our society will respond to the unfolding of the HIV/AIDS epidemic; we cannot know without ambiguity, the response of key social institutions such as the family, which will bear the brunt of the impact of HIV/AIDS as its consequences of illness and death develop. Yet to understand these processes as they occur is a critical national project which has to underpin our response to the epidemic. To develop strategies, allocate resources and initiate projects in the absence of such understanding and without increased research is to shape a response without a context.

Although it is critically important to try and predict the future potential path of the disease, it is as important to understand the empirical present: the swathe that HIV/AIDS is currently cutting through the social fabric. Data analysis will no doubt give us important clues to the potential unfolding of the disease, but it will not provide predictable models of social impact. Nevertheless the complexity and difficulty of engaging with untidy social realities should propel, rather than deter, such investigation.

The family

At the heart of the social context is the family. The family, both as an ideal and a structural phenomenon, constitutes probably one of the most fundamental building blocks of society, the glue that holds myriads of communities in bonds of complex interdependence. On one hand, the family, as a pre-existing network of care, could constitute one of South Africa's most important social resources in the country's attempts to address the consequences of the HIV/AIDS epidemic. On the other hand, the HIV/AIDS epidemic is a profound test of the integrity and durability of the family as an institution. The illness of people with HIV/AIDS, the death of mothers and fathers, and the orphaning of children, all place an enormous burden on the ability of the family to operate as an agent of socialisation, economic support, nurturance and care. The intention of this review, therefore, is to begin to examine the ways in which the family as an institution and the individuals who together make up the collectivity of the family are in fact facing and grappling with the extraordinary challenges which HIV/AIDS has brought to the heart of our society.

It is important to note, in this examination of the institution of family, the family's profoundly complex and ambiguous nature. It is at once a potential site of the deepest nurturance and simultaneously it holds the potential for the greatest damage and violation. People are born into families and it is in families that they make sense of themselves and the world around them (CSA, work in progress). The family combines in unique and sometimes volatile ways, the economic and the intimate, through ties of blood, sex, money, tradition, need and desire.

Families under construction

According to Statistics South Africa, there are just under 10 million households in South Africa (Stats SA, 1998). Yet what does this tell us about families?

Families can be constituted in many ways. The history of South Africa has led to the development of many different family structures – from the wide extended family to the nuclear family. There are families headed by grandparents and families headed by children. There are families of mixed race (where white parents have adopted black children), families of mixed race couples, families with only women or only men as parents, single parent families, and families that are a mix of blood and kin ties. Marriage and blood create many complex ties that link people together and create obligation and support networks. Customary law creates polygamous families and formal law creates monogamous families. There are cultures where the descent and power in the family and community networks is through mothers in matrilineal structures, and those where the power of the male line holds through patriarchy.

What in fact is the family? *The Oxford Dictionary of Sociology* offers one definition: "The family is an intimate domestic group made up of people related to one another by bonds of blood, sexual mating, or legal ties. It has been a very resilient social unit that has survived and adapted through time" (Marshall, 1996).

Susan Ziel, examining the South African family, defines the family as a "social institution comprising an ideological component and a concrete component where the former refers to a set of ideas about marriage, procreation and residence and the latter to the actual domestic arrangements (households) which people reside in" (Ziehl, 2001:41). The family is thus both a structural and an ideological phenomenon. The family also has critical regulatory functions in terms of some of the most primary and intimate processes of society – namely sexuality and socialisation. Within the family, life is produced through reproduction and subsequently, honed, developed and socially located through the processes of socialisation. These processes of socialisation, in general, reflect and reproduce the contours of power in the broader society, locating the young, the old, male and female in hierarchies which mirror their wider social status. The ideal of family as a realm of integrity, security and social coherence remains a powerful public motif, despite the persistent contradiction, of violence, sexual abuse, neglect, abandonment and disintegration.

Despite their inferior social and political status the integrity of the South African family hinges largely on women. The epidemic, with its disproportionate impact on women, will therefore have a particular effect on the ability of the family to adapt to the demands of the epidemic.

The family is not a neutral space, but a context in which power is contested and exercised in daily negotiations between members. Sometimes the exercise of power within the family is brutal and violent; sometimes it is exercised with love and care to socialise and nurture. Understanding the impact of HIV/AIDS on this intricate and fluid terrain does not make easy generalisations possible. But at the heart of the HIV epidemic is this difficult institution. This is where the consequences of the epidemic are played out, where those who are sick hope – but do not always find – nurturance through illness and death, where family members not infected themselves are faced with an irrefutable reality which challenges familial bonds in hitherto unforeseen ways and makes denial, if not impossible, at least more complex.

HIV/AIDS is certainly not the first test that the South African family has faced. The ravages of apartheid, particularly the impact of the migrant labour system on South African families, have been well documented. Despite the challenges of long periods of forced physical separation between husband and wife, between children and parents, and between siblings, the family has persisted, perhaps changed and adapted, but never become extinct. Emotional, economic and social bonds, although severely frayed, sometimes to the point of breaking, have in many instances survived. Looking back at the history of South African families the HIV/AIDS epidemic can be seen as the exception; looking forwards into the future it will become the norm and the way in which families are defined.

The perfect family?

The family is associated with a series of assumptions and idealisations about the nature of the identities individuals should assume through the family life-cycle – as child, as teenager or youth, as adult, and as an 'elderly' person. However, the way in which these identities are actually lived out is at all stages fundamentally shaped by economic and social imperatives which make possible and impossible the realisation of certain identity presuppositions embedded in the social fabric. For example, the social belief remains strong that children should live a life of innocence, nurtured, untouched by responsibility, when in fact many children have battled with the responsibilities poverty thrusts upon them and which make impossible this type of unmediated, idealised childhood. HIV/AIDS, which is leaving many children without even a semblance of parenting, is bringing these idealisations into stark relief.

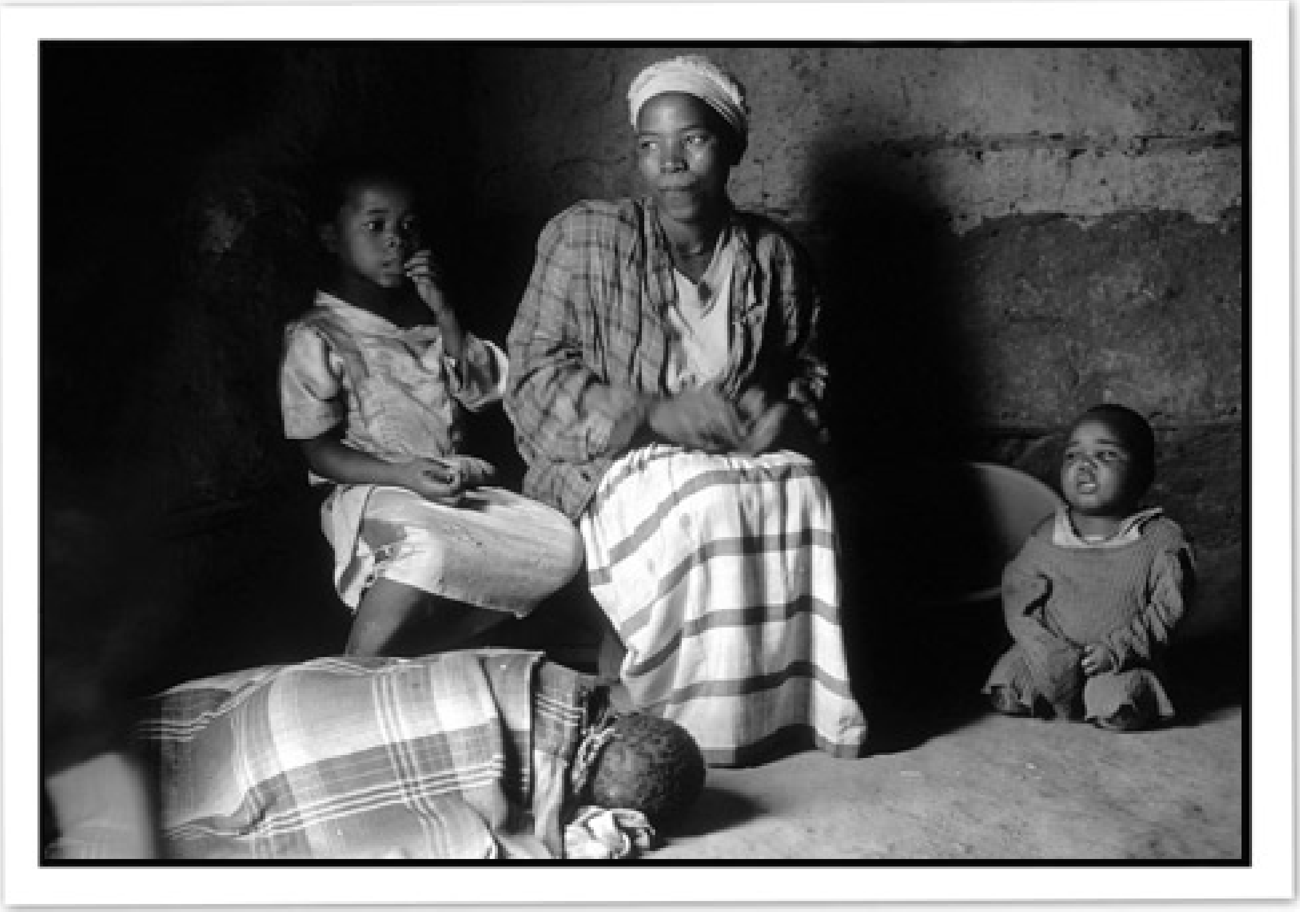
The role of adults as productive and reproductive members of society is also being challenged by early deaths due to HIV/AIDS which obviate the possibilities of production and reproduction. The apogee of a life well lived is old age, ostensibly an easeful flow into rest, as the elderly reap the fruits of a life of productivity and reproductivity. In this ideal still productive children care for the elderly, while they are accorded a special status drawn from years of lived experience, which, if shared, will facilitate the life journey of both adults and grandchildren. The reality, exacerbated by HIV/AIDS, is more often a life of even more grinding poverty combined with loss of economic power, the burden of rearing the small offspring of sick and dead adult children, and a reduction in their social status. Material desperation makes the access of the elderly to government pensions far more powerful than the much more elusive contribution of knowledge and experience which helped binds the elderly to society in less dire times.

The real family?

In Africa the family, like all other social institutions, is complicated by the legacy of colonialism, and, more recently, the impact of globalisation, which brings a multiplicity of ideas and forms of family to bear in a rapidly changing social context. The African extended family has interacted with and influenced imported European models of family. Despite urbanisation, the ethos of the 'extended' family remains a powerful ideological discourse in South African society. The corporate, inclusive nature of the extended family that expands obligations and ties beyond the nuclear unit of father, mother and children, has historically made survival possible in contexts of extreme poverty and social hardship. The epidemic of HIV/AIDS is placing renewed pressures on these networks of care, but they remain resilient, as will be shown later in this *Review*.

In acknowledging the significance of the extended family, it is important to again not overlook the sometimes overbearing networks of power implicit in this family form (as in other family forms), which bind and circumscribe the young and females in particular.

In the context of the family, multiple gender and generational identities intermesh and interact, creating shifting operationalisations of power. Older patriarchies intersect with newer patriarchies. These power structures are profoundly implicated in the unfolding of the HIV/AIDS epidemic in South Africa. Women in many contexts remain unable to protect themselves against infection. This is the legacy of the system of patriarchy, which has defined relations between the sexes for many hundreds of years.



HIV/AIDS thus challenges some of the most fundamental organising principles of the 'traditional' family. It insists on a very concrete assertion of self by women in the already extremely contested terrain of sexuality. Only recently have women won the legislative right to refuse non-consensual sex within marriage.

How do women negotiate these complexities of power within the family? Direct challenges to men may lead to life-threatening consequences such as loss of income, violence, abuse or abandonment. The context of poverty and unemployment in which many women live further weakens their ability to control their sexuality and hence their lives.

Disease and social power

Disease therefore operates not as an independent variable but as a highly visible marker of social power. It traces the outlines of hierarchies already deeply entrenched but usually embedded but unremarked in the ordinary fabric.

The focus of many intervention programmes nationally and globally has been on changing behaviour as a way of reducing 'risk' activities which may increase the possibility of HIV infection. This has led to an extremely acontextual approach to HIV/AIDS that carries with it numerous assumptions about the nature of society, and hence about what are 'aberrant' as opposed to 'healthy' behaviour practices. Only recently have global approaches to HIV/AIDS begun to recognise the importance of context (Barcelona Conference, 2002). However, context has become one more 'variable', which must be understood and managed in order to 'modify' individual human behaviour. Although an important development, the new approach to context is still limited and appears divested of the critical dimension of power.

These approaches deny the ongoing multiplicity of 'ordinary' human behaviour in varied contexts. Conventional approaches have been rooted in a positivist methodology which assumes the possibility and desirability of social functionality, of all social parts operating rationally and concordantly as a coherent whole. The belief in the possibility of this kind of social unitarianism permeates much social thinking and hence global attempts to address social problems. This approach also draws deeply on beliefs about the omnipotence of science and rationalism. This is the Western inheritance of the Enlightenment, which asserts that with the proper 'knowledge' human behaviour can be made rationale and malleable to 'reason'.

While the Enlightenment made and continues to make an indispensable contribution to human thought, in the context of the current HIV/AIDS challenge it underlies an extreme naivete about social processes and considerable overestimation of the power of a rationalist discourse, particularly in contexts such as Africa, where such discourses continue to exist in fierce competition with the transcendental and mystical. In the African colonial context, people have long drawn on a multiplicity of discourses to create meaning malleable enough to effectively negotiate and traverse the complexities of disease and power.

The desire for coherence, for neatly defined solutions in an increasingly complex and unfathomable world, is understandable. However, this approach avoids what is not superficially explicable, and consequently it hinders a critically unblinkered engagement with society as it is. We need to avoid a series of otherisations where the 'at risk' and the safe, the morally upright and the morally dubious, are securely demarcated. Rather, we need to connect with the multiplicity of social experience as the conventional context in which HIV, like all other disease, is embedded.

AIDS: A challenge to familiar certainties

HIV/AIDS – like all social upheavals – forces an interrogation of the assumed, the normative, the common sense. In particular HIV/AIDS presents profound challenges to patriarchy and sexuality as the performance of manhood. It requires new forms of sexual power from women, despite the severe limitations on their practicable ability to exercise these required new forms of power and identity in contexts of economic dependence and sometimes violent, frequently coercive, forms of subjugation.

Specifically, HIV/AIDS challenges conventional sexuality and implicates gender and generational hierarchies directly. HIV/AIDS is forcing a direct engagement with the discourse of sexuality and gender in terms of the visionary perspective of the constitution, and disputing deeply ingrained, common-sense understandings, and negotiations of sexuality and gender. These engagements prod at a whole range of often unspoken, but known taboos. It forces the vocalisation and articulation of these taboos, a breaking of entrenched and complex codes of silence. Nevertheless silence continues to reverberate through the cleavages of generation and gender. *I cannot speak because I am young, old, male, female, infected.*

At the same time as appearing to require new forms of sexual power, HIV/AIDS also elicits new types of policing which extend beyond universal attempts to circumscribe adolescent sexuality, and to incorporate sexuality essential to the reproduction of society itself – sex within the family – in the context of conjugal relations. How can these new challenges be negotiated? In this way, the epidemic must also force a reappraisal of the notion of 'adolescence' and the restrictions placed by society on young people. HIV/AIDS is redefining and challenging as never before our understanding of what constitutes 'adult' and 'adultness' in terms of rights and behaviours, and 'adolescence' in terms of rights and behaviours.

(Over) extended families or new families?

Does HIV/AIDS and its effects in fact afford a rare opportunity, an unforeseen historical moment to (re)fashion identities and social structures that significantly challenge entrenched constructions of patriarchal power? This research indicates that the effect of HIV/AIDS on families is profoundly dependent on prior relationships. In families whose bonds were strong before a member becomes HIV positive, emotional resources and networks of care are activated and often strengthened by the new challenge HIV presents. The family rallies around the sick person, offering love and inclusion. The importance of support to the family in the form of counselling and other social, political and economic interventions is fundamental in facilitating and bolstering the ability of the family to care. However, if a family was already in a state of decay or tension, the burden of HIV can weigh too heavily on the brittle balance of power and interaction, propelling some families to reject and exclude those who are infected, their illness constituting an untenable threat to erratically maintained family cohesion.

Sometimes the burden of HIV decisively breaks bonds upheld in such precarious circumstances.

Thus, the alternative is that HIV/AIDS could lead to the resurgence and reaffirmation of conventional hierarchies as a putative barrier against disease. What is actually needed is a profound re-examination of these forms of authority, and the establishment of new forms of authority that provide for nurturance and socialisation but which do not perpetuate forms of power that subjugate.

Moral regeneration

South Africa has recently seen the emergence of a 'moral regeneration movement', asserting a set of ostensibly universal moral values. These were named by deputy president Jacob Zuma in his speech at the launch of the moral regeneration movement as "goodness, honour, respect, justice, and integrity". Zuma identified a 'moral crisis' in South Africa. In his address to the second conference on moral regeneration, Zuma posed traditional African value systems in opposition to the decay of modernity. "By holding these colloquia on the challenge of moral regeneration we have, in fact, confirmed that we are already traversing the path of renewing our value systems against an onslaught of social, moral, and political decadence, which masquerades as modernity. We have interrogated the idea that the past, simply by having passed, is no longer instructive on good conduct and behaviour. We debated whether the present, by virtue of its currency, is right in everything. We attempted to chart the right way to a future of stability, growth and development for our nation" (Zuma, 2000).

The Moral Regeneration Movement posits South African society as a 'moral' society in implicit opposition to characterisations of Africanness, and particularly within the context of the HIV/AIDS epidemic, African sexuality, as corrupt and 'immoral'. The Moral Regeneration Movement's brochure asserts: "Our people have high moral values which are evident in all our cultures. We must transform the anti-social acts that threaten our society" (*Moral Regeneration Movement Brochure*, 2002). The movement posits as a solution to these moral aberrations the "revival of the spirit of *ubuntu/botho*, using all the resources available in government and civil society" (*Moral Regeneration Movement Brochure*, 2002). An affirmation of the values of the past will be integrated with the radical vision embodied in the South African Constitution; the brochure contending that "[the Moral Regeneration Movement] is committed to establishing the values expressed in our Constitution" (*Moral Regeneration Movement Brochure*, 2002).

The Moral Regeneration Movement's brochure also echoes President Mbeki's assertion of African identity, and of African solutions to African problems: "As President Mbeki said in his state of the nation address to Parliament on 8 February … moving from the understanding that, as we were our own liberators in resistance against apartheid, so too should we today act as our own liberators in dealing with its legacy" (*Moral Regeneration Movement Brochure*, 2002).

The symptoms of this moral decay are identified as the classic concerns of social ordering: "[l]ack of respect for the sanctity of human life; breakdown of parental control of children in families; lack of respect for authority, seen through the brazen breaking of the law and total disregard for rules and regulations; crime and corruption; abuse of alcohol and drugs; abuse of women and children and other vulnerable members of society, lack of respect for other people and property" and perhaps most significantly, "a general attitude of self-centredness and not caring about other people" (Zuma, 2002).

Deputy president Zuma directly links the "weakening of the institution of the family, and the changing nature of the family" with the "breakdown of the moral fibre in our society". He cites the following statistics as evidence of this breakdown: "In 1995, 42% of children under seven years of age were living only with their mothers. Data from the 1996 Census showed that 333 510 children had untraceable fathers, 24 325 had untraceable mothers while nearly 90 000 households were headed by children aged from ten to seventeen years of age" (Zuma, 2002).

In response to what he sees as familial decay and broader social malady, Zuma proposes the strengthening of "the foundations of our hard-won freedom and democracy by building a strong moral society based on a common code of ethics and behaviour" (Zuma, 2002). For Zuma, "some of the answers we are seeking may lie in our past practices, customs and traditions", specifically in terms of the family. "[W]e need to revisit the notion of the collective upbringing of children … we need to go back to the basics and promote the notion of 'Every Child is My Child', which formed the rock upon which communities were built" (Zuma, 2002).

AIDS and morality

Zuma links the challenge of HIV/AIDS directly to the question of morality: "I also hope dear South Africans, that in your deliberations today, you will not forget the imperative of strengthening partnerships against the HIV/AIDS epidemic, and we will look at how this relates to the issue of restoring the moral fibre of our nation" (Zuma, 2002). Zuma sees the moral fibre of the nation as expressed in its capacity to care: "We should emerge with a programme, which says we all care enough to educate others in our communities about the imperative of changing behaviour to arrest the spread of HIV/ AIDS. Part of reviving the moral fibre of our nation and restoring our capacity of caring, includes taking part in the home-based and community based care initiatives in our communities" (Zuma, 2002).

What is missing from these important re-assertions of African identity and African value systems, including the critical social resource of African communitarianism, is a recognition of power, particularly an acknowledgement of the persistence of patriarchy and the way in which this is implicated in some of the most severe consequences of HIV/AIDS. These are values of the past which need to re-evaluated, not re-generated.

This approach fails to develop an understanding of the social forces that create the possibilities for infection. It sets up notions of marriage and family values as 'protectors' from the epidemic and creates new categories of the 'other' – the morally regenerated as opposed to the morally degenerate. The forms of family that helped to cohere society in the past

are no longer necessarily applicable. It is critically important to sift through the past, to find what remains of worth for contemporary contexts. The values of communitarism and *ubuntu* remain an exceptionally important social resource, but these values cannot be an affirmation of the old against the new, or their relevance will be lost. Communal values are already increasingly being rejected by younger generations, who interpret them in opposition to a modernity which is understood as requiring the pursuit of individual material accumulation as the most legitimate and viable route to 'social progress'.

Moreover, extreme material deprivation, which can on the one hand make survival possible through extended networks of care, can also make the practice of altruistic values increasingly unfeasible. Without the social context that makes possible the exercise of *ubuntu* through family and community networks, communitarism will gradually become an arcane ideal. Many contemporary families face poverty so extreme that it fashions its own type of individualism, where the immediate need to survive obviates the possibility of a more communal approach to suffering and deprivation. Despite this, in the face of HIV/AIDS, many continue to make heroic efforts to care, to incorporate, and to alleviate suffering.

In conclusion then, rather than simply calling for a return to ill-defined, amorphous notions of 'morality', it is crucial that we make it possible for families, as centres of care, to stay intact, for men and women to hold equal positions in their relationships, for children to be cherished for their intrinsic value, not their social utility, for openness around matters of sex and sexuality, illness and death and for a reinterpretation of notions of *ubuntu* to signify authentic caring and acceptance. Under the guise of morality it has been, and still is, possible to oppress others and to stigmatise those living with HIV and AIDS and their families. We do not need a reflexive, defensive return to traditional values; but instead an attempt, though admittedly difficult, to maintain continuity with valuable historical legacies while incorporating, the new and innovative, into a meaningful contemporary set of publicly shared values.

The morality of care

Throughout the country, numerous small community based organisations, often almost entirely run by women, have been established. They provide care, counselling and support to the afflicted and dying against enormous odds and despite a lack of resources. Perhaps the starkest example of this impulse to care which is burgeoning throughout South Africa are the networks of 'home care'. As the HIV/AIDS epidemic has worsened and the death toll due to the disease escalated, one of the most striking local social interventions has been the development of a network of home care to tend for the terminally ill in their own homes, in order to both reduce the burden on the state health system, and to provide people with the opportunity to spend their last days with family, while still receiving basic medical attention from trained home carers. A recent report on home-based care in South Africa defines home-based care in the following way, "Home-based care provides an alternative to institutionalised health care, and has received greater emphasis with the advent of HIV/AIDS. The World Health Organisation (2001) defines home 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 order to provide appropriate care and support for people with HIV/AIDS, especially in less developed countries with minimal resources and health budgets, a comprehensive integrated approach that addresses the medical, psychosocial, spiritual and emotional needs is necessary" (*Integrated Community-based Home Care*, 2002).

At the beginning of the AIDS epidemic, numerous hospices were pioneers in AIDS care in anticipation of the extra demand to care for the dying that the epidemic would create. These hospices have, however, remained largely underutilised, as many people prefer to die at 'home' among family and friends. Hospices were the interface between hospitals and home-based care programmes. Hospitals in South Africa have been discouraged from admitting AIDS patients and caring for them until they die. This is premised on the notion that people with AIDS should not take beds away from other patients. Also, because of the ways in which AIDS developed, with long periods of greater or lesser degrees of illness, requiring different kinds of care and nursing, it was believed that people with AIDS should be cared for at home – surrounded by those whom they love, and who love them.

A recent report compiled by the Department of Health to evaluate progress on the government's strategic plan for HIV/AIDS, reports that by March 2003 a total of 466 home/ community based care programmes were in place, there were 9 553 volunteers attached to these programmes and 370 172 people were accessing these services (*Tracking Progress on the HIV/AIDS and STI Strategic Plan*, 2003).

Originally, home-based care was a middle-class concept premised on two assumptions that are, however, often inapplicable in the South African context. The first premise is that people who require care will have a home, and a home in which there will be the items necessary for care or that these items can be obtained. The second premise is that that there is an absence of stigma, prejudice and hostility to people with HIV and AIDS (Crewe, 2002).

Although significant efforts have been made to adapt the traditional home care model to the South African context, the reality in South Africa is that many homes simply cannot take on the demands of care, and that a large proportion of people requiring care do not have homes that can accommodate an ill and frail person. In addition, ongoing stigma coupled with poverty often militates against home-based care as an effective response. The Departments of Health and Social Welfare have not yet put in place an efficient and comprehensive home-based care programme, coupled with home visits and access to welfare grants. Many PLWAs are hence very much worse off at home, despite being surrounded by family and friends, than they would be in hospitals, or hospice or community care. Many families are also much worse off than they would be if their loved ones were in any of these forms of care.

Despite these drawbacks and as the AIDS epidemic intensifies, across South Africa groups of women go out daily to visit and care for the sick and dying in their homes. These home carers share what nursing and medical expertise they have, and negotiate labyrinthine family dynamics to stay with, care for and comfort the ill until their death. Then they go out again and again to walk with other individuals and other families along the path to death.

Knowledge of HIV – 'from discrimination to care'

One of the key obstacles to communities' capacity to care has been the stigmatisation of the infected. This is a defensive mechanism to produce an 'other', a social identikit of the infected that creates illusory boundaries between the sick and healthy and which can lead to the social quarantine of the potential contaminant. An interviewee at the Khanya Family Centre suggested that "it's just unfortunate, when we started talking about HIV/AIDS, it was looked at as a sexual sin, who wants to be associated with sin, especially a sexual one, but I think with time, and where we are now regarding HIV in our country…people are now beginning to change their attitudes" (Khanya Family Centre interview, July 2003).

The social rejection of persons with HIV and the AIDS ill has been a key challenge: "the stigma is always there … like the issue of the secrecy around the death, normally the community will spread around that somebody died of HIV/AIDS … we find that the family even know about it, it's there … As a community maybe we pretend that it is something far away from us, or is it due to the fear that they will also be stigmatised?" (Khanya Family Centre interview, July 2003).

A survey conducted by the Kaiser Foundation in 2002 of 771 HIV/AIDS-affected households in South Africa similarly maintained: "An indication of the stigma associated with HIV/AIDS was the fact that even in their final sickness, many people preferred not to disclose their HIV status to family members. Only half of the households surveyed said that the sick person they were caring for had HIV/AIDS. Households who were not aware of the underlying cause of the person's ill health most often mentioned opportunistic (HIV-related) infections such as tuberculosis or pneumonia" (*Hitting Home,* 2002:25).

The community organisation Vatech also illustrates this reluctance to acknowledge HIV/AIDS: "Those who didn't want to tell they're HIV positive, they used to hide their hospital files. Now when death comes you have to take the mattress off, you have to take the blankets off, it's where they find the card, when they find the card, that's where they find that the person is HIV positive" (Vatech interview, July 2003).

Nevertheless a consensus appears to be emerging among community organisations that although ostracism and stigma are still very much in evidence, there has been a reduction in the depth and extent of stigma. This shift is probably being shaped by the increasing array of information available through various HIV/AIDS awareness campaigns. But perhaps even more persuasive is the pressure of the experiential, the increasingly intimate association with illness: "Communities are realising that there is no way they can run away from HIV, everyone is affected by the infection of the family member, neighbour, the closest person to them" (Khanya Family Centre interview, 2003).

In particular, the softening of stigma has been most evident within the family nucleus itself. A Khanya Family Centre worker who was interviewed explained: "It is not like in the olden day, you're HIV positive, you're not my child, go and find a place to stay. Now families find it difficult but at least they were there for them. It's not like that anymore, it's like, you're still my child, I still love you … actually it is kind of like binding them together" (Khanya Family Centre interview, July 2003).

Similarly the Kaiser Family Foundation survey found that "80% of those who had been open about their HIV status said that the household had been very supportive" (*Hitting Home*, 2002:iii). While many of those infected with HIV fear the rejection that the disclosure of their status may elicit from family members, often rejection within the family unit is not in fact experienced. As an HIV/AIDS co-ordinator from CARE explained, while the majority of PLWAs may still be unwilling to disclose, particularly with the right preparation, many do not get as negative a response as they expect (CARE interview, July 2003).

Communities are made up of families

The response of wider community networks to disclosure is often more complex. The Kaiser Foundation report concludes that, "only 35% of those who had revealed their HIV status reported a supportive response from the community. One in ten reported hostility and rejection" (*Hitting Home*, 2002: iii). Hence many families, while rallying around a sick or infected member, may keep the person's HIV status secret within the family, in order to create boundaries to protect the family unit and keep at bay potential social denunciation of the entire family, elicited by the infection of one member. As one community worker explained, "The families, they are still trying to make this a 'family thing'" (Ebenezer interview, July 2003).

Ironically, attempts to keep the experience of HIV/AIDS within the family may undermine the ability of families to come to terms with the challenge of HIV/AIDS through the assistance of external agents such as community support organisations. Some of these organisations report individuals being reluctant to be seen entering their offices for fear of public association with the disease of HIV/AIDS. Nevertheless where intervention is effected, it appears that families are showing an important capacity for change on the basis of a deeper understanding of HIV/AIDS. While many families initially react with shock, shame and even rejection of the person living with HIV/AIDS, the community organisation Vatech contends that given counselling and 'education', families frequently come to terms with the fact that a family member is HIV positive, and are able to support and accept them (Vatech interview, July 2003). Minnie Themba of Vatech recounts the poignant response of families who have undergone counselling: "We didn't know we were doing the wrong thing" (Vatech interview, July 2003).

There are also many instances where families are not open to this type of intervention and the HIV-positive person is decisively rejected. In some families the ill are not physically expelled from the home, but are ignored and isolated. The exclusion of the person living with HIV is an acknowledgement of their condition, but an acknowledgement which rejects rather than cares for their vulnerability,and is instead an affirmation of their status as diseased or 'contaminated'.

In some instances rejection is a physical performance of exclusion. The ill may be actively 'hidden' by the family, in fear of community censure or shame connected with the sexual associations of HIV/AIDS. As Minnie Themba explains: "Others are hiding them in the bedrooms. Saying no, he's not here" (Vatech interview, July 2003).

Some of the terminally ill are bodily cast out of the home, and families build outside shacks for the ill. This is intended to prevent anticipated contamination of the family by the HIV-infected person and as a desperate and harsh attempt to manage the physical consequences of illness, such as vomiting and diarrhoea, which can make the presence of the terminally ill in confined home spaces without sanitary facilities untenable. The Kaiser Foundation survey found: "One in six of AIDS-sick individuals in the households surveyed could not control their bowels and about the same number could not control their bladders. About 20% could not wash without assistance" (*Hitting Home*, 2002:ii). The survey outlines the very real challenges that families face in the care of the terminally ill: "The households worst affected by HIV/AIDS are also the most underserved by basic public services such as sanitation and piped water" (*Hitting Home*, 2002:ii).

Only 43% of households in the Kaiser Foundation survey had a tap in the dwelling and nearly a quarter of rural households in the survey had no toilet at all. "These harsh circumstances substantially add to the burden of caring for an AIDS-sick person, as well as the patient's suffering and loss of dignity" (*Hitting Home*, 2002:ii).

The lack of basic infrastructure combines with the symptoms of HIV/AIDS to create an extremely difficult environment for both the carer and the ill: "One fifth of the sick individuals had to have assistance walking even on level ground, while almost half had to be helped on stairs or uneven surfaces. This becomes a particular problem when toilet and washing facilities are not in the house, or are even not in the immediate vicinity of the dwelling. Chronic diarrhoea becomes even more debilitating when the sick person may have to struggle outside to relieve him or herself. Only 20% of rural households in this survey had access to a flush toilet. And substantial proportions of both rural and urban households still depend on pit latrines or buckets" (*Hitting Home*, 2002:16).

Thus HIV/AIDS incorporates death and illness into the fabric of daily family life, particularly given the lack of state resources for hospital care. In the context of poverty and sickness, how is it possible to manage illness and death with dignity, as an affirmation of the value of continuing life, when social deprivation makes the degradation of illness so stark, so unalleviated?

Despite all these hardships and deprivations, many families do care for the ill. The possibility of care, however, is greatly enhanced if families are already aware of a member's HIV status and have had the opportunity to prepare themselves for the possibility of illness. Unfortunately many of those infected, fearing rejection, deny their families the opportunity to care by hiding the nature of their illness until its ravages are so severe that they are irrefutable. Under these circumstances the potential for family rejection and stigmatisation is significantly increased.

Extended family

The activation of networks of care embedded in the 'extended' family has been posited as one of the most feasible responses to the consequences of the HIV/AIDS epidemic, particularly the orphaning of children. But what in fact is the extended family, and does it exist in South Africa?

Ziehl writes: "A number of scholars have shown an interest in the question of whether modernisation, urbanisation and industrialisation have resulted in an homogenisation of family patterns in South Africa. This has generally taken the form of asking whether among Black South Africans, in particular, extended family households have become less common and nuclear families more common over time" (Ziehl, 2001:36). Ziehl distinguishes between the nuclear and extended family forms in the following way: "A distinguishing feature of the nuclear family pattern is the rule that upon marriage a couple sets up an independent household … A distinguishing feature of the extended family pattern is that upon marriage the couple joins the household of one of the spouses. In cases of communities which reckon descent in the male line, this means that the wife joins the husband's family" (Ziehl, 2002:38).

These simple characterisations of families as nuclear or extended belie the considerable fluidity inherent in all family structures, as the movement through different stages of the life-cycle adds and subtracts members on a continuous basis. Movement between families adds further fluidity to the institution of the family. For example, Manona points out that although the three-generational extended family is still the predominant household type in South Africa," there are also instances of households being extended laterally through the inclusion of collateral relatives – usually adult siblings" (cited in Ziehl, 2002:38).

Ziehl also hypothesises that children frequently move between extended families: "Given the tradition of relying on family labour it is likely that many Black children move frequently between different extended family households … Budlender (1998) gives us a clue in this regard since she shows that according to the October Household Survey, 40% of African children were living with both biological parents; 46% with their mother only; 2% with their father only and 13% with neither. Given what we know about how common the extended family is, most of the latter category would probably be children living with their grandparents" (Ziehl, 2002:44).

The differences between the nuclear and extended family forms are therefore structural, but as of much import are the differing ideological and cultural assumptions, which distinguish the nuclear and extended family structures. While apartheid undermined the abilities of families to structurally enact the extended family, the ethos and ideal of extended family remained strong. People separated by thousands of kilometres and many years of migrant labour would continue to perceive themselves as kin. It is possible, however, that processes of modernisation and globalisation are having a more profound impact on the ethos of the extended family as Western values, embodied in the nuclear family form, penetrate South African society more deeply.

The debate about whether the extended family still exists in South Africa is an extension of a long-standing discussion in European family sociology about whether industrialisation and urbanisation inevitably lead to a change in family type from more structurally extended forms to nuclear households. Research into the history of the family in Europe has revealed that there has not been a simple linear progression from one family form to another, mirroring processes of urbanisation. In Africa the interaction of colonial and African family forms, and the coercive nature of urbanisation in South Africa particularly, has added considerable complexity to development of the family form.

Simkins (1986) argued: "Perhaps just over half of South African households are nuclear in structure. If there is a trend towards the nuclear household, it is a very weak one. More complex forms will be distributed in varying measure and to a very substantial degree throughout South African society for as far ahead as one can see" (cited in Ziehl, 2001:38). Russell states in this vein that there is "compelling evidence … of the persistence among black metropolitan households of distinctive patrilineal householding principles, which prove resilient and compatible with industrial urbanisation. It alerts us to the probability that as Africa becomes more firmly entwined in the world economy, distinctively African social family patterns are likely to emerge and persist. In South Africa they are likely to predominate and prevail" (cited in Ziehl, 2002:33).

Most recently Moller contended: "Contrary to common knowledge, the multi-generation household is not on the decline; the majority of African elderly still live with children and grandchildren … factors such as respect for the elderly in the family setting, improved services and government transfers to elderly households, the African renaissance and demographic trends bode well for the continuity of the multigeneration household as a living arrangement of choice in the future" (cited in Ziehl, 2001:39).

The consensus then is that in South Africa, despite processes of urbanisation, forced removals and migrant labour, the extended family form and value system remains durable. As Kayongo-Male and Onyango argued in 1984: "It was mistakenly assumed by early urban theorists that the urban environment inevitably destroyed the extended family, because of a type of environmental determinism" (Kayongo-Male & Onyango 1984: 34). Instead they point to the ways in which the extended family has itself shaped the urban environment: "the urban environment may have so many pressures that the extended family becomes stronger in response to such pressures …In Africa, the extended family often financially assists migrants in towns, in order to help the migrant obtain work quickly" (Kayongo-Male & Onyango, 1984:35). Nevertheless the traditional extended family has been impacted by and shaped by processes of colonialism and urbanisation, creating a increasingly hybrid family form, "traditional values of family life are not only being retained but are actually being integrated with modern family characteristics with a resulting synthesis of diverse systems of family life …Thus African family life is neither purely traditional nor purely Western" (Kayongo-Male & Onyango, 1984:105). However, much of this debate and these findings predate the realities that HIV and AIDS are bringing to extended families and the ways in which global economic forces have operated in the last two decades.

What then are the distinguishing features of the extended family that could bolster an effective social response to HIV/AIDS? Extremely significant, given the growing number of children who have lost one or both parents to HIV/AIDS, is the historically communitarian nature of child-rearing in African extended families. As Diane Kayongo-Male and Philista Onyango write, "Perhaps the most striking characterisation of socialisation in the African family is the large number of agents of socialisation, as opposed to nuclear family systems where only the parents are involved in the socialisation of their own children … traditionally, a child was socialised by the whole community in the sense that he could be corrected or disciplined by any adult if he misbehaved" (Kayongo-Male & Onyango, 1984:19).

In Africa the involvement of grandparents in the lives of children has also formed an important part of the socialisation process: "Grandparents were other important agents of socialisation in traditional African society. They were instrumental in introducing young people to more sensitive topics such as husband-wife relationships and sexual behaviour, as well as the larger societal roles, values and traditions. They relied largely on story-telling, proverbs and songs as techniques of socialisation. After the age of ten or so, grandmothers were more closely involved with female grandchildren and grandfathers with male grandchildren" (Kayongo-Male & Onyango 1984:20). Thus it is evident that the role that grandparents are currently playing in the context of the HIV/AIDS epidemic combines an historical engagement with the care and nurturing of children with the pressures of contemporary social realities. What distinguishes the current role of grandparents is that rather than forming part of a web of complementary socialising agents within communities, as parents die grandparents are increasingly being forced to take sole responsibility for both the economic and social care of grandchildren. The middle generation with its breadwinning ability and its legal guardianship of children is being lost.

Although the context of poverty in South Africa has long put pressure on the idealised role of grandparents, with elderly pensioners often providing the sole source of income for large numbers of unemployed family members, HIV/AIDS is increasing the burden of grandparents even further, taking away even the modicum of social and economic support which adult children, even in the most extreme circumstances, are able to offer while alive.

Another characteristic of the extended African family which is drawn on in the context of the HIV/AIDS epidemic, and which is similarly being placed under renewed pressures in the form of child-headed household, is the role of older siblings in the socialisation of younger family members. As Kayongo-Male and Philista Onyango argue: "siblings were very heavily involved in the socialisation process of younger siblings. Elder siblings sometimes had authority equivalent of their parents over the young children. The elder siblings were highly respected by their younger brothers and sisters, and were expected to sacrifice for the younger ones as if they were their own children.

"Much of this type of responsibility has been carried over to the modern times with older children being expected to put the other children through school if the older ones obtain employment" (Kayongo-Male & Onyango, 1984). Here again, although older children may in the past have been expected to take significant responsibility for younger siblings, this type of care was mediated within the context of a broader family structure, of which sibling support formed one component. In the current context, older siblings who are still children themselves are being increasingly compelled to take sole responsibility for the welfare of their younger siblings when both parents die and the extended family network is unable or unwilling to absorb them.

Kayongo-Male and Philista Onyango (1984) also argue that fostering of children as an expression of collective responsibility for child-rearing is common in African families, although they acknowledge that the nature of this fostering differs between regions in Africa, sometimes reinforcing kin solidarity, and sometimes functioning as a means of offering children expanded educational or employment opportunities. While the extent to which fostering has been an established part of the family system in South Africa has not been extensively researched, the movement of children between households recorded by Budlender would seem to indicate that a substantial number of children, rather than living with their biological parents, are residing with relatives who are able to offer them enhanced opportunities. The incorporation of children into families other than their own or members of the wider kin network has been an important counter to poverty through the pooling of all available social resources to ensure that children are given the best access possible to resources through familial networks.

Thus it is apparent that South Africans are already drawing on a historical reservoir of African values and approaches to family, such as collective responsibility for children and the involvement of multiple caregivers. Therefore, arguably, what is required is not a blanket reassertion of 'traditional' African values, but an interrogation and reworking of these 'traditions' to find African approaches to family that are of contemporary value and relevance, and which could be meaningfully strengthened in the context of HIV/AIDS.

However, the ability of the extended family to absorb the extensive social pressures posed by HIV/AIDS in combination with poverty should not be overestimated. As a Khanya Family Centre community worker explained, "I think the problem is poverty and unemployment. I cannot afford my own children, how can I bring in my nieces and nephews? … most of the time we try at all costs to explore placement with the extended family but it is a bit of a burden, a problem … the rate of unemployment and poverty, people find themselves battling, they don't want to take them on" (Khanya Family Centre interview, July 2003).

In this context a recent UNAIDS report argues, "The extended family can only serve as part of the solution to mass orphanhood if adequately supported by the state, the private sector and the surrounding community. This need for support is desperate in the worst-hit regions where the capacities of families are being eroded by economic decline and deepening poverty … but it is also clear that families are willing to take in an orphan if support is made available' (*Report on the Global HIV/ AIDS epidemic*, 2002) Thus, in the context of the HIV/AIDS epidemic the institution of the extended family offers an important potential means to counter some of the worst social consequences of HIV/AIDS; nevertheless, if it is to play this role, mechanisms will need to be found to support extended families in expanded care and economic support functions.

In advocating the strengthening of the extended family as a support system in a time of social crisis, it is critical not to overlook the detrimental ways in which power can be exercised in the extended family and which undermine efforts to respond to HIV/AIDS. Women, in particular, caught within a network of obligations and duties rooted in the extended family, sometimes struggle to exercise the personal autonomy required to protect both themselves and their children from HIV infection. For example, pressures on women from female in-laws to breastfeed their children, because breastfeeding is widely believed to be essential to bonding and nurturance, is cited by a number of NGOs and PLWAs as an obstacle to the prevention of mother-to-child transmission of HIV (CARE interview, NAPWA interviews, July 2003).

Women also find themselves the object of blame in the context of the extended family, where guilt attributes to women in essentialist ways, as one PLWA and NGO worker explained: "men don't die, women cause male illness and death" (SAKHI'SIZWE interview, July 2003). With the association of prior guilt, it appears that patrilineal in-laws frequently perceive women as the original source of illness within the family, leading to ostracism and lack of support at times when support is needed most.

A Khanya Family Centre worker recounts the story of one family where both parents subsequently died: "When both parents were still ill, the paternal in-laws were blaming the woman and their son died first and what they did, it destroyed the children because they had six children, so the parents have now died, the children still having those problems of coming and staying together as a family … these children are left on their own now, they are supposed to pick up pieces, they still cannot see eye to eye as siblings due to things that were not of their own making" (Khanya Family Centre interview, July 2003).

Women are often left extremely vulnerable after the death of their spouses, and in fact their continuing survival is often perceived as a testament to their guilt. After protracted periods of caring for an ill spouse who subsequently dies, this can constitute an extraordinary emotional burden. Khanya Family Centre workers explain that patrilineal in-laws may blame the female spouse for the death of their male relative, and will consequently be reluctant to shoulder the burden of looking after a surviving female partner, but concurrently assert entitlement to any property associated with the relationship: "They want to know how much money they left, so they can take" (Khanya Family Centre, interview July 2003). A Khanya Family Centre worker outlines an illustrative story: "When the husband died, the in-laws told the woman that she must 'go home'. They think of money, this poor women, this man was now three weeks at the hospital, not talking, just looking at you like this … you couldn't see whether he sees you or not but the poor woman was at the hospital day and night, day and night" (Khanya Family Centre interview, July 2003).

Children as 'assets'

The possibilities of the exploitation of vulnerable children by members of the extended family are also very real. Anecdotal evidence suggests that in some instances, members of the extended family will undertake to care for children who have lost their parents, as a means to obtain access to resources such as homes left by deceased parents, or even child care grants. In other instances, family members will take over the care of small children, but exclude adolescents on the premise that they are able to fend for themselves, or because the inclusion of a young adult in a new family is likely to strain internal family relationships more than the incorporation of generally more acquiescent young children. The decision to take in children is also influenced by sometimes coldly pragmatic calculations, for example how 'useful' will a child be to the family – what kind of labour and household duties can they perform in return for how much required care?

Continuing stigma regarding HIV/AIDS also presents an obstacle to the incorporation of children left without parents. The fear of contamination creates further barriers to their inclusion within the wider family network.

The impact of stigma plays out in other ways as well. In some instances a parent may die without telling any family members the source of their illness. Family members may take in children care and support – an additional expense that was unexpected. A further complication emerges when parents verbally nominate a primary caregiver to take over after their deaths, but fail to make legal provision for a particular family member to take over custody of surviving children. As a consequence, a child may become contested property between relatives. An Ebenezer home care worker explains, "My cousin, she passed away in 2001. So she didn't tell us she was HIV positive … before she died, she took her son and say, she must stay with me. After the funeral I go to Boksburg. I took him to stay with me in Atteridgeville. I didn't know that this boy is HIV positive. After two months he started to get sick, very serious, I take him to hospital … they didn't want to tell me what's wrong because I am not the mother, I talked to the social worker … they showed me the result, he was HIV positive … the grandmother want to take him because he is sick, up till now we are still fighting … they took him to Pietersburg until he died (at age 13). They just tell me, come to the funeral" (Ebenezer interview, July 2003).

Gender

According to UNAIDS, "A decade ago women seemed to be on the periphery of the epidemic; today they are at the epicentre. Fifty five percent of HIV-positive adults in sub-Saharan Africa are women. In many southern African countries, teenage girls are infected at a rate five or six times greater than their male counterparts. Although HIV/AIDS is a disease affecting both men and women, recent trends are showing that more and more women are becoming infected and at very young ages" (*HIV/AID Epidemic, An Inherent Gender Issue*, 2003).

A recent national survey of HIV prevalence found that "…women have a higher HIV prevalence than men" (HSRC survey, 2002:20). The comparative national HIV prevalence rates for men and women are 9.5% and 12.8% respectively. For young women between the ages of 15 and 24 years, HIV sero-prevalence is estimated to be 17.7%, as opposed to a sero-prevalence rate of 12.8% among young men in this age group (*Nelson Mandela/HSRC Study of HIV/AIDS*,2002:49).

The consequences of these differing HIV prevalence rates are already making themselves felt in terms of shifting patterns of mortality. A Medical Research Council (MRC) study on the impact of HIV/AIDS on adult mortality found: "The mortality of young adult women has increased rapidly in the last few years with the mortality rate in the 25-29 year age range in 1999/2000 being some 3.5 times higher than in 1985" (*The impact of HIV/AIDS on adult mortality*, 2001). According to the MRC, the consequence of this increasing mortality was that by 1999/2000 mortality for women in early adulthood was higher than for women in old age: "[I]n the case of females, the age distribution of adult deaths has become bi-modal and the peak for the younger adults is higher than the peak for the older women" (*The impact of HIV/AIDS on adult mortality*, 2001:32) The increase in female mortality has been particularly significant since 1996: "there has been a slow increase in adult death rates … In the case of women there was a slight increase up until 1996, followed by a marked increase in the 20-49 year age range over the last two years, with the emergence of a young adult peak" (*The impact of HIV/AIDS on adult mortality*, 2001:27).

While male mortality rates have also increased, previously high mortality rates among men mean that the increase in male mortality has not been as dramatic as that in female mortality. Men also generally die of AIDS at a later age than women do, with peak mortality occurring between 30-35 years. Peak mortality for women occurs between 25 and 29 years of age (*The impact of HIV/AIDS on adult mortality*, 2001:35).

How does one make sense of these grim statistics, particularly in terms of the narrative of South African women and particularly given the central importance of women to South African families?

The HSRC survey posits a combination of biology and social context to explain differing prevalence rates between men and women: "There are biological and social reasons for this. Women's reproductive systems make it easier for them to be infected with HIV, and men are more effective in transmitting the human immunodeficiency virus … Biology alone, however, does not explain the imbalances between men and women.We have to consider the interaction between gender and biological factors to understand how women and men may be at increased risk because of gender construction. Among these are: the deep-seated encouragement of multiple sexual partners for men; male control over barrier methods; and women's economic situation which make them and their families dependent on men" (*Nelson Mandela/HSRC Study of HIV/AIDS*, 2002:20).

Geeta Rao Gupta from the International Centre for Research on Women (ICRW) explains the concept of gender, "Gender refers to widely shared expectations and norms within a society about appropriate male and female behaviour, characteristics and roles. It is a social and cultural construct that differentiates women from men and defines the ways in which women and men interact with each other. Gender is a culture-specific construct – there are significant differences in what women and men can or cannot do in one culture as compared to another" (Rao Gupta, 2000:1).

Therefore gender location is grounded in human biology, but it is the cultural constructions of that biology, which lend gender its social salience. "The word 'sex' denotes an individual as male or female, and derives from the individual's biological attributes. The word 'gender' extends these physical attributes to create an ideological construct, which is based on the way that society understands those biological differences between men and women. What we recognise and experience as 'masculine' and 'feminine' is socially and culturally constructed as our 'gender', which involves a whole constellation of roles, expectations, social and sexual behaviours" (Bazilli, 1991).

This gendering of social roles has a direct impact on the differential access of men and women to power and productive resources. Rao Gupta argues, "What is fairly consistent across cultures is that there is always a distinct difference between women's and men's roles, access to productive resources, and decision-making authority. Typically men are seen as being responsible for the productive activities outside the home while women are expected to be responsible for reproductive and productive activities within the home. It is clear from over 20 years of research on women's roles in development that women have less access to, and control over, productive resources than men" (Rao Gupta, 2000:1).

Gender thus structurally locates individuals within the social whole. Gender location profoundly shapes social experience, contouring the world in ways that appear irrefutable and making available only parts of the common cultural legacy to men and women respectively. Inherent in gender location are, therefore, both delimitations and potentialities. The destabilisation intrinsic to a socially dynamic environment, such as the spread of HIV, creates the context in which established gender identities are most likely to be challenged.

Over the past ten years of the HIV/AIDS epidemic, gender and sexuality have become recognised as critical to an understanding both of the rapid spread of HIV/AIDS within the South African context, and the way in which the disease has developed. Rao Gupta asserts therefore that, "We known for at least a decade that gender and sexuality are significant factors in the sexual transmission of HIV, and we now know that they also influence treatment, care and support" (Rao Gupta, 2000:1).

Many of these processes of gendered power are evident in the trajectory of HIV/AIDS in South Africa. The way in which gendered power is played out within the context of HIV/AIDS involves a complex confluence of inherited and lived power relations. These enactments and negotiations of power involve all aspects and stages of the disease of HIV/AIDS from disclosure to care. Men and women respond differently and are treated differently on disclosure, through illness and during death.

As one women living with HIV/AIDS put it, "Men are more rejecting and they are more in denial … I think it's the power, the power that they have, that they are the head of the family, that thing is the one that makes them not to accept easily" (PLWA interview, July 2003).

A closer examination of the social milieu reveals that the environment of gendered power in which women live can severely inhibit women's ability to change behaviour, however willing they may be, and however inherently 'rational' such change would be.

As the report of a conference on gender and HIV argued in 2000, "Current HIV/AIDS prevention strategies commonly promote monogamy, fidelity and condom use, in connection with morality and religion … since these strategies have failed to address the underlying concepts of masculinity and high-risk or even violent practices of sexuality, they have proven to be insufficient and even harmful. Due to systematic gender inequality … women have not been able to enforce these strategies *vis-à-vis* their male partners. Often, they have added to the existing burden on women's lives, as safe sex negotiation has become the exclusive responsibility of women" (*HIV/AIDS: Grasping the Reality of its Gender Dimension*, 2000:2).

Interviews with women living with HIV and NGOs working with HIV-positive men and women, conducted as part of this review, similarly reveal the complexity of the lived experience of sexuality, gender and power for men and women. Both men and women negotiate the difficult new demands created by illness and death through the interstices and crevices of power.

Rao Gupta elucidates the link between gender and sexuality and the relationship of power to both, "Sexuality is distinct from gender, yet intimately linked to it. It is the social construction of a biological drive. An individual's sexuality is defined by whom the individual has sex with, in what ways, why, under what circumstances, and with what outcomes. It is more than sexual behaviour: it is a multidimensional and dynamic concept. Explicit and implicit rules imposed by society, as defined by one's gender, age, economic status, ethnicity and other factors, influence and individual's sexuality … Power is fundamental to both sexuality and gender. The unequal power balance in gender relations that favours men, translates into an unequal balance in heterosexual interactions which increases both men and women's vulnerability" (Rao Gupta, 2000:1-2).

In addition human subjectivities regarding sexuality are diffuse and frequently contradictory. The assumption of coherence, of a simple cause-and-effect relationship to sexuality, refutes this undeniable density. Leclerc-Madlala, for example, has examined the contradictory ways in which both male and female sexuality are constructed. Constructions of male sexuality pose men both as victims of women's primal charms, as well as active initiators of sex with a multiplicity of partners, and the latter is seen as an essential marker of manhood. Constructions of womanhood, on the other hand, continue to value reproduction and motherhood. However, new cultures of materiality are increasingly creating revised conceptions of womanhood, where women are actively using sexuality as a resource through which they can acquire other economic, social and emotional resources, not by means of the traditional institution of marriage, but through a multiplicity of relationships with men which leave some forms of autonomous power intact.

It is clear, however, that despite the sometimes incongruent nature of sexual identities, these subjectivities are not entirely without form. They clearly interact with and construct power in ways, which may be ambiguous, but are never arbitrary. Constructions of sexuality in the era of HIV/AIDS attempt to affirm male power through the performance of sexuality, while positing women as the original source of disease. These constructions do not tamper with male authority and instead form a defence against women's attempts to assert new types of sexual boundaries.

Despite severe limitations on female power, the HSRC survey nevertheless indicates that women are attempting to protect themselves through abstinence and the use of condoms. Whether abstinence can be regarded as an assertion of female identity is open to question, but given prevailing cultures of sexuality, which prescribe sex as a critical part of identity, even for women, perhaps the power of this approach to the problem of infection should not be underestimated. The HSRC survey thus reports, "Important trends identified when comparing behavioural responses of women aged 15-49 include a greater proportion of women in 2002 having no sexual partner in the past 12 months; and greater proportions of women in 2002 having used a condom at last sexual intercourse (28.6% vs 8%)" (Nelson Mandela/HSRC Study of HIV/AIDS, 2002:21).

The Gendering of Care

In a profound irony, it is women, carrying out their traditional role as child-bearers and child-carers, who are discovering the existence of disease in their families, but this 'discovery' attaches to them as blame, since in their discovery they are perceived as creating the disease.

A CARE co-ordinator explains: "Women fear direct violence from their partners on disclosure. In partnerships it is women who are being tested, often as a result of pregnancy" (CARE interview, July 2003). In general women are far more likely to engage with the health system, both for themselves and for their children, creating multiple points of contact with medical institutions, and so they are also more likely to draw out information about HIV status. Men, on the other hand, attempt to hold themselves aloof from the health system, seeking sometimes the intervention of traditional therapies, rather than the western medical science.

As one community worker put it, "they [men] don't get sick, even when they get sick they don't go to doctors, they don't go to the clinic, they don't get pregnant, they go to witch-doctors" (Khanya Family Centre interview, July 2003). Another community worker argued: "Most of men like to say they are bewitched, it is witchcraft, they have been eating something which is no good for them … they don't want to accept that AIDS is there" (Vatech interview, July 2003). No doubt these differing responses to the 'medical' are shaped by an ethos of machismo that rejects any sort of vulnerability, combined with an historically fraught interaction between colonialism and disease that consistently treated the colonised as 'other' and inherently diseased.

The consequence of men and women's differing experiences of AIDS is that the 'knowing' of women about HIV/AIDS is not seen by men as knowledge about the empirical, but in fact a creation of that reality. They are the bearers of disease, they can through their 'knowing' embody illness and contaminate men. Women are accorded an extraordinary amount of power in this sense, but it is negative power. They create disease and, according to some mythology, they are even the fundamental source of disease and male mortality. Leclerc-Madlala noted this interaction between gender and blame in her research in KwaZulu-Natal: "Blame for the current HIV/AIDS epidemic falls squarely on women, according to local narratives in St Wendolin's … Common discourse portrays men as passive victims of HIV infection that is carried by and passed along through women" (Leclerc-Madlala, 2002:12).

As a woman living with HIV/AIDS explained, "Sometime the men will blame the women for bringing the virus in the house because in many times women are the ones who find out first, especially at antenatal clinics, men they don't like to go to doctors, even clinics, they go when they are terminally ill" (PLWA interview, July 2003).

The blaming of women for illness extends to a complete denial of ownership of disease for men – since women are the source and carriers of disease, 'the problem' does not belong to men, it adheres to women. "They still believe that HIV/AIDS, sexually transmitted disease is a woman's problem … some men still believe that" (Khanya Family Centre interview, July 2003). As another community worker explained this projection of blame, "Men decide to spread the virus when they get it. Everything which is wrong is about the women" (Vatech interview, July 2003).

The reluctance of men to 'own' the disease as a mutual problem is also linked to the framing of women as property objects. Sullied, diseased property needs to be got rid of, not healed: "Men are men, they can't deal with it … there is this belief that a man should have three or four women, if one gives problems, find another" (Kwaze Kwase interview, July 2003).

As much as men blame women, women also assume their essential guilt, as this story recounted by a Khanya Family Centre caseworker indicates: "Normally the women are scared that the man is going to get angry … I have another case of a boyfriend infected the girlfriend and the girlfriend was pregnant with twins, and he was worried about telling her … we arranged that she had counselling with the sister … the first thing she said when she was told she was positive was: 'How am I going to tell my boyfriend? He's going to be angry with me, he's going to dump me', women never think that they were infected by [men] … it could have been him but instead just because she was the one who discovered she would think that I'm the one who brought this … maybe they are scared, maybe the issue of financial security …" (Khanya Family Centre interview, July 2003).

While women are frequently cast as the purveyors of disease, they are often involved in complex and delicate emotional stratagems designed to 'coax' men both to accept the knowledge of HIV as a mutual challenge, and to seek care for their own illness. As an NGO worker pointed out, although HIV/AIDS education campaigns have largely been targeted at youth, who are the most vulnerable to new infections, it is women who are already in relationships who find it most difficult to negotiate new power relations within already well-established familial hierarchies (CARE interview, July 2003). Thus some women, after testing positive, say nothing. Instead, they carefully negotiate with their partners a joint testing session and enact a performance of discovery through which both partners' HIV status is revealed as a collective problem, not a disease born and created by the knowledge of women.

While conventionally women are accorded and accept the blame for HIV/AIDS, there are other models of response, which provide hope for an alternative, more co-operative approach between men and women: "There's a couple that I'm seeing and with this one, the difference the man is also active, he comes to the group, they are prepared to talk about the condoms, he'll be the one who talks how important it is that they should wear condoms … they never blame each other, the woman was the one who discovered when she was pregnant, and as a result she (took medication) and the baby its negative … they are always together, at times the guy would be the one who goes to fetch the baby at the crèche … you can see that they've accepted and they are trying to work together" (Khanya Family Centre interview, July 2003).

In general, however, the gendering of the disease remains pervasive, and has a series of detrimental consequences for men, women and the family unit as a whole.

The denial of men frequently disallows their families the opportunity to care, even where significant willingness to do so exists. Community workers explain that many men never disclose their HIV positive status. Instead the nature of their illness, sometimes masked for many years, inevitably manifests itself, creating suddenly apparent illness and a rapid death without medical treatment being possible.

A significant burden of care falls to women, care which is not reciprocated when they fall ill. As a community worker explained, "Women go all out to help, they don't leave men to die alone" (Kwaze Kwasa interview, July 2003). The survey conducted by the Kaiser Foundation concurs: "The main caregivers are women – in more than two thirds of households women or girls were the primary caregivers. Almost a quarter of caregivers were over the age of 60 and just under three-quarters of these were women … Children under 18 were the caregivers in 7% of households, with girls again most likely to fulfil this role" (*Hitting Home*, 2002:17).

Thus the demographics of the disease mean that the gendering of care is now experienced out as a drawing out, across generations of the burden of care, between mother, daughter and granddaughter. Therefore the old and young, but almost always females, are taking on caregiving roles. Instead of HIV compelling a re-examination of gender roles, the burden is being displaced vertically across generations along the female line.

The capacity of the family to care can be further complicated by the fear of women that draws them into intricate silences, which they hope will mask the illness of their own children, and hence not risk rejection by male partners. "You know what is the mother doing, the brother is sick in her bedroom, the sister is sick in her bedroom, then the mother hides away from the husband, the husband asks what is wrong with these children, the mother doesn't want to say, the brother doesn't know the younger sister is HIV positive, the younger sister doesn't know the brother is HIV positive … when people come, she'll hide the other one, when she knows they are coming to see the younger daughter, she is scared that if the husband can know, the husband can leave her" (Vatech interview, July 2003).

The mother's silence is intended to protect the entire family from social ostracism, but in this masking she denies, possibly with their collusion, the opportunity for ill siblings to acknowledge even to each other the nature of their illness and hence provide comfort within the family itself.

When women themselves fall ill, community organisations report that in many instances they are sent back to families in rural areas to die quietly, invisibly. As one woman living with HIV/AIDS explained, "When women become ill, they send them to families or 'just leave them to die' but women always take care of their men when they are terminally ill…" (PLWA interview, July 2003).

While the return of women to the homes they come from may stem from a need to be with their original family at the end of their lives, in many instances this return appears to be motivated more by a failure of the new families which they have created through marriage, to care for them.

Ill women constitute an untenable financial and emotional burden. The fact that many women have already lost male partners through separation or divorce prior to illness, means that the possibility of care by a male spouse is even further reduced. A Vatech community worker described the 'disappearance' of a women for whom the organisation was providing care: "Her family said she was at the hospital, but she was not there, her clothes were thrown out of the house" (Vatech interview, July 2003). Her children wandered the township unsupervised, afraid to go to an empty home they thought was occupied by their mother's ghost.

Individual women's stories of disclosure: "I blamed God, myself and my husband, the three of them"

The following individual stories are included because they help elucidate the often complex processes and fragile equilibrium of family relationships. Through these stories it also becomes possible to perceive micro processes of power at operation within women's lives, to understand women's subjective understandings of these operationalisations of power and to explore a few of the myriad ways that women navigate the complexities of tragedy within the context of HIV/AIDS:[1]

> *I found out I was HIV positive in 1995, I was expecting my daughter who is seven years old now … at the antenatal clinic I was tested without my consent, when the results came I was told I was HIV positive at eight months pregnant … by the time I was told I was HIV positive I didn't know anything about HIV and AIDS, I heard a little bit about it, that there is a disease which kills people. I thought maybe I was going to die, I won't even give birth to my child but after the counselling, I started to understand and accept my status.* (35-year old National Association of People Living with AIDS (NAPWA) support group member, interviewed July 2003)

Women therefore often articulate themselves as subjects of a medical system, which denies them agency by taking decisions on their behalf and conducting unsolicited testing at antenatal clinics.

On discovery of their positive HIV status, denial and acknowledgement, passivity and action intermesh and are played out through, sometimes contradictory, thought and action, as is illustrated by the story of a 35-year-old woman who found out she was HIV positive:

> *I was shocked, scared because for me AIDS was next to death, the adverts that were there on the TV was of a skeleton person in a box. So my biggest fear was that I was going to die … I went home for two months, I didn't think about it, until there was a day there was an advert on TV about HIV/AIDS, that's when it started working on me.* (NAPWA support group member, interviewed July 2003)

The process of coming to terms with HIV/AIDS is often complicated by lack of knowledge. A middle-age women infected early on in the epidemic became seriously ill two years after she tested HIV positive. Only then did she start to understand the consequences of this unusual illness:

> *I thought maybe the pain was AIDS … I thought maybe if I drink some tablets I will be okay. So I started to get very, very sick in 1990, I stayed at general hospital that is when I started to understand what is HIV, what is AIDS, now I can start to look after myself because I was very sick.* (NAPWA support group member, interviewed July 2003*)*

The pain of coming to terms with disease and the apparent destruction of families and possibilities is sometimes intense:

> *At first after I found out I would wake up in the middle of the night and the first thing that would come to my mind is: I'm HIV positive. I used to cry, cry, just wake up and cry and ask God, why God, why, why … I fell in love, I met a guy, I'm planning to marry, you know because I have been struggling with boyfriends, this one I wanted to marry, so I asked Him [God] that question, because I wanted a good life, why am I positive, why? I used to cry a lot but I no longer cry.* (33-year-old member NAPWA support group, interviewed July 2003)

The equation of HIV/AIDS with immanent death and the horror of discovery on the verge of giving birth to new life is repeatedly noted by women, a substantial number of whom discover their status only through what ideally should be a process of affirmative anticipation. Not only is their joy and the possibility of new life tempered by the possibility of death, but this discovery also often separates them from their partners. What should have been a shared experience – the creation of, or expansion of, a family – becomes a threat to the family.

HIV/AIDS is thus experienced as a tragic and sudden foreshortening of hope. In the case of one woman of 33, who had not had children:

> *I was planning to have them. I found out in March 2003. I suspected my boyfriend was HIV positive … so I went for a test … my boyfriend doesn't want to talk about such things, he thinks that he will be discriminated, also my boyfriend wanted to have a kid, I thought it safe to be tested first.* (33-year-old voluntary counsellor of NAPWA support group, interviewed July 2003)

This woman's important caution, however, became a source of blame within the relationship, a wilful invocation of disease through knowledge:

> *To be quite honest he made it clear that if you are positive, don't even think about coming here because you started it. He gave me that attitude, don't bring trouble, why would you want to go for a test, you want it [AIDS], otherwise why would you go for a test? He said I want a problem.* (33-year-old member of NAPWA support group, interviewed July 2003)

For this woman, the unspoken 'knowing' weighs heavily, creating inexpressible fear:

> *One day I was with some of my friends and they were discussing about the symptoms and one of the things they are talking about is a swollen foot and my boyfriend had that quite a number of times. I was shocked because I knew deep down in my heart, that the person I'm sleeping with is having this HIV and he insisted on having a child, that is without a condom. He wanted me to be pregnant and when I asked him about his swollen foot, he got violent, aggressive, I suspected otherwise why would he get angry, he's denying.* (33-year-old member of NAPWA support group, interviewed July 2003)

The subtle stratagems through which women, on discovery of their own status, attempt to introduce the possibility of HIV infection to their partners and the consequences for sexual practices, represent a carefully trodden navigation of potentialities of rejection and the power to exclude and untether women.

> *I didn't tell my husband straight away. I was diagnosed in August, I disclosed to my husband the following February.*

> *What made me to disclose, the baby was now grown up, he wanted to have sex with me, at the support group I was told to use condoms. It was my own way of introducing condoms to him, when I told him, I didn't tell him straight that I was positive, I told him that my daughter was tested positive, and when he said which means you are also positive and I said which means you are also positive … he went for a test, his results were negative.* (35-year-old NAPWA support group member, interviewed July 2003)

Despite the knowledge of the danger of HIV infection, women still cling to a complex series of hopes embodied in their male partners. Some are prepared to act out a profound pretence in pursuit of these hopes:

> *I am still with him. Just that when I came back from the test, I just said, because he made it clear that if you are positive don't come back, and he asked me: "And so?" And I said: "I'm negative" because I don't want to lose the relationship either, but he made it clear that since you have started with the problem, don't come back with it. So to keep the relationship, I acted excited.* (33-year-old member of NAPWA support group, interviewed July 2003)

While disease will be overtly denied it is simultaneously acknowledged through circuitous processes:

> *I do suspect that he is aware that he is positive, it's just that he don't want to talk about it. Because the last time he talked about children, he talked about adoption. He wants his own children but he actually agreed that if you don't want to get pregnant we can adopt. So I said I don't want to get pregnant, it scares me.* (33-year-old member of NAPWA support group, interviewed July 2003)

Although probably infected by her partner, after an initial testing of her husband's possible receptivity when she became ill, M, a middle-aged woman, waited five years before broaching the subject again:

> *My husband didn't even know about AIDS, I don't even talk, after that I just kept quiet. Then I got very, very sick and I start to tell my husband after a long time. I asked him, do you know about the HIV and my husband said, I don't want somebody living with HIV/AIDS because that somebody is very bad. After that I thought I am not going to tell this man, he's going to kill me. I didn't tell my husband for more than five years.* (NAPWA support group member, interviewed July 2003)

Even when M decided to let her husband 'know' her status, she utilised a system of unspoken signals developed through years of marital habit. Nevertheless, after five years of silence, her fears of rejection were not confirmed:

> *I didn't tell him straight. I was writing something in my book, and I hide my book and put it in the table and my husband like to read my things and read it and he say: "Hey, can we talk?" I said: "Yes, we can talk." He said: "You have AIDS?" I thought he was going to kill me, going to do something wrong but he just did nothing.* (NAPWA support group member, interviewed July 2003)

Fearing for his own health her husband went for testing himself, but the snare of silence was perpetuated as he fell ill, but would not acknowledge the nature of his illness:

> *I can see the symptoms, sometimes getting pain, sometimes getting sick but he won't talk … he told me if you disclose, can you just disclose for yourself, I said, fine, I'll just disclose for myself.* (NAPWA support group member, interviewed July 2003)

Underpinning some women's narratives is the ubiquitous experience of sexual violence in South Africa, and the new lethal potentialities which, in the context of HIV/AIDS, are now located in this already substantial violation.

> *I didn't blame my husband because what happened to me was in 1994, I was raped while I was staying with my husband, I was going to look for a job … I told my husband what happened and he was also supportive to me but there was no education on HIV/AIDS but I was tested and the results came back negative and there was not yet this thing of a window period, we will test you again … so we continued sleeping together up until I got pregnant in 1995. That's how I really know that the man who raped me is the one who infected me … I really got to terms with this rape thing through this HIV and AIDS counselling.* (35-year-old NAPWA support group member, interviewed July 2003)

At the same time that the rape of this woman represents an extreme act of violence against women, the response of this interviewee's male partner offers the possibility of a different type of masculinity, which does not reject but nurtures the violated woman.

The internal ripples and breakages which HIV/AIDS causes in families also emerge from this woman's story of disclosure to her brother, her 'favourite in the family' (PLWA interview, July 2003). The irony of denial also locks family members in mutual silences as a putative barrier against disease and masks multiple experiences of illness:

> *I disclosed my status to my young brother who comes after me, he rejected me very much. Even now we don't even visit each other, later on he became ill, he was diagnosed HIV positive and he's still on denial now. He hates me because I am open about HIV/AIDS, he hurt me because I was trying to support him, to convince him to take drugs, now he's very, very sick. It's worse now because I no longer even visit him.* (35-year-old NAPWA support group member, interviewed July 2003)

Such an experience inevitably inhibits a PLWA from facing rejection again through further disclosures:

> *Maybe it will be just the same like this one, whom I chose, he was my favourite in the family.'*

Thus the 'secret' remains between husband and wife:

> *This husband of mine, even if I want to disclose, he'll say, hai wait, so I'm doing it for him but with me I don't care.*

The secret, however may be selectively revealed in the offer of care to those who are also infected:

> *Sometimes if there is someone who is sick I go and do counselling or home-based care, I end up disclosing. Sometimes maybe the mother will be one in denial, or the person who is sick, I end up telling them that I am also in the same position, but it becomes our secret, it stays within us.* (35-year-old NAPWA support group member, interviewed July 2003)

As women live with these secrets, they worry about the future:

> *My main concerns are for my children, if they can grow up now while I'm still alive, if I can take care of them, especially the older one, she will finish her matric next year, if I can live up to her finishing her tertiary education so that she can look after her young sister.* (35-year-old NAPWA support group member, interviewed July 2003)

The importance of boundaries in people's subjective constructions of disease, which even with the knowledge of HIV, keep the possibility of illness at bay emerges through a 26-year-old woman's story. She found out she was positive when she became pregnant five years ago. She did not receive counselling at the time:

> *I was married; my husband has since passed away. I was very shocked, I didn't expect, like sometimes you don't expect like what I did was I got married very young at the age of 19, he was my first boyfriend, I just stuck with him so I didn't expect to be positive.*(NAPWA support group member, interviewed July 2003)

Z is one of a generation of young adults, who have been the subject of extensive HIV awareness campaigns:

> *I tested negative at school so I used to be worried because there were a lot of people who were near to me that died, friends and relatives, but I didn't think I would get it. Then you find out you are HIV positive and you say why me, because I think I have been doing everything right, you won't believe it, only to find that you are positive, you just have to stay positive as well.* (NAPWA support group member, interviewed July 2003)

The notion that women who adhere to conventional moralities and who engage in marriage and monogamous relationships will be protected from HIV recurs repeatedly in women's struggles to come to terms with their illness. These women want to remain uninfected, however they are still unable to take the necessary steps to ensure protection against the virus, as this involves the renegotiation of power and power relations and contending with the censure that is placed by society on women who wish to talk about and negotiate safe sex, pleasure, security and stability.

M, a middle-aged woman was infected early on in the epidemic. She discovered her HIV status in 1988 in a context where there was very little public information about the disease:

> *I was sick, I got a pain in my breast, then I go to a doctor, the doctor take me to the central clinic, they took a blood test, the doctor just told me I'm HIV positive … this was the first time I see somebody with HIV and AIDS apart from myself, I was starting to see somebody like me and I was thinking, if I can tell somebody, the people will think I'm a bad somebody because I didn't think no-one had AIDS, and they were saying AIDS is a bad sickness, if you have AIDS you are a very bad somebody, you are very naughty, but I was not naughty, I was married at that time. I got married in 1986.* (NAPWA support group member, interviewed July 2003)

M reiterates her astonishment that the boundaries of a moral life were not enough to protect her:

> *I didn't go to Hillbrow, I was married, I was sitting at home, I didn't do something wrong but I got HIV … when I found out I was HIV positive I said why me?, I'm in church, I'm married, I was not in the street and I say why?, I go to church every Sunday and I get HIV … I was blaming my husband, blaming myself to marry this man, I was also blaming God.* (NAPWA support group member, interviewed July 2003)

The terrible toll which HIV/AIDS is taking on families and the enormous burden of care it is exacting, is matter of factly articulated by this interviewee:

> *My family, my side, they've all gone because of HIV, they died. My sister also, she got five children [between the ages of 2, and 19], I look after them, I've got three, I look after the three, the big one has got two child, so I look after*

> *them. It's ten children and I've got also my brother who's living with HIV/AIDS, also he's not working, I must look after him as well, but if I'm here, the little I got I can share, but the problem is if I'm not here.* (NAPWA support group member, interviewed July 2003)

On the other hand, it is also clear that women are actors in their own stories in difficult ways, which belie stereotypes of virginal victimhood:

> *I blamed myself, to be honest we knew there were condoms, but we only used them when we felt like it. I knew that there was these condoms, that there were these deaths because of AIDS … if I had taken the condom issue seriously I wouldn't have ended up being HIV positive.* (NAPWA support group member, interviewed July 2003)

Nevertheless there are also serious limitations on women's abilities to protect themselves, in the face of a partner's denial:

> *I don't blame that person [who infected me], I remember that person used to be very sick and there was a time that I went with that person to the doctor and he had a rash, now I know because I have more knowledge. I said to the doctor: "What's wrong with this person?" And he said: "No, you guys will discuss this at home." We never discussed anything, he said: "No, there's nothing to worry about." I went to my friend, and said: "What if this person has got AIDS?", but jokingly, to me it was like he knew he was HIV positive and he didn't even use a condom.* (35-year-old NAPWA support group member, interviewed July 2003)

Instead of legitimately externalising blame, women thus all too easily assume their culpability. Z explains:

> *I blamed myself, I thought maybe I did things too early, I was too fast, I rushed into things…I knew about AIDS.* (26-year-old NAPWA support group member, interviewed July 2003)

This young woman carried the burden of her secret through her husband's HIV-related illness and death, unwilling to let her family know, not in fear of rejection, but out of concern for the emotional burden her disclosure would place on her mother, in particular:

> *My mother's got depression, she's been sick, that's one of the reasons I just can't tell my family, especially my mom, she's depressed. Because it was just like my husband passed away, in three months my brother passed away (stabbed to death), my father and mother separated, all this happened within the space of three months.* (NAPWA support group member, interviewed July 2003)

The emotional toll of these events manifested itself physically through the body:

> *One day I just woke up, I couldn't even talk, my whole right hand side was paralysed, all these things, I'm positive, my husband is dead, my brother is dead, my mother is depressed because my father is separated, she was sick, she was in the hospital. I just woke up with a stroke.* (NAPWA support group member, interviewed July 2003)

On recovery from the stroke, she went to counselling:

> *The counselling was amazing, you understand why all these things happen. I pray a lot, particularly when my mother is depressed ever since my brother is dead, she's not going to work, she's on sick leave and now I tell her I'm going to die, uh uh, I can't even tell her I'm sick as well because I am the only one who is left, only me and my brother, my*

> *father is far away, we are not that close. He used to go away and come back since when I was young, until he decided to leave finally … So that's why I'm attending these support groups, for my mother, so that I can be able to tell her.* (NAPWA support group member, interviewed July 2003)

Her decision to seek counselling and disclose to her family, reveals the importance of role models, who help to facilitate the difficult path of disclosure for those around them:

> *My cousin tested positive, she disclosed widely, she was attending support groups. I just thought, oh, maybe if I attend these support groups I can just do the same. I was inspired by her speeches, the way she's doing things, the way she's carrying on, its just like she's normal, everyone in the family, even my mother is supportive of her. I'm just worried about my mother, I think she just take things too seriously, because she's got this depression for a very long time, she's always going to the clinic, I'm just worried about her.* (NAPWA support group member, interviewed July 2003)

This story also highlights the importance of ensuring that social welfare services such as counselling and support, and women's health services are widely available and accessible. It points too to the value of community support programmes in which women will feel supported and able to discuss the many issues that confront them not just as individuals, but also as facilitators of family cohesion.

Gendering the social processes

It is clear that the differential experience of the HIV/AIDS epidemic for men and women is a consequence of deep-rooted, long-term individual and social processes which are currently cohering around the disease of HIV/AIDS, as a reflection of a pervasive gendering of social processes. To address these types of entrenched power relations will require long-term socialisation, starting in early childhood. The educational system could provide a critical mechanism through which new constructions of gender identity can be posited and developed.

In the short term, NGOs and CBOs concur on the urgent need to incorporate men more effectively in programmes designed to address HIV/AIDS. Men's ability to avoid engagement with the medical system, because of their generally limited involvement in child care and because they do not become pregnant, means that the preponderance of those being tested and finding out their positive status are women. As a consequence, in the vast majority of instances it is women who bring the news of illness to the family.

The predominance of women as bearers of 'bad news' feeds and reinforces already deeply established characterisations of women as inherently contaminated. If this cycle is to be broken and men and women are to perceive themselves as facing a joint challenge, then active interventions will have to be made to ensure that a substantially increased number of men test for HIV, even taking the lead in this process, to refute myths of women as carriers of disease. Increased early testing by men will enhance the possibility that more men, knowing their status, will not engage in sexual activities that endanger both themselves and women.

Specific interventions therefore need to be developed which engage men in terms of the subjective, family and social contexts in which they are currently located, not in terms of a putative ideal. This social milieu is the lived familiarity of a highly patriarchal context in which subjective constructions of manhood disallow vulnerability and illness, and structurally a world in which men tend to emphasise the spaces of work and recreation. If men are to be reached, they need to be 'found' at these places – the workplace and social venues – rather than in the health settings which women are more likely to frequent.

Programmes need to be designed which are able to incorporate men drawing on men's perceived strengths in order to affirm forms of power that are not destructive and hierarchical. Some NGOs have found that running very factually oriented Wellness Programmes is one way of engaging men through a medium less potentially emotionally challenging than more conventional approaches such as counselling, which demand immediate vulnerability and emotional openness. It will also be critically important to increase the number of male role models involved in counselling and education processes, which are currently overwhelmingly dominated by women – men who live out a different norm of heterosexuality and who can help create new archetypes of masculinity.

Advocating an engagement with men in terms of the pervasive reality of patriarchy is not to affirm these power relations, but to attempt to find a practical entry point, from which men may be drawn into shifting their personal subjectivities regarding male identity.

On the other hand, women need to seriously grapple with their own acquiescence in patriarchies which would not survive without their tacit collusion. An example of this is that NGOs report the struggles of NGO workers themselves, with significant cognitive knowledge of HIV and gender relations, to actually assert new forms of power in their own relationships.

Generations

Intermeshed with the patriarchal constructions of society are generational hierarchies that assign identity and social location in terms of chronological age. These assignations have been under pressure in South Africa for some time, the dominance of young people in the insurrections of the 1970s and 1980s being the clearest example of this contestation of traditional generational roles in which the young are acquiescent and subordinate. The current context of HIV/AIDS epidemic is, however, placing renewed strains on conventional generational roles. Children take on mounting burdens of 'adult' responsibility, as adults who would in other circumstances circumscribe the roles and activities of children, die and as the elderly are forced to step into this adult vacuum, to try and create and affirm generational and other boundaries that are being systematically interrogated by the social dislocations caused by HIV/AIDS.

The biological phenomenon of birth and death are not socially neutral phenomenon. Complex processes of cultural transmission adhere to the constant addition and removal of individuals from society through biology. Each new generation comes afresh into contact with cultural legacies, which are repeatedly appropriated, adapted and assimilated in innovative ways to meet the challenges of new social contexts and the imperatives of successive historical eras. Previous generations may cling to cultural attitudes, feelings and values which constituted the 'drama of their youth', the cultural orientations, data and attitudes which they assimilated in youth, forming the oldest, most resilient stratum of consciousness, "which tends to stabilise itself as the natural view of the world" (Mannheim, 1952:115).

In general processes of cultural transmission between generations occur unremarked and unconsciously "the most important aspect [of cultural transmission] … is the automatic passing on to the new generations of the traditional ways of life, feelings and attitudes … All those attitudes and ideas which go on functioning satisfactorily in the new situation and serve as the basic inventory of group life are unconsciously and unwittingly handed on and transmitted: they seep in without either the teacher or pupil knowing anything about it" (Mannheim, 1952:114).

Conscious processes of cultural transmission make explicit those components of the cultural heritage which are under strain. Thus, "rational elucidation and reflectiveness invade only those realms of experience which become problematic as a result of a change in the historical and social situation, where that is the case, the necessary transformation can no longer be effected without conscious reflection and its technique of destabilisation" (Mannheim, 1952:110). South Africa arguably is located in exactly such an historical moment, where the demands created by HIV/AIDS in conjunction with other social pressures are creating a context where the automatic processes of cultural transmission from one generation to another are being made the conscious object of cultural construction, perhaps most noticeably through the processes of the Moral Regeneration Movement.

HIV/AIDS, a potentially terminal illness, inescapably implicates the biological processes of birth and death directly. In fact, in its direct alteration of fundamental and previously assumed patterns of mortality, it engages with these processes in a unique and devastating manner. Inevitably the profound demographic changes which HIV/AIDS causes will destabilise assumed processes of cultural transmission in hitherto unforeseen ways. While this destabilisation cannot necessarily be welcomed because of its associations with death and illness, it could compel creative engagements with cultural ascriptions which remain unquestioned in more secure times. The pressure on the very young and the old to assume roles which conflict with conventional generational identities may be born out of necessity, but needs to be met not with a reflexive reassertion of the 'traditional' and the ideal, but a constructive engagement with current social realities which dictate unexpected life courses.

To fail to engage with this experiential reality, in favour of a mechanical assertion of what should be, will be to leave millions of South Africans of all generations, who cannot live outside these cultural ascriptions, without support in rapidly changing and distressing times.

Thus generational hierarchies, like gender hierarchies, shape the experience of HIV/AIDS. This shaping process permeates all aspects of the disease. In terms of basic understanding of the disease, it appears that awareness campaigns targeting the young, although creating critically important understanding among sexually active adolescents and young adults, are not effectively engaging with adults, who in personal processes of boundary making may in fact reject information about HIV, for fear that they too may be implicated in the disease.

In the words of one interviewee: "Especially the young ones, they do have this information, the ones who don't want this information are the adults, maybe they are scared that as old as I am, how can people say I'm HIV positive? HIV positive is most in young children" (Vatech interview, July 2003).

Generational hierarchies also create mutually interlocking silences between children and adults, which makes difficult the sharing of information, often necessary for both children and adults to find the most effective means of responding to HIV/AIDS. Thus on the one hand, children socialised into various forms of subordination to authority do not ask for information, even when a parent is sick or dead, and neither are they offered information. This failure of adults to offer information may be motivated by a very legitimate concern to protect children from the burden of the knowledge of a parent's illness. However, it does not incorporate the awareness of children which, although often unarticulated, remains a powerful, and if not supported, destructive part of their consciousness.

Thus families negotiate the generational boundaries in different ways, sometimes revealing information to children, sometimes not:

> *It depends on communication within the family, whether there's that or not … just last week in my group we were talking about this, some grannies were just saying, "I didn't*

> *tell them". Others said, "No, I told them, I prepared them from the time when their mother was ill (*Khanya Family Centre interview, July 2003).

As a result surviving children frequently do not know the cause of their parents' illness and death. Sometimes if they are HIV positive themselves, they do not know the source of their own illness:

> *And in groups when you start talking about HIV, that's when some of them start thinking back about the symptoms, and they will start saying really, and my mother … like one lady will say openly, my parent died of HIV, at least the environment is safe for them to look back, that when they will start telling each other if they thought, maybe suspected that the parent was positive* (Khanya Family Centre interview, July 2003).

A community home care worker looking after a young HIV-positive relative who had lost his parents, and who subsequently died himself at age 13, illustrates the struggles of young children to grapple with disease without necessary knowledge:

> *I didn't tell him he was HIV positive but one day we were watching something, I was putting this Nkosi Johnston photo. He said to me: "Oh my God, I just look like Nkosi Johnston." I didn't know what to say. He was asking me … I think his father told him he was HIV positive, but not straightly. He was giving him tablets, tablets, tablets. The boy was asking him: "Why are you giving me tablets all day?" He was very intelligent that boy, very intelligent* (Ebenezer interview, July 2003).

The relief of acknowledgement of what in fact is 'known' but not named for both parents and children is illustrated by a Khanya Family Centre caseworker:

> *It's also happening with the PLWAs, as soon as they feel safe that they should disclose to their children, lately, they would say my child accepts and he told me he was suspecting that maybe I was positive but he was afraid to speak to me* (Khanya Family Centre interview, July 2003).

While it may be conventionally assumed that it is adults, particularly older adults, rather than younger people who are most resistant to openness regarding HIV/AIDS, it is evident that continuing stigma related to the disease leads some young people to actively encourage a parent's secrecy about their status:

> *It's not easy for some of the children, I had one who came home very angry with the mother, that why you keep on telling the community that you are positive, someone has just told me that somebody's spreading that you are positive, so she was like stopping her mother from talking about HIV* (Khanya Family Centre interview, July 2003).

As much as parents may battle to disclose the nature of their illness to their children, children struggle equally to disclose their own illness to their parents, in fear of both parental rejection and burdening parents emotionally. The obligation of the medical profession to maintain confidentiality often means that young people are able to keep their status secret from their parents up to the point of death:

> *N's mother was so supportive, she looks after her, she does everything, they put her in Sebokeng Hospital, take them to Natalspruit, take them to Baragwanath. If you say to the doctor they musn't tell your parents they won't. They were all over the place with her, but she died without telling them. We found out by the time when they took her to*

doctor … by that time she was not talking, she was not talking at all.

The doctor asked the parents what was the problem, they say they don't know. The doctor told them that their daughter had AIDS, the woman nearly died on the spot … she's been looking after her [daughter] for five years, looking after this child, washing for her, doing everything. When the mother asked: "Why don't you tell me so I can know?", she said: "No, mama it's not like that, it's meningitis, pneumonia, all those kind of disease" … she just name them. The daughter came to us, she told us: "You must never say I've got AIDS, you must never say that (Vatech interview, July 2003).

The wrong sort of families: child-headed households

> *Living today are an estimated 14 million children who have lost one or both parents due to AIDS. Approximately 80% of those children – 11 million – live in sub-Saharan Africa … Forecasts indicate that the number of children orphaned by AIDS will rise dramatically in the next 10-20 years, especially in Southern Africa. In South Africa alone, it is estimated that, by 2010, there will be 1.5 million children orphaned as a result of AIDS.* (Report on the Global HIV/AIDS epidemic, 2002)

The most recent and comprehensive survey of HIV prevalence in South Africa includes a small section on the question of orphans and child-headed households. The study confirms that:

> *HIV/AIDS contributes to orphanhood, and for this reason there is an interest in estimating the magnitude of the orphanhood problem … the study found that 13% of children aged 2-14 years had lost a mother, father, or both. The study also found that 3% of children had lost a mother. In addition this study found that 8.4% of children had lost their father* (Nelson Mandela/HSRC Study of HIV/AIDS, 2002:67)

The report continues:

> *Many community-based assistance programmes report an increase in household headed by children, or consisting only of children. However, no national data on child-headed households has yet been reported. In this survey, just 3% of households were reported as being headed by a person between the ages of 12 and 18 years of age, and could thus be called child-headed households. The percentage observed was 3.1% in urban formal areas, 4.2% in urban informal areas, 2.8% in tribal areas and 1.9% on farms* (Nelson Mandela/HSRC Study on HIV/AIDS, 2002: 67-68).

The numbers of child-headed households encountered by community organisations would seem to belie the small percentages found in the Human Sciences Research Council survey. For example, in 2000 the Khanya Family Centre on the East Rand conducted research to try and ascertain the extent of the 'orphan problem' on the East Rand. It found 339 orphans at a sample of 20 schools in Katlehong, Thokoza and Vosloorus. Sixty percent of the orphans were staying with grandmothers, 20% were with parents dying of HIV and 20% were living on their own. Given the fact that many children in HIV/AIDS-affected households do not attend school, it is likely that the actual number of children living without adult care is even higher than this estimate.

A survey commissioned by the Kaiser Family Foundation and conducted by Abt Associates in conjunction with several other organisations found that of 771 households surveyed, 'almost a quarter (22%) of all children under the age of 15 in the sample were maternal orphans in that they had lost either their mother or both parents. The greatest number of these orphans were girls' (*Hitting Home*, October 2002:23).

Health Economies and HIV/AIDS Research Division (HEARD) at the University of Natal has explored the severe consequences experienced by children orphaned through AIDS:

> *Orphaned children generally experience measurable declines in nutritional status and reductions in schooling … these experiences can greatly reduce a growing child's ability to acquire skills and knowledge to escape deprivation. Very young orphans, whose mothers die of AIDS, have higher mortality rates than other orphans because approximately one third to one half of babies born to infected mothers are themselves infected with HIV through mother-to-child transmission. Children face problems both during the illness in a prime age adult within the household, and after the death of the adult. These problems include withdrawal of children from school, decreased access to food and medicines … lack of accommodation and income, theft of property and inheritance, sexual abuse, economic exploitation and further declines in health status.* (*The Hidden Battle*, 2002: 15)

It is clear that far more research into both the conditions and extent of the impact of HIV/AIDS on children is required. The bare statistics above give only the most cursory insight into the processes involved in a child losing both his or her parents, and the subsequent struggle for survival without parental protection. UNAIDS sketches the emotional vulnerability of such children:

> *The vulnerability of children orphaned by AIDS and that of their family starts well before the death of a parent. The emotional anguish of the children begins with their parents' distress and progressive illness. This is compounded as the disease causes drastic changes in family structure, taking a heavy economic toll, requiring children to become caretakers and breadwinners, and fuelling conflict as a result of stigma, blame and rejection. Eventually, the children suffer the death of their parent(s), and the emotional trauma involved. They then have to adjust to a new situation, with little or no support, or they may suffer exploitation and abuse (Report on the Global HIV/AIDS epidemic,* 2002).

Many child-headed households are dealing with the trauma of multiple familial deaths unassisted. The pressures on the family social unit prior to HIV/AIDS means that many children have only one parent to lose, generally their mother, as many fathers have long since abandoned the family prior to a mother's illness. The Kaiser Family Foundation found in this context that 72% of the households it surveyed were female headed (*Hitting Home*, 2002:13).

Where both parents are present prior to the onset of HIV/AIDS, they frequently die within a short time of each other, leaving children to come to terms with the death of a mother and a father in quick succession. On the death of their parents children are often left in a state of extreme aloneness, created by the prior progression of illness. The processes preceding death often involve a slow isolation, almost a type of insubstantiation, as the family continues, phantom-like, hidden from the 'public' purview, removed from the skein of social networks. As parents sicken, the whole family often gradually withdraws from the community, the neighbourhood and even relatives, retreating decisively from public spaces. When parents do die, death merely formalises a social absence already long established, sometimes not even particularly noted in its conclusion at death.

An increasing number of children pushed prematurely into the role of caregivers during the crisis of sustaining the household and keeping their parents alive, withdraw, along with their parents from the social connections, which are so crucial to their subsequent survival. Having exhausted all resources, financial and emotional, an increasing number of children appear to have been compelled to perform the extraordinarily harrowing task of physically burying their dead parents, in the backyards of their homes without public ceremony. One community-based organisation, CARE, attending to 90 families in Gauteng, allege that it has encountered 9 incidents of such secret burials among the families it has assisted.

According to the children themselves, extensive depletion of family resources as a result of HIV/AIDS make the cost of a conventional funeral prohibitive. Perhaps also the silence around the illness has calcified so substantively by this point that its shattering is unthinkable for children, already so untethered from social bonds. Death remains unutterable. The conventionally incorporative rites of the funeral become clandestine, fraying fundamental bonds in communities which used to mourn and celebrate together.

Illness also interrupts education and propels children prematurely into the economy. As parents become ill and die, children often stop going to school in order to generate small amounts of income, sometimes through informal criminal activities such as begging or stealing:

> *The ability to stay in school … suffers significantly when a child loses one or both parents. In the late 1990s, a survey of 646 orphaned and non-orphaned children in Kenya found that 52% of the children orphaned by AIDS were not in school, compared to 2% of the non-orphans. Among the orphaned children, 56% of girls and 47% of boys had dropped out of school within 12 months of a parent's death. Girls often drop out of school because they assume the responsibility for parents who are ill, or because they must look after household duties in the parents' stead, including that of caring for younger siblings. Other children leave school because they are discriminated against, are psychologically distraught, or cannot pay the school fees (Report on the global HIV/AIDS epidemic,* 2002: 135).

The Kaiser Family Foundation report confirms that: "Children under 18 were caregivers in 7% of households, with girls … being most likely to fulfil this role … in 40% of households caregivers had to take time off from work … or school … One in five caregivers spent school/study time caring for the sick person. This too has serious implications for the educational development of these individuals" (*Hitting Home*, October 2002:17). After parents die children are left running homes and trying to meet a range of material needs, including the provision of school shoes and clothes, books, paraffin, electricity, water, without any source of income, with few skills, and with dependent siblings. The fact that children are able to meet this challenge at all is testimony to the hitherto unacknowledged resources of children themselves.

Organisations such as UNAIDS contend that the resourcefulness of children in the context of crisis needs to be consciously acknowledged, implicitly challenging understandings of children as passive recipients of adult direction, "Empowering affected children first of all means regarding them as active participants, rather than mere victims. Many children already function as heads of households and as caregivers. They are a vital part of the solution and should be supported in planning and carrying out efforts to mitigate the impact of HIV/AIDS on their families and communities. Children in households with ill parents should also participate in decision-making regarding their future foster care. This is crucial for succession planning, which helps parents (who know they are living with HIV) prepare for the future and provide their children with the necessary care and support" (Report on the Global HIV/AIDS Epidemic, 2002: 138).

On the other hand, despite the hardships and loss experienced when parents die, the head of the Kwaze Kwasa community based organisation argues that the reality of extreme neglect of children prior to their parents' deaths means that for some children there is actually an improvement in their circumstances after they lose their parents. They are now able, usually with the assistance of supportive organisations, to access a number of forms of material and social care (Kwaze Kwasa interview, July 2003).

Moreover Centre for the Study of AIDS director, Mary Crewe, articulates significant cautions regarding the question of child-headed households, notwithstanding the demonstrated resilience of children, "It is important to ask whether a democratic state, one which pins hope on collective socialisation and child rearing, and one which has signed and ratified the Convention of the Rights of the Child, can tolerate – and whether it should support – child-headed households. In almost all respects such households signal the possibility of child abuse and a dereliction of state duty to protect young people. They should not be allowed and the basis for their ongoing existence – keeping siblings together – should be challenged. Other ways can be found, not only of keeping siblings together and protecting their inheritance and property, but also of ensuring that young people bereaved by AIDS receive post-trauma counselling, education, care, food and clothing, love and parenting, and social affirmation' (Crewe, Comment, 2003).

Who is the head of the family?

The legal and social system of the country has yet to acknowledge this inversion of conventional social hierarchy forced upon communities as a result of the consequences of HIV/AIDS (possibly in fear of affirming the social inversion). As one community worker explained, there is "still a gap now working with child-headed households, the problem here is that legally, and according to the policy of the country, these children, they can't apply for grants, but realistically they are still on their own, you find that the eldest child is 18 years old, he or she is still a child according to the act, she cannot be a principal custodian, so again that's where the impact of HIV/AIDS on families, really is mostly there" (Khanya Family Centre interview, July 2003).

Khanya Family Centre, among numerous other organisations working with children affected by HIV/AIDS, identify the difficulties experienced as a result of the fact that despite the increasing numbers of child-headed households, or households in which young children are shouldering considerable responsibility, current legislation does not recognise the 'adulthood' of these children and the extremely adult nature of the responsibilities they are compelled to bare. Hence many young people under the age of 21, although they may be responsible for several siblings or have cared for a dying parent are unable to access grants as foster parents because they have not reached the legal majority of 21. Khanya Family Centre posits a possible solution to this dilemma, "What we are thinking, it's very new, we haven't tried it yet, we are thinking of placing the foster parent that we have trained, placing the children with them, so that she can be the foster parent and apply for the grant, but the catch is, policy says that these foster parents must stay with the children, but these foster parents of ours are not physically with the children so that's where again we really need to challenge our government…what about before that child reaches the age of 21?" (Khanya Family Centre interview, July 2003).

Stigmatisation of children whose parents have died of AIDS is a further barrier to proper care.

While children in HIV/AIDS-affected households experience stigma and rejection, they can also experience love and care. A community worker explained, "when we ask them [the children] the means of survival they will tell us that the neighbour, when they got the grocery, they would share the grocery" (Khanya Family Centre interview, July 2003).

The collective experience of illness and death, underlined sometimes by isolation, stigma and the rejection of relatives, can deepen bonds between siblings creating a kind of collective solidarity against the adult world, "and remember most of them are actually betrayed by their family, by their relatives, other adults, the only thing that they are left with is the relationship between themselves, they hold onto that" (Khanya Family Centre interview). They are also, ultimately, betrayed by society.

Although bonds between siblings may be strengthened by the common experience of tragedy, the burden of care for older siblings thrust into a premature parental role can be severe. Older siblings, still children themselves, and often still perceived by younger siblings as such, battle to establish the authority necessary to keep the household together, given the ambiguity of their role. A Khanya Family Centre social worker explains:

> *We had this case of a girl who was sixteen, she had a problem of fighting with her sibling, the sibling was 14 years old, you know how 14 year olds are developing mentally, they think the whole world revolves around them … if you are a parent and children, it's normal sibling rivalry, you deal with it as an adult but because they were siblings and this other was only two years older than this other one, the 14 year old was just so out of control, she actually tell the sister that you want to behave like my mother, you are not my mother. We had to place them in foster [care]. It becomes very difficult for the older one and also difficult for the young one to understand that she [the older sister] is not the parent but at the same time she is.*

In some instances older siblings will find the burden of care so overwhelming, they flee. There are reported cases where an older sibling has left younger siblings without informing them, and just disappear without telling anyone about their whereabouts or where they are going.

Teenage girls in particular, may have not only their siblings to care for, but sometimes their own infant children. "One girl was actually taking care of seven of her siblings and her own child, so the other day she was saying, 'I'm just too tired' … at some point she was also contemplating suicide, it was just too much" (Khanya Family Centre interview, July 2003).

For boys, the potential for delinquency, both as a form of rebellion and a means of survival, is high. As one NGO worker put it, "Teenage boys are teetering on the edge of crime" (CARE interview, July 2003). The impulse to crime is bolstered in the absence of parents by a lack of socialisation regarding conventional work ethics, which prescribe waged employment for remuneration rather than immediate entitlement to material goods (CARE interview, July 2003). While girls also seek material comfort, a CARE NGO worker argues that for teenage girls relationships, ensuing pregnancies and the children born of these unions constitute an important source of fulfilment in a context where everything else is shared with family members (CARE interview, July 2003).

The question of involvement in childcare in child-headed households is closely linked to constructions of masculinity. Younger male siblings are more likely to assist with childcare as they do not yet see themselves as 'men'. However, according to CARE, the older boys get and the closer they approach manhood, the more social pressure there is on them to work and to earn an income. The reality of few opportunities for employment does not reduce this social expectation. On the other hand, it remains acceptable for girls, even at an employable age, to stay at home and look after children without earning (CARE interview, July 2003). It is possible, therefore, that although some male siblings may be willing to share the burden of childcare, social assumptions and pressures reduce the potential of this happening, even if employment opportunities are limited and male members of the household could productively assist with childcare.

The responsibilities of surrogate parenthood also rob teenagers of the opportunity to explore and experiment with relationships, hindering their own process of social development:

> *We also had this one young man, he started staying with his siblings when he was about 17 years old, you know he was such a responsible child … at 21 he didn't even have a girlfriend, he said, "How can I have a girlfriend because I have to take care of my brother and sisters, I'm like a mother and father to them" … It's unfortunate, this delays their development socially, but again we expect them to be parents so they are in two different worlds, the responsibility of being a parent and delaying your own development* (Khanya Family Centre interview, July 2003).

The best interest of the child?

Institutions such as UNAIDS, together with other international organisations funding HIV/AIDS related work, argue the (sometimes contested position) that "…orphans are more likely to cope if they can live in surrounds that are as familiar, stable and nurturing as possible. The consensus is that orphans should be cared for in family units through extended family networks, foster families or adoption. At the very least siblings should not be separated from, and children should remain in, or close to, the communities. Even child-headed households, can be viable although hardly ideal, options if given enough community and state support. While Africa is still in the early stages of the orphan crisis, many children and many communities are coping, and their resilience and fortitude should not be underestimated. Millions of orphans have already been absorbed into extended family networks, even in the poorest communities. Formal and informal fostering arrangements are also common in some countries. Indeed, many societies in Africa have retained the structures and ethos of community-based orphan care-traditions that have helped them cope with previous calamities (*Report on the Global HIV/AIDS Epidemic*, 2002: 136).

UNAIDS argues further that, "formal institutions, such as orphanages, have proved to be a tiny and inadequate part of the response. The financial costs of maintaining a child in one of these institutions outstrip the costs of other forms of care,

making orphanages, as currently managed, an unsustainable option. Furthermore, such institutions often leave children without the social and cultural skills they need to function successfully as adults" (*Report on the Global HIV/AIDS Epidemic*, 2002: 136). As a Khanya Family Centre worker argued: "If they [the children] are institutionalised, they won't be able to integrate back when they are above 18, so rather than taking them away the community has to look after them while they are still young" (Khanya Family Centre interview, July 2003).

While formal institutions may be a small part of the solution to the problem of children orphaned by HIV/AIDS, they are also a significant part of the solution, providing refuge for children, where it is impossible or undesirable for them to be incorporated into family and community networks. Some childcare organisations express concern about the treatment of children who are fostered or incorporated into families already overburdened socially and economically. Abuse, neglect and abandonment become very real dangers in these contexts. Therefore innovative institutional solutions also need to be investigated, in order to attempt to create nurturing, home-like environments for children outside traditional family structures. A recent UNAIDS report illustrates one example of such a creative institutional solution in Romania, "a family-style group home was purchased and renovated, enabling 10 of the orphaned and abandoned children from the Municipal Hospital's Children's Ward to be housed in a more nurturing environment. The home, which opened in August 2001, allows for children to be raised by 'social mothers' and to attend local schools" (*Report on the Global HIV/AIDS Epidemic*, 2002: 136)

The prevailing consensus, however, is that, where feasible the most desirable option for children is that they remain as closely integrated as possible within the communities in which they have grown up. Continuity, familiarity and place are crucial to children. Children usually want to be cared for where they are; they resist the further wrench of dislocation from their homes, however apparently inadequate and under-resourced. Dislodgment of children to homes they are not familiar with, particularly if siblings are separated, or to institutions, compounds the already dislocative trauma of losing one or more parents.

A Khanya Family Centre worker commented: '[W]e find that most of the times, with the child, they are more comfortable to stay as a family, they don't want an outsider to come and stay with them and prefer if a foster parent would come and visit them, more than to stay with them' (Khanya Family Centre interview, July 2003).

In South Africa innovative new initiatives are currently being conceptualised to renew and bolster African traditions of communitarian responsibility for child care while simultaneously drawing on the knowledge and experience of community organisation developed during the 1980s in the struggle against the apartheid state. This type of organisation emphasises the systematic mobilisation of collective social resources from the microcosm of the home, the street and the neighbourhood block. This organisational experience and memory, combined with the cultural inheritance of communitarianism, could constitute a powerful local response to the orphaning of children.

A Khanya Family Centre Worker explains: "We are trying to establish child-care committee, taking back … no child is an orphan in African society, communities can take care of their children. The aim would be to have people in the communities who can be able to help these children" (Khanya Family Centre interview, July 2003).

The emphasis in the child-care committees would be on mobilising resources within communities: "In the community, you find that even before you can go outside looking for external resources, you find that there are internal resources, there are community organisations, women's societies who want to pop up something, those committees will be able to assist those people, invite community members to maybe pop up something towards the needs of the orphans" (Khanya Family Centre interview, July 2003).

A Khanya Family Centre worker explains how child-care committees would attempt to mobilise all available local social resources: "what happens, it's a committee where all the stakeholders come together, they have parents, teachers, other service providers like sisters, nurses, CBOs, the faith based organisations, they would assist the committee to identify the orphans with the help of the school….the committee will look at the needs of the children and try to involve more people in assisting the children" (Khanya Family Centre interview, July 2003).

The child-care committees would also have an important monitoring function in ensuring that government grants to assist children are used appropriately, "and as one of the functions of the committees … normally we encounter families that applied for the grant, received the grant only to find out that the parent doesn't use money for the needs of the children and then the community will be able to come to the committee members and give information about those kinds of things" (Khanya Family Centre interview, July 2003).

Child-care committees would also attempt to substitute for the, ultimately irreplaceable flexibility and continuity, of parental care which, at least theoretically, is continually available to meet the needs of children as and when they arise.

This type of care, is not easily substituted by formalised care, which takes its form from the rigid structuring of the work place and as a consequence creates considerable lacuna in care for children whose needs do not end with the work day, "And if there are many children, the committee will be able to assist those families, because you find as social workers we are only here eight hours, the committee will be available 24 hours a day…with child-headed households we allocate caregivers, people who will play an adult role, people who will visit those children on a regular basis…these people are able to help us to assist [child-headed families]" (Khanya Family Centre interview, July 2003). Already many NGOs and

CBOs around the country have mobilised such caregivers who visit children daily or weekly to try and provide them with at least the semblance of adult guidance and protection.

While these proposed initiatives are an important attempt to address the escalating incidence of child-headed households, it is also critically important to ask whether this type of care is adequate for the next generation of young South Africans affected by HIV/AIDS. Extensive national social resources need to be urgently mobilised to ensure that the most comprehensive and systematic approach possible to the care and support of children suffering the consequences of HIV/AIDS, are implemented, not as an erratic response to crises in local areas, but as a collective national effort required to safeguard, the potential of the country, embodied and signified by these children.

Thus the needs of children extend far beyond the immediate necessitates of survival, currently being met through food parcels issued by the Department of Social Welfare, "that is not the only need the child has, they need toiletries, clothing, school uniform, school fees, fees to pay the water and electricity, some don't have electricity, they need paraffin, so we are trying to look at a holistic programme that will involve them in food gardening, more trying to develop them, rather than issuing them with food parcels. We are saying that if you want them at the end of the day, if you are not there, they should be able to do something for themselves, we offer them life-skills, assist them to come up with programmes to generate income" (Khanya Family Centre interview, July 2003). Therefore, while it is vital that children are fed, children's needs are not solely limited to these basic survival requirements. If children are to develop into contributing, resourceful members of society, they will require a range of other forms of support – emotional, psychological, social and intellectual – in order to be able to fulfil even some of their potential and ultimately

Khanya Centre workers conclude therefore that child-care committees would not only ensure better care for children themselves, but would concurrently strengthen the social bonds of society itself. They contend that while childcare grants are essential, the allocation of large amounts of state resources directly to child-headed households may reinforce the ability of communities to refute the collective responsibility for child-care. Instead, they argue, through child-care committees communities will be directly engaged in a collective effort to care and as a result of this revival and re-emphasis on corporate responsibility, the bonds of society itself will, ideally, be strengthened, "Child-care committees are a better option than more assistance directly to child-headed households, people in the community would actually be engaged to help those children while they are staying on their own … maybe we also need to look a lot at community enrichment in terms of life skills, child development, HIV/AIDS, domestic violence, child abuse, discipline of children…question of discipline of children is also a problem, with a granny who is 60 years old looking after a 15 year old child" (Khanya Family Centre interview, July 2003).

Grandparent-headed households

One of the as yet, relatively unexplored consequences of the HIV/AIDS epidemic and the shift in patterns of adult mortality which this has occasioned, is the mounting obligation of care which falls to grandparents, often the most immediate and closely involved extended family members, when HIV/AIDS illness and death strikes a family. Grandparents are frequently compelled to care for children whose parents, their own adult children, have died due to HIV/AIDS. Like children who take on the sole responsibility of the care of siblings after parental death, grandparents similarly have to cope not only with the trauma of loss of one or several young adult children, but also with a series of escalated economic and care burdens precipitated by the death of adult children who may well have been breadwinners prior to their illness, "It's so unfortunate because what we are finding with HIV/AIDS, it tends to run in families, you find one granny having three daughters die of HIV/AIDS…most of them who we are seeing have more than one child who has died of HIV/AIDS. Then the grandchildren are also HIV positive" (Khanya Family Centre interview, July 2003).

As in every aspect of the HIV/AIDS epidemic, the major burden of care appears to be falling to women, "It's a problem, everyday we get new cases of grannies coming in … Even though the grandparents are both there, it would be the grandmother who goes to meetings, to get help" (Khanya Family Centre interview, July 2003). Nevertheless some NGOs are reporting that grandfathers who are at home, no long breadwinners and probably facing less social pressure to prove manhood, are more likely to be involved in care than fathers (CARE interview, July 2003). A Khanya Family Centre worker illustrates with an example, "there are two grandfathers in the support group…there is one that we are also helping, he had three of his daughters dying of HIV/AIDS, he's left with two grandsons" (Khanya Family Centre interview, July 2003).

Grandmothers inheriting the care of grandchildren face a number of unique challenges. Despite the conventional assumption that grandparents are elderly, the reality of youthful childbearing in the South African context, means that many 'grandparents' are in biological terms middle aged rather than elderly, "We even have got grannies who are in their thirties…I think very few of them are above 60, mainly 40-60" (Khanya Family Centre interview, July 2003). While on the one hand the youthfulness of these 'grannies' may be an advantage in terms of superior physical and emotional resources to expend on the care of young children, it also means that they are not eligible for government pensions, which constitute an important economic resource for many impoverished families. Many grandparents do not appear to be aware of the other forms of support which they can access, "Most of the grannies were not aware they could access the social grant … what we did was to give them education on different types of grants and how they can access them…we need to look more at whether they are aware of the services that are available to them" (Khanya Family Centre interview, July 2003).

Even when grandparents are informed or do know of the social support available to them, some face considerable obstacles when adult children who have died fail to leave or fail to acquire prior to their illness crucial documentation which grandparents subsequently need in order to access social support for their grandchildren, "Immediately when people come to our PLWA support group, we start by helping these mothers to apply for documentation for their children…she dies, she leaves her mother with the children without ID and such things, so its better off if we get them at that level. Some grannies are fortunate enough that their children have left documentation" (Khanya Family Centre interview, July 2003).

Grandmothers confront another obstacle in terms of accessing social support, which reflects the same type of legislative idealism that leads the state to define legal majority from the age of 21. In this instance, the insistence by the state, that fathers, who have frequently long abandoned their families, should be held primarily responsible for the maintenance of children after the death of mothers. While in its assertion of men's joint responsibility for childcare, this legislation is important, it does not recognise the very real obstacles in actually making fathers accountable for their children and in this attempt to assert the co-responsibility of fathers, the detrimental effect on the capacity of able and willing grandmothers to care for their grandchildren. "A major challenge that grandmothers face, is that they are requested if they know the whereabouts of the father, a granny would not normally have that information and that normally would delay the process. [The government] believes that the father has to maintain the child and the social services should be the last resort … they also believe that some grannies might be hiding, they know the whereabouts [of the father]" (Khanya Family Centre interview, July 2003).

Not only are the emotional, social and economic responsibilities of grandparents increasing as a result of the impact of HIV/AIDS on families, but grandparents, as caregivers of adult children are unintentionally, through lack of understanding of the transmission processes of HIV/AIDS, facing the danger of infection and illness, "due to ignorance, we have also been discovering that there are grannies that are HIV positive … we think that maybe the doctor didn't share the information, maybe the granny was looking after her daughter, only to find she is HIV positive … They have information about HIV but they never thought it would be so close to them … so … they don't take precautions because she's my daughter … she's just sick … this is my child's blood" (Khanya Family Centre interview, July 2003). While these examples illustrate the extraordinary level of care which is in fact taking place in families, it is essential that in this task of care, family members are equipped with enough understanding to prevent their own illness, and hence not lose yet another critical human resource in the effort to counter the social impact of HIV/AIDS.

Although some grandparents are cognisant of HIV/AIDS as a result of extensive public awareness campaigns, when faced with the challenge of HIV/AIDS in the family, many grandparents feel ill equipped to respond. CARE NGO describes a "desperate desire for information" at HIV/AIDS information workshops held at Baragwanath Hospital (CARE interview, July 2003). According to CARE, the vast majority of this information is already publicly available. However, the combination of the means through which information is primarily communicated, i.e. written sources, combined with changing public information campaigns as more has been learnt more about the disease, is causing considerable confusion, particularly among adults who are not the subject of more direct awareness campaigns provided through the education system. Those faced with the direct challenge of HIV/AIDS in the family, struggle to interpret shifting and multiple messages about the disease. In this regard the initiation of 'door to door' campaigns where individual households are directly engaged on the topic of HIV/AIDS, has facilitated an important deepening of knowledge in some communities (Kwaze Kwasa interview, July 2003).

It is likely that the failure of some grandparents to take adequate care when nursing ill children, is not only the outcome of a lack of information about HIV/AIDS but also a consequence of denial of the nature of their adult child's illness, "And with grannies, if one of them can say openly I know that my daughter's died of HIV/AIDS, you begin to see others, say oh, maybe it could be that my daughter, my son was also HIV positive, its just that we didn't know about this disease … and there are those who still do not want to say HIV/AIDS, they just say the syphilis" (Khanya Family Centre interview, July 2003).

Death

The shifting patterns of mortality and increasing number of deaths due to HIV/AIDS is compelling a fundamental interrogation of the boundaries of life and death and the interstices between the two. People living with HIV/AIDS and HIV/AIDS activists are resourcefully working with the clay of life itself, to assert new spaces of vibrancy in the intersection between life and death. In these constructions, life and death no longer exist in absolute polarity but in a dynamic interaction where death does not inevitably take life, but instead where life can be rescued and refashioned from the heart of death itself. Through the recognition of death and mortality as central to the meanings invested in life, the HIV/AIDS epidemic is, instead of allowing death to become a sanitised, routinised phenomenon, confined to private spaces of grief, is making death explicit and in this process explicating much about the life which it circumscribes. As Deborah Posel, quoting Zymunt argues, "The conscious or repressed knowledge of mortality…is constitutive of the idea of society, and the ways in which its conditions and limits are imagined" (Posel, 2003: 6).

Thus the magnitude of death due to HIV/AIDS is disallowing rigid boundaries between life and death. Posel quotes a Soweto undertaker on the pressures that this is placing on traditional rituals of death, "People used to bury their loved ones at weekends, but these days it's not uncommon to find cemeteries packed with mourners during the week. With the AIDS plague, attending funerals has become a common occurrence, so much so that some people say they can no longer be bothered to attend" (cited in Posel, 2003: 21). These deteriorations of the ceremonies of death mark, paradoxically, the corrosion of critical affirmations of life which, are implicit in formal acknowledgements of death. Thus, through the ritual of the funeral, each death is marked and mourned. The rites of death make death, like life, both unique and universal, it is experienced by all humanity, but each death is incomparable, embodying a particular life. Thus these rituals trace the continuities between the universal and the distinctive. What happens when the demands of multiple deaths creates an incapacity or even unwillingness to meet the banality of death with an affirmation of the uniqueness of a lost life?

However, premature, unnatural and unwarranted death is nothing new to South Africa. In what ways does HIV/AIDS engage death differently? On the one hand it is evident that that there is a qualitative shift in who is dying. HIV/AIDS strikes young women disproportionately, as well as children. Neither young women nor children have been immune to various types of death, prior to HIV/AIDS and particularly in the context of the privations of apartheid. However violence, the other major causative agent of death, besides illness, prematurely took the lives of a significantly larger proportion of young men, both in contexts of political and criminal violence. Death due to illness, and particularly illness among the ostensibly 'innocent and vulnerable', demands complex social responses which do not permit the 'perpetrators' to be easily quarantined in jails. There is no institutional parallel to the social justice system, which can contain the threat of disease. In this instance, both the 'perpetrator' and the 'victim' are the social body itself. How is it possible to heal, to manage this new social hazard without the dichotomisations that lie at the heart of our response to the other major source of premature death in South Africa, violence?

Posel argues that it is the exceptional confluence of extraordinary death and the unprecedented hope of life offered by democratic transition in 1994, which make the impact of death as a result of HIV/AIDS unique in the post-democratic context, "during the apartheid era, the spread of disease within South Africa remained relatively slow; it was exactly the moment of liberation which saw its acceleration. Historically, as well as symbolically, therefore, new life has been accompanied by new death … the nature of death by AIDS is completely at odds with the new imaginaries of life…producing a host of symbolic and moral inversions" (Posel, 2003:19).

Part of the way in which these contradictions have been managed is through silence. During the anti-apartheid struggle, the cause and circumstances of many political deaths were celebrated, detailed, evoked and repeated. While HIV/AIDS activist organisations such as the Treatment Action Campaign (TAC) are consciously attempting to personify those who die as a result of HIV/AIDS, in perhaps the majority of contexts of HIV/AIDS-related death the circumstances of death remain unmentionable. Possibly in an attempt to refute the power of death, no one speaks, no explanation is offered. None is asked for. Death is construed as silence/blank, nothingness. The irony is that these silences are loud, affirming rather than denying the force of death. The unmentionably of HIV/AIDS is not dissimilar to the taboos which have attached to illnesses related to other diseases such as tuberculosis. It is evident therefore that it is possible to mould new meanings around death due to HIV/AIDS, and many communities are currently engaged in just such reconstructions of meaning through the defiance of silences and prohibitions. These reconstructions draw on a history of the assertion of life in the face of death. During resistance to the apartheid regime, the death of 'heroes of the struggle' was mourned but also claimed as a celebration of life, of strength, of vision and future embodied and performed at mass rallies for the dead.

Nonetheless social approaches to death are often not contiguous and conflicting social currents pose death in different ways. As a Khanya Family Centre worker explained in terms of the relationship between children and death, particularly significant in the context of HIV/AIDS, "In our African way, we do have a way in which we deal with death … normally children are not told, even before the spread of HIV/AIDS, when people come for condolences, we are seated on the mattress, we tell children, go out. The secrecy of death has been there, but we need to begin talking about it … If you look at dealing with trauma, and understanding that children are also traumatised, that's when we realise, for sure it was okay in the olden days, but today children are exposed to a lot of death and violence, anyway so maybe we need to change" (Khanya Family Centre interview, July 2003)

Another PLWA reiterates the silences children experience around death, "In African tradition if someone close to the child has died, the auntie, granny, mother must whisper in the child's ear and that is the end of it, it won't be talked about. When they are older they start questioning" (PLWA, comment, July 2003).

A Khanya family centre worker asserts that in the context of HIV/AIDS, "some people even do not allow a child to ask, what happened to my mother, just asking … it helps if the child is allowed to talk, it helps the child through the trauma" (Khanya Family Centre interview, July 2003).

In some instances, the social fears of the family of the deceased mean that while the person infected with HIV/AIDS was open about their status during life, in death they are mute, the cause and source of their illness unuttered by families reluctant to publicly affirm the nature of their illness.

Nevertheless despite the danger that the volume of death, will force an ordinariness of meaning around death, there is every indication that South Africans are in the face of these pressures, and at the sites of death themselves, attempting to reassert the vigour and power of life.

In an increasing number of communities individual deaths due to HIV/AIDS are being marked as an affirmation of the possibilities and value of all life, contaminated and uncontaminated. These 'open burials' assert the potential of early intervention in the processes of disease through disclosure as well as enacting a public celebration of the courage of those who faced its ravages. Vatech community worker illustrates, "N's mother she was very supportive, N's mother she was very proud. The mother, she even stand in church and say I am not mourning for my child. The coffin was here…she say my child who is dead here was doing counselling to me, he was picking me instead of I picking her up … it was like it was not a funeral" (Vatech interview, July 2003).

Thus some families incorporate local HIV/AIDS activists into funeral proceedings which then become an educative event both celebrating the life of the deceased person in an active demonstration of inclusion, rather than stigmatisation and simultaneously disseminating information about the virus, not only as a cognitive exercise but as an emotional experience embedded in the loss of a human life. As Vatech community worker explains, "When there is death you see how supportive the parents are. What they do, they call and put us on the programme. Ask us to light the candles at the church. Want us the organisation to talk about this disease and how did they cope. By so doing in the churches, the other parents who are hiding their children, its now they came forward" (Vatech interview, July 2003). Community organisations and PLWAs themselves report that the disclosure of disease, which occurs at some funerals, greatly facilitates processes of disclosure for others. Thus, through death, the hope of life is offered to others.

Another PLWA and NAPWA activist gives further details, "sometimes we disclose at funerals, maybe the person will talk while they are still alive that at my funeral I want NAPWA to come, wear your T-shirts and tell the people what killed me … sometimes they may not have told anybody in the family or in the community, you find that the person is now terminally ill and people are gossiping, talking a lot and the person who is ill cannot talk about it and then they will give instructions … Like last year a close friend of mine passed away. She even write a letter what she wants me to do at her funeral. That I must tell the whole community and the family because the family was worried that she was bewitched and the community was always gossiping at her about her illness. Then it was a very good thing to do because people came to NAPWA

after the funeral, some they came out, they disclosed, they said we are also having the same problem…some of her neighbours even came for HIV education and counselling" (PLWA interview, July 2003).

New families; new communities; new society

As this review has shown, HIV and AIDS are forcing individuals and families to find new ways of managing their way through the society in which this epidemic is playing itself out. It has shown that within families and within relationships talking about HIV/AIDS, personal infection and individual fears is often very difficult and sometimes even unachievable. In the same ways that it is sometimes unfeasible to talk about HIV and AIDS within the family, so too is it often not viable for families to talk about HIV and AIDS and how they are coping with the disease within the communities in which they are located.

What the epidemic has shown is that the assumption that families will automatically be able to protect society from the epidemic and give care when family members need it – is often not borne out in reality. South African families have had a complex and often disrupted history through colonialism, apartheid, migration, poverty and social unrest and this history which created many complicated social and political relationships and patterns of behaviour, still needs to be addressed in order to constitute a new security and stability founded on inclusive, democratic values deeply embedded within the social fabric. This already ongoing process is now overshadowed and complicated by HIV and AIDS and the irrevocable impact the epidemic will have on the already fragile and contested cohesion and integrity of the family and on its ability to survive and to nurture those belonging to it.

The epidemic unexpectedly allows for a re-examination and interrogation of the family as a social institution, a social institution which will inevitably play a critical role in the response to HIV/AIDS. It allows debates to develop about the extended family and the extent to which it has survived the past and the extent to which AIDS could or should strengthen family and kinship ties. It also allows for debates about how to make sure that families are able to survive the epidemic and retain integrity and identity. It allows for debates about where it is best to place young people who have seen the family structure they were raised in disappear and who have to forge new identities. It allows us to ask questions as to whether already over-burdened, extended families are the best places for young people or whether these families are not already unable to cope with the demands upon them. Finally, it allows us to ask if we can use this epidemic to create new families and new societies.

The reality of the epidemic therefore forces us to re-evaluate what we mean by family and community, to question the apparently fundamental norms which have previously underpinned these institutions and to look beyond social convention, for the most effective means to care and protect the socially vulnerable in the context of HIV/AIDS.

Creating new families means reassessing questions of lineage and blood ties and seeing how these can be maintained even if family members are receiving care and support in another structure. It means looking at the possibility that young people can be socialised and old people supported by different social institutions that could be called families – and it means reassessing the ways in which social security grants are tied to particular notions of age and parenthood. It means protecting young people and old people from exploitation and abuse and exploring how a variety of family forms, headed, for example, by men only or men in committed relationships, by women only and women committed in relationships, by a combination of adults and many children – none of whom might be blood related, can be considered as families. It also requires us to re-think some form of institutional care that can replicate the nurturing and role modelling offered by the most functional families, rather than the strictures and repression historically associated with 'orphanages'.

Creating new families would also help craft new societies, ideally through ground-breaking, innovative social institutions, which are malleable and resilient enough to respond meaningfully to rapidly changing social conditions. This would be a society, which embraces both the young and old when in need of comfort, care and support and which would, rather than turning away from people who are suffering and who are different, be able to find ways to promote the creation of new institutions of care and protection for them.

At all times the International Convention on the Rights of the Child should underpin how we think about families and the epidemic. Protecting those rights is paramount and if that means creating new families and communities that is what we must do. The CRC lays heavy emphasis on family and kinship ties but only where these are able to cope and fulfil the rights.

HIV and AIDS and its impact on the family creates the space for us to examine the kind of society we aspire to post-AIDS and this must force us to step back and re-examine our old certainties. We must protect families as an important means to create 'belonging', a sense of place, intimacy and connectedness for adults and children, but our vision and view of family must be expansive and accepting and include all kinds of non-traditional opportunities. We can allow families to become overwhelmed by the needs created by HIV and AIDS – or we can think anew about what it means to strengthen the family, as a centre of care, against this epidemic.

Strengthening the family means finding new definitions and solutions, which will in turn offer the possibility for enriched communities that can embrace a wide range of social formations, and this in turn will strengthen the country.

What we are really seeking is a way that as a nation we can come through this epidemic a stronger, more coherent and compassionate society. We can either stand by and watch the epidemic and misguided policies tear at the fabric of families, communities and society – or we can take the reality of this epidemic and see how we can stitch together new belonging and new identities so that all young people, all older people and all parents and most significantly all family members living with HIV and AIDS will feel that they belong in a society that is first and foremost based on inclusion, care and support. That they belong in whatever institution they call their family, in whatever community this new family is based, creating a secure and stable base for a new society that understands that to deal with AIDS, shoring up existing institutions is not enough. What we have to create is a new vision of how we live now – how we live and belong with HIV and AIDS.

Endnotes

1) Interviewees' names are not used here to protect their annonymity.

Credits for photography

Photography coordinator: Giséle Wulfsohn.

Photography suppliers: South Photographs – Page 2, top right and bottom left.

Picture NetAfrica – Back cover far left and top left on page 22.

iAfrika Photos – All other pages.

Bibliography

Abt Associates, *Hitting Home*, How Households Cope with the Impact of the HIV/AIDS Epidemic. A Survey of Households Affected by HIV/AIDS in South Africa, The Henry Kaiser Family Foundation, Social Surveys, Memory Box Project AIDS and Society Research Unit, UCT, October 2002.

APRODEV*, HIV/AIDS Grasping the Reality of its Gender Dimension, APRODEV, GOOD-Gender Orientation on Development*, Annual Conference Report, Oslo, Norway, September 2000.

Bazilli, S, *Putting Women on the Agenda*, Johannesburg, Ravan Press, 1991.

Crewe, M, *For home-based care you need a home*, public address, 2002.

Cross, C, *Sinking deeper down: HIV/AIDS as an economic shock to rural households, Society in Transition*, 2001, 32 (1).

CSA, Unpublished research by the Centre for the Study of AIDS (CSA), University of Pretoria, undated.

Department of Health, *HIV/AIDS/STD Strategic Plan for South Africa, 2000-2005*, Government of South Africa, May 2002.

Department of Health, *Integrated Community-based Home Care (ICHC) in South Africa*, Government of South Africa, August 2002.

Department of Health, *Tracking Progress on the HIV/AIDS and STI Strategic Plan for South Africa, June 2000-March 2003*, Government of South Africa, 2003

Gordon, M, *Oxford Concise Dictionary of Sociology*, Oxford University Press, 1996.

HEARD, *The Hidden Battle: HIV/AIDS in the Family and Community*, Health Economies and HIV/AIDS Research Division (HEARD), University of Natal, Durban, 2000.

Hlongwane, C, *Caravans, Cats, Geese, Foot and Mouth Statistics, HIV/AIDS and the Struggle for the Humanisation of the African*, March 2002.

Kayongo-Male, D and Onyango, P, *The Sociology of the African Family*. Essex: Longman, 1984.

Leclerc-Madlala, S, *Youth, HIV/AIDS and the importance of Sexual Culture and Context*, AIDS and Society Research Unit, Centre for Social Research, Working Paper No.9, June 2002.

Mama, A, Challenging Subjects: Gender and Power in African Contexts, *African Sociological Review*, 2001, 5 (2).

Mannheim, K, The Problem of Generations, 1952, in *The New Youth Pilgrims: Youth Protest in Transition*, David McKay Company, 1972.

Medical Research Council, *The Impact of HIV/AIDS on Adult Mortality in South Africa, MRC Technical Report*, Burden of Disease Research Unit Medical Research Council, September 2002.

Moral Regeneration Movement, *Freedom and Obligation*, A Report on the Moral Regeneration Workshops 1&11, July 2000.

Moral Regeneration Movement Brochure, GOVZA, undated.

Nelson Mandela Foundation and HSRC, *Nelson Mandela/HSRC Study of HIV/AIDS. South African National HIV prevalence, Behavioural Risks and Mass Media, Household Survey*, 2002.

Posel, D, *A Matter of Life and Death: Revisiting 'Modernity' from the Vantage Point of the 'New' South Africa*, draft paper presented at Wits Institute of Social and Economic Research (WISER).

Rao Gupta, G, International Center for Research on Women, Washington, D.C, USA. Plenary Address X11th International AIDS Conference, Durban South Africa, 2002.

Ridgeway, N, Draft Paper, Culture Contamination and Contagion, Or if I Touch you I might Get what you've Got, *Lets Talk about Sex Series*, Wits Institute of Social and Economic Research (WISER), 6 May 2003.

Robbins, S, First draft, The Colour of Science: AIDS, Science and Citizenship after Apartheid, Paper for conference on 'Science and Citizenship in a Global Context', IDS, 12-13 December, 2002.

UNAIDS, *South Africa, Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections, 2002 Update*, UNICEF, World Health Organisation, 2002.

UNAIDS, *Report on the Global HIV/AIDS Epidemic*, UNAIDS, July 2002.

Van Aardt, C, *The Demographic and Economic Impact of HIV/AIDS in South Africa*, Bureau of Market Research, 2001.

Ziel, S, Black South Africans Do Live In Nuclear Family Households – A Response to Russel, *Society in Transition*, 33(1), 2001.

Ziel, S, Documenting Changing Family Patterns in South Africa: Are census Data of any Value?, *African Sociological Review*, 5(2), 2002.

Zuma, J, Opening Address by Deputy President Zuma at the launch of the Moral Regeneration Movement at the Summit held at Waterkloof Air Force Base, Pretoria, 18 April 2002.

Organisations Interviewed

AIDS Counselling Care and Training (ACCT), Chris Hani Baragwanath Hospital.

Bambanani Support Group, Vereeniging, Gauteng.

Community AIDS Response (CARE), Norwood, Johannesburg.

Ebenezer Community AIDS Project, Sunnyside, Pretoria.

Khanya Family Centre, Katlehong Resource Centre, Katlehong, Gauteng.

Kwaze Kwase Katorus Women HIV/AIDS and Home-Based Care, Katlehong South, Gauteng.

National Association of People Living with AIDS (NAPWA), Esselen Clinic, Johannesburg.

SAKHI'SIZWE AIDS Care Initiative, Braamfontein, Johannesburg.

The AIDS Consortium, Braamfontein, Johannesburg.

VATECH, Vosloorus, Gauteng.

Centre for the Study of AIDS

The Centre for the Study of AIDS (CSA) is located at the University of Pretoria. It is a 'stand alone' centre which is responsible for the development and co-ordination of a comprehensive University-wide response to AIDS. The Centre operates in collaboration with the Deans of all Faculties and through Interfaculty committees to ensure that a professional understanding of the epidemic is developed through curriculum innovation as well as through extensive research.

Support for students and staff is provided through peer-based education and counselling, through support groups and through training in HIV/AIDS in the workplace. A large number of student volunteers are involved in the programme, as are many community groups, ASOs and NGOs.

To create a climate of debate and critique, the Centre publishes widely and hosts AIDS Forums and seminars. It has created web- and email-based debate and discussion forums and seeks to find new, innovative, creative and effective ways to address HIV/AIDS in South African society.

AIDS Review, published annually since 2000, addresses major aspects of the South African response to the HIV/AIDS epidemic. *Review 2000*, entitled *To the edge*, addressed the complex question as to why, despite the comprehensive National AIDS Plan adopted in 1994, South Africa has one of the fastest growing HIV epidemics in the world. *Review 2001*, entitled *Who cares?*, dealt with the levels of commitment and care – in the international community, in Africa and in South Africa. *Review 2002*, entitled *Who cares?*, dealt with the levels of commitment and care – in the international community, in Africa and in South Africa. *Review 2003,* entitled *(Over) extended*, evaluates age, demographic changes and changing family and community structures. *Review 2004* will look at the ways in which men have been constructed by this epidemic.

Centre for the Study of AIDS
University of Pretoria
Pretoria 0002

Tel: +27 (12) 420 4391
Fax: +27 (12) 420 4395
csa@up.ac.za
www.csa.za.or

University of Pretoria

Centre for the Study of AIDS
University of Pretoria
Pretoria
0002

Tel: + 27 12 420 4391
csa@up.ac.za
www.csa.za.org