Wo! Zaphela Izingane --It is Destroying the Children-
Living and Dying with AIDS

Prepared for

The CINDI (Children in Distress) NETWORK

By

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July 1999
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Executive Summary

This is a qualitative study of death and dying in the context of AIDS. As such, it is a study both of the social processes and responses that surround death as well as where AIDS derived deaths fit in. As we know little about either of these aspects in contemporary South Africa this exploratory work aims to bring out people’s perceptions and experiences – especially as they are being played out in poor communities in and around greater Pietermaritzburg.

While the inevitability of death is recognized as a natural part of life – how, when and under what conditions we die depend, in significant measure, on a range of social and economic factors. These are confounded further by AIDS for at least two reasons. Firstly, as a syndrome that leads to death AIDS is different from other terminal illnesses because individuals succumb to multiple illnesses, many of which are treatable and non-fatal under other circumstances. Secondly, AIDS related deaths are different because they impact most forcefully on that segment of the population that historically has been at the heart of social and economic production and reproduction in our society – young adults. Both these dimensions shape people’s perceptions and experiences of AIDS related deaths.

All death is painful and hard to bear. In looking at people’s perceptions of good and bad death in relative terms this study finds that responses to AIDS are ambiguous. Although AIDS carries stigma for the living, people regard AIDS’ derived deaths as timely because they are an outcome of terminal illness and because they release people from pain and suffering. At the same time, such deaths are untimely because of the age of those who are dying and especially, because of the social and economic impacts of youthful adult death.

This study shows death to be a complex process that has a forceful, mostly negative impact, which extends far beyond the dying individual and the event of death itself. The economic and social pressures in the family begin long before an individual’s demise. Loss of income and health status is accompanied by a costly pursuit of treatment, if not cure, as people struggle to understand and find a satisfactory explanation of the condition they find themselves or those they care for in. With death itself the lives of surviving individuals and their families are reshaped, often in a fundamental way. Families compact, expand or disintegrate altogether. Basic needs – food, shelter, clothing, education etc – become even harder to meet as they are jeopardized through inadequate preparation for death, too few resources within surviving families and the limited responsiveness of “community”, broadly defined. Through all this, the aged and children are made particularly vulnerable and responsible, being the least resourced and the most burdened.

This study highlights the extreme hardship and suffering that (young) adult death brings for those who survive. It suggests that there is a real need and a window of opportunity
for major social intervention to support those living with AIDS, including those who are HIV positive. And that this intervention needs to be driven by practical, multi-sectoral social interventions in a range of areas.

**Acknowledgements**

This research was made possible thanks to the initiative and generosity of the CINDI Network (Supported by the Nelson Mandela Children’s Fund) affiliated to the Pietermaritzburg & District Community Chest F/R No 06/6000/87/000/9. Appreciation is extended to the National Department of Welfare, which financed and supported the research, the National Department of Education for supporting and UNICEF for sponsoring the publication. Gladness Xaba, Busi Skosana and Surie Baijoo made an invaluable contribution through their work in the field as well as diligent translation and transcription of hours of tapes. We also want to thank Thandekile Hlongwane, who agreed to come as an intern onto the project, Thandanani staff; local members of community child care committees and other community welfare initiatives, as well as members of ANC branches who helped the research team access respondents. Most importantly, we wish to thank the women and men who generously agreed to participate in this research project as respondents. Through their courage they have given us insight into the pain and suffering that AIDS and non-AIDS related terminal illness and death inflicts on ordinary people and their families. The ideas and arguments expressed in this report are those of the author.
Glossary of Terms

Amagama amathathu – The three letter word
Amagobombo – Traditional treatment for student Sangoma
Amandiki – Bewitchment
Idili elikhulu – Last cleaning ritual
Idliso – Food poisoning
Impepho – Incense
Ingculazi – Syphilis
Intelezi – Traditional medicine to chase away evil
Into yakhe – His/her thing
Intsholongwane – Virus
Inyanga – Traditional healer
Izinyanga – Traditional healers
Ububane – The destroyer
Ukuhlambuluka – Cleansing ceremony
Umashaya buqe – Total destruction
Ugcunsula – STD
Umeqo – Bewitchment
Umthandazi – Spiritual healer
Umswani – Digested grass in the cow’s stomach
Yizinqe – Backside
Yizo- Yizo – It’s it
**Introduction**

The notion of “Living with HIV/AIDS” has largely been interpreted as an individual, bio-physical condition. People who are said to be “living with” the syndrome are those who are infected by the virus. Undeniably those infected are living with HIV/AIDS, but it is important to put their disease in a social context. The very fact that as individuals they live in relation to others means that it is not only they who live with HIV/AIDS. Their illness sends shock waves into a social web which has as its epicentre their immediate family but which extends to more distant relatives, friends, neighbours, colleagues and casual acquaintances. The very scale of these micro social shocks has mezzo and macro impacts, which require a level of social mobilisation that extends well beyond the particular circumstances and experiences of the individual who is diagnosed as HIV+.

A critical component of living with AIDS is the fact that it is a terminal illness that requires individuals and those around them to face death. As much as death is a physiological process, a universal and at the same time uniquely individual experience, it is also a social process, since we can plan for dying in anticipation of death. Every society has developed a meaning system to manage and explain death, elaborating and rehearsing rituals and ceremonies that affect the dying, the dead and their survivors. It is these social responses that shape how we die. (Kalish 1980)

As in many other fields of social enquiry, little attention has been paid to the sociology of death and dying in South Africa. The little we know about the social practices that surround death, people’s perceptions of death and dying or the degree of their exposure to death comes from sporadic studies in anthropology, nursing science, psychology, statistics and archaeology.

This research is an exploratory qualitative investigation of poor people’s perceptions of death and dying in seven peri-urban and urban communities in and around Pietermaritzburg in the KwaZulu-Natal midlands. Using a structured guide, 15 focus group discussions were run with adults (over 35 years of age) and young adults (20 to 35 years). Of 120 focus group participants, the majority (n=112) were women. Two of the focus groups were with people living with AIDS. A further 10 in-depth interviews were conducted with one or more individuals in each community who had been diagnosed as terminally ill. Eight of the in-depth interviews were with women, two were with men. In addition, a structured questionnaire was administered to individuals from four institutions considered to be key to the management of terminal illness and death. The research was carried out over the period April to June 1999.

People were selected to participate in the study because they have personal experience of death in their families, are caring for somebody who is terminally ill, or are terminally ill themselves. What is striking is that five of the 10 people interviewed in the case studies and one or more participants in most of the focus groups have experienced multiple deaths - two, three or even four close family members dying – in the recent past.

“I have seen it all. My husband was very ill. My daughter and grandchild died in my absence. I was just told when I got home that they had died. Then my other
grandchild was the last one to die.” (S1 Focus Group)

“The first one was my son. He was about 20 years old. He died in December. The second one was my eldest son. ...They all died one after another ... Then it was the child – two years old. The mother of the two-year-old died ... the same problem, she also lost lots of weight. She was 23.” (CS10-S)

This suggests that death is a close, sometimes frequent presence in the homes of the poor and, therefore, that some of the assumptions in the literature about exposure to death prior to the impact of AIDS might need to be qualified.

**Concepts of Death**

There is a general perception of death as something inevitable, something that is part of the human condition that affects everybody.

“Death does not choose because everyone dies and it is something that is meant to be. We all remain on this earth for a certain period and when our time comes, we die.” (X1 Focus Group)

“Death does not choose, whether you are rich or poor, it affects us in the same way.”

“No matter who you are, it will come.”

“Whether you are young or old ... It doesn’t choose because even an infant is affected by it.” (S1 Focus Group)

Death is something that people regard as omnipresent and out of their control.

“Death comes whenever it pleases.”

“Death comes unannounced.”

“Death comes when you least expect it.”

“Death is like a thief. It comes at any time.” (E2 Focus Group)

“Death cannot be stopped. It is always there.”

“You should expect it at any time for anyone.” (A2 Focus group)

“Death is like the blink of an eye, because I could be well today and die the next day.”(X1 Focus Group)

At the same time as death is seen to be a universal equaliser, indiscriminate and inevitable, people have notions of death as something that has a reason or cause.

“There is a lot that can be said about death. Once you die it cannot be stopped. Death is inevitable but every time a person dies, it’s for a reason.” (CS3-W)
1.1 Appropriate and inappropriate death

It is the cause of death that makes people understand death as something that is timely and appropriate or untimely and inappropriate. In all the focus groups there was general agreement that timely or appropriate death is associated with old age.

“An appropriate death is death that comes when you are old. The people say the person has rested.” (H2 Focus group)

“For me its all the same, nobody anticipates it.”
“An elderly person can die of old age but that doesn’t mean its because it has been anticipated. It will be because their time would have come.” (S2 Focus Group)

A counter voice to this consensus can be found, but it relates to another aspect of death, namely the experience of loss and pain that is associated with it. To wit:

“The death of a person, whether young or old, is not acceptable. Like, I stay with my granny and her death will not be accepted.” (C2 Focus Group)

Many people also believe that death is appropriate when it comes after a long illness or after much suffering even if the illness is short, no matter the age of the person. Mostly, they find this kind of death acceptable because they can prepare themselves in some way for the death, they have time to care for the person and because the death itself is seen as a release from suffering.

“I think any death resulting from an illness is acceptable.”
“It is acceptable because the person has been ill and you know they are going to die.” (A1 Focus Group)

“A good death is when somebody has been ill for some time and then dies, and the family has done their best by taking the person to the inyanga (traditional healer).” (A2 Focus Group)

“A prolonged illness of a young or old person often prepares us for death and it is thought that it is best that they die because they will be at rest.” (X2 Focus Group)

Where illness is seen as something natural, death arising from such an illness is also seen as something that is a natural consequence. For some a good death is one that comes quickly and with little suffering for the person who is dying. For others death itself is seen as a release from pain and, as such, is considered to be good.

In most of the focus groups people described deaths that resulted from sudden illness (e.g. heart attacks), road accidents, physical violence (shooting or stabbing) or suicide as inappropriate. For them, such deaths happen suddenly and unexpectedly. They give people no time to care for or spend with the person before they die. They also mostly are inflicted on a person without “good” reason and are described as “shocking”.
“I have experienced sudden death and saw that as just as bad. She just collapsed. She should have been ill and I would have nursed her.” (C1 Focus Group)

“I would say that my two brothers died inappropriate deaths because I am still sore about my older brother’s death who died for 20 cents, something which could have been talked about and resolved. We would have given that 20c to him. My other brother, who I am born after, was living somewhere as a lodger. What we were told by those who were there at the time is that he was on the pavement when the car hit him. In his case we did not even get an opportunity to be around him to give him hope that he would survive, because he died on the spot.” (X1 Focus Group)

“My sister was the first one to become very ill, to such an extent that she had to be admitted in hospital. When she came back from hospital she was not really fine. She did not look ill the day that she died ... I went to work but I was called to go back home because she had died. A month later my brother became ill. We had been told to come and fetch him from hospital. The next day I did not go anywhere ... we bathed him and soon after that he died. Then it was my other sister. She had a heart condition and I think that my brother’s sudden death stressed her too much and she died the next morning when we woke up. The sudden death of my sister who had a heart condition was more painful than the deaths of the other two who had been sick for a long time. “ (S1 Focus Group)

Apart from accidents or violence, disease-derived illnesses and old age, participants also indicated that people could become ill and die in other ways. Clan feuds (“faction fighting” or “revenge killings”) are a known cause of death but they are mentioned only infrequently by participants, as a thing more of the past or of other places.

“There were revenge killings during the violence, but now we bury people who have been ill.” (A2 Focus Group)

“That happens a lot in the rural areas, it is not as bad in the townships.” (S1 Focus Group)

People also attribute illness and death to non-biomedical causes – particularly idliso or poisoning, when a person’s illness or death is attributed to the deliberate administration of poison by another individual or family, and amandiki or bewitchment, when an unrequited spirit disturbs and preys on the living. Death as a result of either of these is seen as bad and inappropriate, requiring living kin to respond through ritual and sometimes by taking social action.

“The death I have experienced in my home has been very difficult and I have noticed that it is not the same as in other homes. It was ... when my older brother hanged himself because of an argument he had with someone who did not see eye to eye with him. When my family wanted to take harsh measures against that person, I told my family that he did not kill my brother. My brother decided to take his life.” (X1 Focus
“My eldest child was ill and she was bewitched. She died and we buried her and she has left me with her two sons.” (E1 Focus Group)

1.2 Aids Related death
AIDS related deaths fall ambiguously along the continuum of appropriate and inappropriate death. Much of the reason for this ambivalence derives from people’s perceptions and experiences of the social responses to AIDS. The first point to note is a general awareness of HIV/AIDS as a growing cause of death in communities, reflecting the advance of the AIDS pandemic.

“It (AIDS) is spreading very rapidly.”
“It is spreading a lot because many people in this community are infected with it ... and chest complications are also spreading. (They were) not as common as they are today and I think what is making them spread so rapidly is alcoholism.” (H1 Focus Group)

“People used to die from stab wounds and accidents, but now it is these diseases that are causing death. These diseases are new and were not there before ... cancer, TB and this new disease, which people do not talk openly about.” (M2 Focus Group)

“I think that AIDS is there because there are lots of deaths and there are funerals every Saturday.” (A2 Focus Group)

“I have seen many people die of AIDS.”
“AIDS is spreading so fast that we desperately need to find a cure.” (S2 Focus group)

People graphically describe the physical signs as well as the symptoms of AIDS related illnesses.

“AIDS and TB have similar symptoms to start with. AIDS starts with chest pains, then a person complains of headaches, sores on the body, loss of appetite then running stomach ... AIDS shows different symptoms in different people. Others have glands behind the ears, others do not have these but have a severe running stomach and end up with chest pains and head aches.”(H1 Focus Group)

“People who have AIDS look very thin.”
“I have seen people fall ill and become very thin, which means they are infected with the virus.” (E1 Focus Group)

The second point of note is that across the focus groups and case studies, participants identify the youth and young adults as particularly affected by AIDS. They all associate the impact of AIDS with people in their late teens, twenties and thirties, but also affecting
those in their forties.

“We feel bad because the youth are dying. We are still young and we would like to live long, until we have grandchildren. Dying so easily worries us although we are contributing to this death.” (C2 Focus Group)

“It is everywhere. The other day I went to S … and I heard that so many people have died of the disease. I was shocked because these children are so young and the people would say ‘can’t they die from something else?’ The sad thing is that these people leave children behind and as you know, children are bearing children at a very young age. I wish to know what will happen to these orphaned children when their grannies die?” (CS5-H)

1.3 The secrecy and stigma of AIDS
Thirdly, in all the focus groups, most participants observed that AIDS is surrounded by secrecy and stigma. People generally do not refer to it by name, often talking about “this thing” (into yakhe), and there is a string of euphemisms commonly used to refer to AIDS.

“Itsholongwane (virus) … Hlengiwe Ivy Vilakazi (HIV) … Ugcunsula (STDs) … Amagama amathatu (the three letter word) … Colgate … umashaya buqa (total destruction) … Yizo Yizo (it’s it) … yizinqe (your backside).” (X2 Focus Group)

“It’s called the father, the son and the holy spirit.”
“It’s called ingculazi (syphilis).” (W2 Focus Group)

“Its called ubhubhane (the destroyer).” (H1 Focus Group)

“I hear lots of people say they will die in the same way that they were brought into this world. People have turned it into a joke.” (S2 Focus group)

Alternatively, people are said often to refer to AIDS by naming it as a more acceptable illness such as TB, chest pains – or as bewitchment.

“People do not speak openly about AIDS. They say that they have idliso (poisoning).” (C2 Focus Group)

“Yes, there is amagobhongo umeqo (like being bewitched through evil spirits) and others have referred to it as pneumonia. You hear some people say that he died of pneumonia, whereas it was AIDS.” (X2 Focus Group)

At the same time, public acknowledgement of knowing the disease in a personal or intimate way is mixed. One or two participants in the focus groups as well as several case study respondents, especially care givers, who were quite forthright – sometimes expressing their anger as well as their acceptance of the illness.
“My daughter came to me coughing and she was so weak she could not do anything. I asked her what the hospital had said was wrong with her and she said that they told her she had pneumonia. I said to her that means she has this disease, because she has been behaving promiscuously. I said to her that I have long been telling her to stop, but she refused to listen to me. She has gone after this disease and now she is stuck with it ... I am 45 years old and can tell when things go wrong. I was long aware of her condition and knew it was this disease, even though she did not want to be honest about it. But I told her she had this disease.” (A1 Focus Group)

“I have seen my children die. My daughter had this illness that is killing many people, and the other one was stabbed to death.” (A1 Focus Group)

“My niece died. She had HIV. She started being ill in December and she died in January. Her whole illness started in April when she complained of earache ... Her doctor called her father and my sister-in-law and told them she was HIV positive. She has a son who is four years old. He lives with me. I stay at home with his grandmother.” (CS9-E)

Yet, in all the focus groups several participants were reluctant to acknowledge the disease and scared of saying they knew what the disease looked like.

“I think that AIDS is in our community because they say that people in E and the surrounding areas have the virus.”

“It is there although I have not seen it, but I have seen people who have the symptoms.” (A2 Focus Group)

“Nobody talks about it.”

“It is not something that is openly exposed.”

“I once heard some of the health workers discussing it at the shops. They were saying that it does exist in this community and that the rate of infected people is quite high.” (H2 Focus Group)

The shame and embarrassment surrounding AIDS comes from its link to sex and particularly unregulated sex, which is typical of and is seen to reflect the uncontrollability of contemporary social life. In both the adult and young adult focus groups several participants associated the spread of AIDS among youth with their waywardness and irresponsibility, as well as the fact that young people do not take advice.

“AIDS is the disease of the youth ... It is caused by not being serious with life ... The youth have many sexual partners ... They don’t behave themselves.” (W1 Focus Group)

“We really don’t know because we do give our children advice on how to conduct themselves sexually and we encourage them to use condoms. But when they are faced with making the decision, they choose not to make use of them. I find that the children are always comparing themselves to our times, because they always say how come I
never used a condom in my days. I tell them that these are their times and that these times are dangerous.” (H1 Focus group)

“We, the youth refuse to listen, because if someone could come to me and tell me that they are infected, it is as if the person is saying this because they have had enough and I haven’t. Some people will only admit that AIDS exists when they find out that they too are infected ... Even when you try and speak to the youth they will ask you if you have eaten a sweet without removing the plastic covering it.” (X1 Focus Group)

In some adult focus groups participants drew attention to the fact that parents contribute to the stigma associated with AIDS as well as its spread by not being open about the cause of their children’s illness or death.

“People do not want to know what will help them. They just want to protect their children, even when they see that something is wrong with them. People don’t want to send their children for medical check ups, thinking that people will laugh at them.” (W1 Focus Group)

“The parents need to be open about their children’s HIV status and talk about it to the community, because people in the community have a tendency to associate this disease with witchcraft, which it is not.” (H1 Focus Group)

Most participants in all the focus groups called for people to be open about AIDS. Generally, they regard openness as a way of supporting and including those who are infected as well as helping others to learn and to act to prevent themselves from becoming infected.

“I think that people who are infected should volunteer and come out in the open about their illness and explain how dangerous this disease is. I think that would make others aware of it.” (C2 Focus Group)

“People should get together and say that it is not a shame to have AIDS.”

“We should meet and talk about the possibilities of being positive. Those who are HIV positive should be open about it.”

“I think that people should come together and do things, whether they are HIV+ or not.” (A2 Focus group)

“We need to be friends with infected people rather than to isolate them.”

“We should stop discriminating.”

“We should not judge them.” (E2 Focus Group)

The very fact that participants call on HIV people to be open and unashamed and for communities to act differently underscores a reality where the social response can be one of scorn and derision.
“Anyone can get the disease, but you often hear people saying that people get infected through their own fault and negligence. What we need to bear in mind is that this disease affects everyone and does not discriminate. It may be easy for me to point at someone who is HIV positive, whereas I might be positive as well but have not been confirmed by a blood test. We all have to bear in mind that it could happen to us and then when it does, we will all need to be loved. We need to accept other people being HIV positive before we can accept our own HIV positive status.” (X2 Focus Group)

“People don’t understand that death resulting from this disease is like any other death, and instead of understanding this, they laugh at you.” (C2 Focus Group)

The call for openness about AIDS seems to carry a mixed message. While for the most part it is a way that people hope to overcome the problem of stigma, responses from several participants suggest that, at least for some, it is a way of exposing and isolating those with HIV/AIDS.

“Parents are often aware if their children have AIDS. They should stop hiding it and let the community know about it because some of these children can be very evil. When some of them discover they have AIDS they don’t want to die alone. They go out and spread it intentionally, killing our children. I blame the parents for keeping this information from the community, because they know when their children have AIDS. They go around telling people that their child has been poisoned (idliso), whereas it’s AIDS.” (H1 Focus Group)

“People should speak once they are infected, instead of spreading it to others.” (S2 Focus Group)

“... people who have AIDS don’t want to admit it.” (W1 Focus Group)

“Your friends also have a right to know, even if they have the potential of telling everybody else ... if you know that you are HIV positive you should say that you are HIV positive ... I agree because people don’t say they are HIV positive and they are making it spread.” (C2 Focus Group)

1.4 Responses to disclosing HIV
The experience of people who have disclosed their HIV status is instructive. While it confirms that responses are mixed, many people find acceptance in their families and among friends.

“At first they rejected me, but they realised later that there was nothing they could do to protect me because I was already infected. Although they could not accept me in my situation, they did not chase me away from home. As time went by they realised they were fooling themselves with what they were doing to me and they began treating me
like the rest of the family. We do everything together and I feel like I belong now.”

“I don’t live with my mother. I live with my aunt and my father’s sister. She is the person who knows all about my illness. I would say she has accepted me, because she does everything for me and she does not discriminate against me. I have to go to hospital once a month and she always gives me money for taxi fare.”

“My family does not have a problem because the person I told is the one who advised me to go for an AIDS test. I think she was already aware of the symptoms. She accepted me and continued to treat me like her child.”

“It took me a while to tell my family, because my mother is ill. She has high blood pressure and is diabetic. I thought if I told her I would be killing her and I thought if I did not tell her I would be killing myself. Eventually, I thought it better to tell my mother because I feared the reaction of my sisters. She accepted me wholeheartedly.”

“I did not have much of a problem. Ever since I became a member of S (the support group) I used to tell them how a person who is HIV should be treated, in a sort of educative way. After some time I asked them how they would feel if they found out I was HIV positive … They said it would not bother them because … I have been educating them all about it. Then, one day I told my granny and although she was shocked, she was able to accept me.” (X1 Focus Group)

Talking about her experience as a caregiver to her granddaughter who died of AIDS, Ma M says:

“We all accepted her situation. The other children also helped look after her and we shared the bedroom with her. We never discriminated against her and we all used the same dishes. … We only discussed her illness as a family. There was no need to tell anybody else … They knew once this word was mentioned they had to love her and be patient with her. They treated her very well. They never showed any signs of ill feelings towards her and they did everything nicely for her.” (CS8-S)

If any pattern of acceptance can be discerned, it would seem that it is most typical where people still have ties with their families of origin. This link between family of origin and acceptance, a link which is made through women, is underscored by the following observations.

“The other day a woman from Gauteng arrived carrying a suitcase and a child to the Centre. I do not know how her family could have let her leave home with her child, being so ill. She died and her child has become nothing, calling for its mother who is no longer there. It would have been better if the child remained with its granny at home instead of suffering like this.” (X2 Focus Group)

“The way I see it, my mother never thought that my child’s mother was a stranger. She
was like a daughter to her and that is why she took care of the child and us and that is how we came to live with her. We all lived together until we went into hospital. (She died). I came out of hospital and carried on with life.” (CS6-M)

Things appear to be more difficult for people who have lost contact with their families of origin, where they have created a family on their own, or where they have entered another family through marriage. This and other studies (Sewpaul and Mahlalela 1996) have found that social rejection seems most strongly directed towards women and that the rejection often comes from male partners or their kin, who beat up or send the women away.

1.5 AIDS – good or bad death?
AIDS is only regarded as an appropriate or timely death because it is illness derived and a death which releases the dying from pain and suffering.

“This new disease that devours the individual until they shiver all over the body makes death appropriate.” (E1 Focus Group)

More often than not, AIDS is also regarded as an untimely as well as a bad death, because of the age of those who are dying and especially the social and economic impact of youthful death. It is also bad because it is death which, even though there is no cure, people feel can be avoided.

Generally, all death is painful and hard to bear. The differences between good and bad death are only relative. This is so, even though some deaths or ways of dying are regarded by some as more acceptable, because they are easier to understand or they give the living and the dying time to come to terms with the temporary nature of individual human existence.

“Everything about death is painful. It cuts you through the core, because you ask yourself what went wrong.”
“For me death is unacceptable, whether one dies young or old. It is the same thing because the sorrow is the same.” (S1 Focus Group)

The causes and timing of death only partly influence the way people understand and respond to death and dying. Experiences and perceptions of death are also complicated by their social consequences. Death is a socially complex process that has an impact over time and space that extends far beyond the dying individual and the event of death itself.

The Impact of Death
Death is a profoundly emotional experience of loss and pain, fear and sadness. Death, especially adult death, also carries a huge social burden. The shock waves of a single adult death extend across a thinly spread, patchy web of ties which are linked precariously to and from grandparents and parents, parents and children, uncles and aunts
and nieces and nephews, grandparents and grandchildren, neighbours and friends.

“My sister died and she left me with her child. She fell ill in July last year and she died on the 5th of March this year. The child is three years old.”

“My daughter died on the 20th March, this year and she left me with two children. The eldest is ten and the youngest is six years old.”

“My daughter was ill and she also had pneumonia. She left me with two children. The eldest is five and the youngest is eight months.”

“My daughter died of a long illness. I don’t know what was wrong with her, she felt something move in the chest area. She left me with two children, the oldest is 15 and the youngest is two years.”(C1 Focus Group)

2.1 Economic pressures

Death has a forceful impact, economically and socially. It pressurises families to reconfigure themselves in multiple ways. Adult deaths not only rob children, parents and partners of somebody they love and care for. They invariably also rob the family of a primary or sole breadwinner.

“What made my mothers death wrong was the fact that she was the only responsible person at home. She shouldn’t have died. We were all depending on her. It was also wrong because she had been ill for a very short period. The doctors couldn’t cure her. She had pneumonia.” (S2 Focus Group)

“My father died. We lived with my father because there was nobody else and my brother was working and living in Durban. My mother did not live with us. It was difficult even after his death because sometimes we don’t have food and we have to look after ourselves. ...My mother died. She was very ill and she was the only person we were depending on. We had to quit school and look for employment. I was in Standard 7 when I left school.” (C2 Focus Group)

“It was very difficult because she was feeding us. She left her child, who has stopped going to school, because I can’t afford to send her. I cried and still cry.” (W1 Focus Group)

“It is indeed painful when someone who is a breadwinner at home becomes ill. The same thing happened with my child and I cried a lot, because I could see that she was dying and she was pregnant at the time. I did not know what was to become of me, because my husband does not work and she was the one who saw to our needs at home. My blood pressure has risen so high that I can’t sleep at night and my feet are always swollen.” (H1 Focus Group)

With adult death the burden of economic and domestic responsibilities, as well as keeping the family together, shifts. Frequently it becomes more concentrated in a single surviving adult – the grandmother, mother, sister or sister-in-law and, less often, the father. Many are able to keep their families going although almost always at a less
“The deceased was the only one working and providing us with money. Now that they are no longer around we only have our grandmother’s pension to see to our needs and that of her children.” (S2 Focus Group)

Responsibilities also get diffused downwards to the children, mostly to daughters, especially where adult female relatives are not available or are unable to take up these additional responsibilities

“If I were to die it would be the end of everything at home because I have taken over my parents place because they are dead. I look after my sister, her child and my children. I have a piece job on a Sunday.” (X2 Focus Group)

“There has been a great change within the family, because everything that my only brother used to do for us while my mother and sister were still alive, he has ceased to do ... Everything my brother used to do he did for our mother. Now there is nobody to stand up to him and say there is no sugar or maize meal in the house. My other sister and I have to see for ourselves, what to do.” (CS3-W)

“Now that she is dead it is very tough because I now have to see to everything at home as I am the oldest child. The grant that the child was receiving stopped when she died because the child was her dependent. So now I do everything she used to do.” (S2 Focus Group)

2.2 Social pressures
The burdens of a loss or reduction in income in the household are compounded by social pressures, which both attract and expel family members. The family unit, no matter how it is constituted, invariably is forced to reorganise itself. Death often brings more dependent children into the family.

“My sister died. She was 30 and she had been ill for a long time. What made her death difficult was the fact that she had two children. The eldest is 14 and the youngest is four months. It is difficult because the child has to be bottle fed now and that requires money. I do not work and I am the one left with these children.” (C2 Focus Group)

“I do not work. My husband is a pensioner and now that my son is dead, his children have become our responsibility now. There is also another child whose mother died who is living with me. It is really tough because we all depend on my husband’s pension. All these children are of school going age. It is really difficult.” (A1 Focus Group)

“When my mother died she left me with my brother, who is ill and my sister’s children who got married and left their illegitimate children with us, who I am looking
after. Three belong to my sisters, one is my brother’s and the other is mine. The one granddaughter has two children of her own. We all struggle together with the help of my father’s pension ...

Three people in my family died. One had four children and the other two had one child each. Their grandmother supports them. The oldest is 14 years and the youngest is three years old.” (S2 Focus group)

Death or impending death also forces families to splinter, as children or even adults are sent to relatives or leave home.

Speaking of her husband’s death, for example, a woman who has cared for and buried four of her kin, said:

“Just before he got worse he said that I should stop scolding our grandson. He said he would like his son to go to school. He said that I must take our grandson to school and he said that if his daughter’s mother wants her back, then I must let her go, because she has no rights in this home. Her rights are with her mother’s family where she was born. He said that his son has the right to this home. I bore that in mind and spoke about it generally to our son.” (CS 1H).

“My family was divided by my father’s death. There were also many problems that resulted from his death. We no longer get along very well with each other, even though we are from the same family. We squabble over small things and we’ve all gone in different directions.” (CS7-W)

“The one who had four children was married. Her husband brought them all back to us when my sister died and he never did anything for his children.”

“Other members of the family choose to leave home and look for help elsewhere.”(S2 Focus Group)

In the process of being dispersed among kin some children leave the communities where they were born or have been living and the community, in turn, loses sight of them.

2.3 Loss of property and security

Keeping together as a unit in one place is contingent on the rights the living have in the house where they reside. Rights to their home often are derived through the deceased person who either was the property owner or, more tenuously, was the person in a relationship with the property owner. Whether a family can continue to live in their home depends on the financial circumstances of the deceased or the precarious goodwill and circumstances of the person who owns the house or the land. The uncertainties around security of shelter increase where people leave no will, written testament or verbal instruction.

“My daughter did not own this house, because she was not married. The house belongs to the man who got her pregnant. They were living together. When the violence
broke out I came and stayed here with them. He is married, but he was staying in this house with J. The house is registered under his name. He has another house where he lives with his wife. He will have every right to chase us out, because it is his house.” (CS2-A)

“She used to work and she wanted to buy us a house. When she died the bank repossessed the house. We have gone back to where we used to live before she bought the house. There was absolutely nothing we could do, the bank told us.” (S2 Focus Group)

“I saw something terrible happen to my neighbour. The father died and when the family went to the office in town the wife was told to get all the documents for the house. They told her that her husband did not include her in the title deed and should the documents be processed, she will have to start afresh and apply for a new home. She was told that if her application did not succeed, then she would be kicked out of the house. She then went about it on the third day of her husband’s death.” (S1 Focus group)

“The children’s father sold their home, spent all the money and sent the children to live with their grandparents.” (X2 Focus Group)

“My husband’s home was taken by his younger brother and I was removed from the house.” (A2 Focus Group)

2.4 What about the children?
Invariably the study participants described their socio-economic status as having deteriorated with the illness and death of adult family members. Repeatedly caregivers said that their own circumstances were such that they did not have enough money to feed and clothe the children in their care. They found themselves feeling helpless and neglectful.

“It left me with deep sorrow. She left me with the children, knowing that I do not work. The children are at school and I have to see to their needs, like food. I have to go out and borrow money to buy them food. When I receive my pension I have to use this money to pay back my debts. It is very difficult for me ... I am very poor and the children come crying to me saying, ‘Granny we are hungry. Granny we need this. Granny we don’t have any shoes’... As I speak some of them don’t have their school fees paid. I feel that I have failed my grandchildren, because I am only receiving a pension. It was better when she was alive because she used to work and we used to help each other out.” (CS10-S)

“A lot has changed. We do not eat well anymore. The children are no longer well looked after although they do go to school. Things are tough.” (CS1-H)

“The children that I know have lost their mother and they are living in dire poverty. You can even recognise these children from far that they are in need.”
“The children are very unhappy, poor and unhealthy.”
“The child I was telling you about that does not live with me is very frail because she does not eat well.” (H1 Focus Group)

“It has a bad effect on the children because I now have to provide for them. Being so poor I can’t provide everything and they have now turned to crime, because they are not well looked after.” (CS5-H)

Several participants pointed to the dislocation, neglect or total loss of adult kin support of children.

“My (deceased) aunt’s children live with us at home. My aunt used to work and her husband was unemployed. When my aunt’s husband got money he spent it all and sold the home and the children were forced to go and live with their father. There were problems while they were living with their father and they had to be removed from him and brought to our home.”

“Where I live there are children whose father died. Their mother was still alive, but she couldn’t manage to take them to school. They were out of school for about three months. I have seen them attending school lately, but I don’t know what happened to change the situation.”

“There is a house near our home where the children were living with their granny. The granny died not so long ago. The children were left alone and the neighbours are taking turns in looking after the children.” (X2 Focus Group)

“There are children who lost their mother who was not married and (they) lived with her brother. These children were neglected and suffering because their uncle did not care for them. He only cared for his children. Their aunt did not look after these children. The children are just loose. They only come home to sleep.” (A1 Focus Group)

Overall there were only a handful of instances where, from a distance, families seemed to be coping “well” in the aftermath of adult death.

Family, and indeed individual survival, hangs on a fragile nexus. It centres on the pensions of the old and infirm and the income of those who are working or are able to generate a livelihood, on the existence and capacity of surviving family members to provide for their care needs, and on the certainties of shelter and place. When death breaks off any of these three streams the integrity of the family is undermined even if it manages to remain in tact, with particularly negative impacts on the survival, care and future of children. The impact of death does not begin with the death itself. Where death arises from terminal illness, social and economic burdens as well as emotional distress begin to be felt long before the person actually dies.

**Caring for the Ill and Dying**

Focus group and case study participants universally describe terminal illness as extremely taxing on caregivers and the family as a whole. It is emotionally demanding, physically
exhausting and costly, financially.

Where death has followed terminal illness, most respondents describe the period of terminal illness as long. In real time terms, in this study people more often than not are referring to a period of anything between two months to two years or even longer.

“My daughter was ill for six months.”

“In my case the illness was not prolonged, but because she was so ill it seemed that it was a long time, although it was only three months. She was in and out of hospitals and that was what made it seem so long.” (S1 Focus group)

“I am left with children whose parents both died. The father was knocked over by a car and their mother fell ill, while she was still working. She had chest complications. She was ill for a very long time, because she became ill just before the Easter holidays and she died by the end of that year.” (E2 Focus Group)

Family members have to manage pain and relieve suffering over a sustained period. They do this by comforting the person and trying home cures.

“It was difficult for me, because when my father was in pain he used to call me and ask me to put my hand on his chest, thinking that my hand would relieve the pain. When he was in a lot of pain he used to ask me to pray and this was difficult because I do not know how to pray. We were also worried about what we were going to eat when he dies, because he was the sole breadwinner.” (C2 Focus Group)

3.1 Seeking medical help

People also seek help from both traditional healers and biomedical doctors – a process which invariably involves many visits to doctors, healers and hospitals and the laying out of a lot of money.

“He said that he wanted to go to Dr M first. He treated him. Eventually, I did not have money to keep on taking him to this doctor for injections. I thought that it would be best if I took him to hospital because they could monitor his condition while he was there.” (CS5-H)

“When the situation got worse we used to pay people to take her to hospital. The hospital eventually sent her away home for good. She was very sick and we had the people from the church to come and pray for her at home. They prayed until they said they were tired and could not pray anymore. We went to izinyanga. Some said she had chest problems, others said other things. We will die having experienced so much pain.” (S1 Focus Group)

“I just went to the umthandazi and he went to the doctor and several other
izinyanga that used to treat him. They said that he was bewitched (umeqo). They did not explain what was really wrong with him. There were several izinyanga that he went to. I think that there were four. All our money was spent on them, including the goats we kept.” (CS1-H)

The costs of seeking treatment are high. The above respondent paid R1,000 to one inyanga and R800 plus an unspecified number of goats to another. She also had to pay for the private doctors she visited.

Some participants felt frustrated and exasperated by the costs and effort they put in to getting treatment without it yielding any benefit.

“The most difficult thing is to see the person in pain and knowing you cannot help. You go to medical and traditional doctors without any results and the money gets exhausted. I regret that I am not working because I would have taken her to a private specialist.” (C2 Focus Group)

“Long illness is bad because you end up leaving your parent with nothing. The parent just moves from here to there and in and out of the chemist to buy pills that have been recommended by other people, which are not effective. After all this, God takes the person away. I saw this with my son. He was huge and when he died he had become very thin. Oh! When my son was ill I hoped he would recover but this did not happen.” (CS5-H)

These costs are compounded by other financial strains that inevitably arise in terminal illness. The most evident of these arises from the person who is ill being forced to give up work or income generating activities because they are unable to continue. In addition, sometimes caregivers too are forced to give up income in order to attend to the ill person’s needs while they are alive.

“I used to sew, but I had to stop so that I could look after my granddaughter.” (CS8-S)

“I had to stop working. I was a domestic worker.” (CS1-H)

3.2 Care giving – a physical and emotions strain
Several participants commented about the routine care needs of chronically or terminally ill people as something that was difficult. They found it hard both physically and emotionally.

“It was difficult (caring for him) because he could no longer get up by himself. We had to help him get up. We had to make a supporting belt, which was tied above him to help him get up on his own. We used to bath him in the morning and in the afternoon when he wanted to. And I would have to massage him whenever he was in pain.” (CS1-H)

“When you are the only person looking after the person who is ill you end up
going mad, because you are alone and you don’t know what to do next, especially if you have to cook, feed, wash and clean up after that person. When people come to visit, they must find him and the house clean ... You have to nurse them and feed them. It becomes very difficult to see someone not being able to eat.” (A1 Focus Group)

“I was deeply hurt by the illness of my child, because I had to nurse and clean up after her, as she could no longer do anything for herself. That was very painful for me. I wish my daughter had died in hospital because of the situation I was in, having no rest.” (CS10- S)

“The doctor told me to take the child away from hospital and that if she lived for longer than a week it would be by God’s good grace. My child could not do anything for herself. I had to bathe her and clean after her and wash her clothes. Just before she died I asked my son to help me bathe her. I told him not to take any notice of the sex difference. He helped me out because it was starting to kill me. The pain I felt from not sleeping night and day, looking after my sick child. She eventually called me and said: ‘Ma, it hurts me to see you suffering, (you) being so old’. She said thank you.” (S1 Focus Group)

The dying themselves are anxious, even preoccupied, by the onerous physical burden that their illness imposes on those who care for them.

“It becomes a burden for the one responsible for your care. Your relative’s love and patience dwindles, especially when you have diarrhoea and when you have to be taken to the toilet often.” (M2 Focus Group)

For several caregivers, the problems of looking after dying family members were aggravated by their own poor state of health and/or age.

“The worst thing for me was when my daughter fell ill while I was also ill, suffering from high blood pressure and weak bones. I did not know what to do and it was difficult to get out of bed to nurse her. That was very painful to me. I prayed to God not to take her away because she had children who were still young.” (H1 Focus Group)

“She did not want to eat and she was vomiting a lot. I used to force her to eat, but she would vomit after eating. I used to nurse and bathe her. It was difficult because I am old and I do not have any strength any more.” (CS2-A)

Those who described themselves as being in a poor state of health, commented that the illness of the person they loved made their own condition worse, while others felt that they themselves became ill, confused and distracted.

“I suffer from high blood pressure and my whole body shivers. It is as if my head is not functioning properly. I feel much better when my sons are around, but once they leave I feel like my daughter, who is ill, is about to die and I hold her close to me ... My blood pressure used to go so high that I would think that I am going mad. I would become very forgetful and when I put something away I would look endlessly for it, only
to find that it had been in front of me the whole time.” (H1 Focus Group)

“Death is very painful because if your child becomes very ill and you, as a mother who is very old, you also become ill and can’t do much. She used to sleep with me in the same room because she could not do anything for herself. I would stay by her bedside day and night.” (S1 Focus Group)

Even though they were not primary care givers in this study, the anxiety and distress surrounding terminal illness is picked up by children in the home and follows them long after the person has died.

“It was also very painful for me because he had taken his father’s place (respondent is crying). I was depending on him as someone without a father and he was the oldest ... It was also very painful for his children because they could see that their father was very ill. They did not want to be separated from him. They wanted to sleep in the same room as him. I could see that it was really hurting the children and they could not eat anymore because their father was not eating. They did not want anything and even when he told them to drink juice they would refuse.” (CS5-H)

“I couldn’t even concentrate at school, worrying about my father’s condition back at home and wondering how he would be when I got back from school. It affected me so badly that I had to repeat Standard 9 that year.” (CS7-W)

The findings underscore that caring for the terminally ill is extremely exhausting physically, financially and socially. It is a burden that is unequivocally born mostly by poor women, many of whom are aged.

Some of these costs might be inescapable, but it would seem that they are unacceptably aggravated by the uncertainties surrounding the health status of the people in their care and the problem of facing death, as we shall discuss in the next section.
Facing Death

4.1 Recognising and acknowledging death

In order to face death people have to become or be made aware of the reality that the person who is ill, or they themselves, have a terminal condition. The realisation that the person they are caring for is suffering from a fatal illness needs time to be taken in. Many participants say they did not know or realise the real health status of the person they were caring for until he or she was close to death. Mrs G (aged 66), for example, describes her son as having died from “chest complications”. He was sick for three years and bedridden for one. She says she only realised her son would die in the year of his death, although nobody told her.

“I could just tell, because he was ill and staying with me and he was discharged from the hospital. I then took him back to hospital and that is where everything ended ... I was in denial, because I kept telling myself that he would recover, but I could see him getting weaker every day. When I tried to help him put his pants on they would just fall off. He used to be chubby ... I felt pain and I wanted to accept it, but I kept telling myself that he would recover. Every time I got my pension I would get someone to take him to the doctors thinking that he would recover … No, nobody explained the illness to me, because I just left him at the hospital and they would admit him.” (CS5-H)

Realising the illness is terminal is also influenced by the way it presents itself.

“My child was sick and eventually died. The only problem that we had is that it was not a serious illness that she was suffering from. It was just that this illness has its moments. We only realised that my child was going to die after we had been to numerous doctors and none could help.” (S1 Focus Group)

Several participants say that others, usually health care providers, made them conscious that the person they were caring for was terminally ill and faced certain death.

“Her doctor called her father and my sister-in-law and told them that she was HIV positive. ... We knew in January, when she was unable to talk ... My sister-in-law explained the whole situation to me, because she had spoken to the doctor and I was going to live with her and nurse her. I was satisfied with the explanation.” (CS9-E)

“My child was very ill and I did not know what was wrong. God helped me a lot because I finally discovered that my child had TB and was admitted at ‘kwaJohn’.” (H1 Focus Group)

“I was satisfied because we could see that she had idliso (poisoning) and the (medical) doctors can’t cure idliso. The traditional healers told us. We could also see that it was idliso and it was there for some time and we could not heal it. She was too weak to use the Zulu emetics.” (C2 Focus Group)
“She had been ill for a year and her health was on and off ... Just before she died we asked the doctors what was really the matter with her. At first they said we should ask her, but she was afraid to say. Eventually, the doctor called me and said because you are older you won’t behave like the young one. And then he told me what disease my granddaughter was suffering from (AIDS) ... I was satisfied because I had seen it happening to other youths before.” (CS8-S)

Some say they would not have wanted to know, because by knowing they would have felt they were giving up or because they could not face the implications of the loss. Talking of experiencing the death of her daughter, Mrs M (age unspecified) says that although nobody explained anything to her, she did not feel that such an explanation would have made her daughter’s death better. She said that she would rather not know.

“It would have been painful for me to know that J was dying. I kept on hoping that she would get better ... I thought she was going to recover. There was no way that I could accept her condition. I never did. I couldn’t let God take her. I thought the doctors would make her feel better and help her recover ... On the day she died she asked me to buy her amahewu and we thought she was recovering.” (CS2-A)

Others feel that they would have been happier to know. It would have made the illness and death easier to bear.

Mrs N (Aged 60), who has recently buried four of her family members, says she was never given an explanation about the real situation regarding their health and what she could expect to happen to them.

“No, nobody explained anything to me. I would have been happy if they told me what was wrong with my children so that we know why they died in the end. It would have been better, because at least we would know what was wrong with them as there are many diseases such as AIDS. If we had known that it was AIDS we would have known what to expect and that there was no chance of them surviving. We did not know whether it was TB or any other illness.” (CS10-S)

Ms M (aged 23) talks with bitterness of her father’s experience.

“Just before he died it was suspected that he might have TB or something else and he was admitted at SANTA, near Edendale. He was ill for two years. He used to be treated by private doctors and we also took him to Grey’s Hospital, where he was admitted for a week. Thereafter he was told to go to SANTA because he was getting worse. We had to hire a car to take him to Grey’s Hospital. If the private doctors I had been taking him to could have detected the illness earlier, he wouldn’t have died. All the time I had been taking him to these private doctors. None of them could tell what was wrong with him, but I could see he was dying .... The doctors did not explain anything to us.” (CS5-W)
Explanations from traditional healers are also far from satisfactory, with people’s dissatisfaction being compounded by insufficient, inadequate, untimely or absent explanation from bio-medical professionals, as the experience of Mrs N (aged 59) underscores. She took her husband to someone who heals through prayer (umthandazi) after he complained of severe pain. The faith healer said he had been kicked by a hairy demon.

“He was complaining about his rib pain all the time. He was getting weak and complained of cramps in his legs. He could not get up because of this cramp and we took him to Grey’s Hospital. It was not clear what was wrong with him. He wanted to go home, but the hospital refused because they wanted to run more tests to establish what was wrong with him. We ended up not knowing what killed him, besides the explanation of the hairy demon that kicked him. We were prepared to find out what was wrong with him, but we could not find out the results.” (CS1-H)

4.2 Talking about death

Where explanations about the illness are unclear or inconclusive, people often concentrate their efforts on finding a cause. And with the pursuit of causation comes the hope of a cure or at least a way of waylaying death. This has several consequences. Aside from the heavy financial toll that has already been suggested, another consequence of not knowing that death will come is that people are able to avoid talking about and preparing for death until close to or at the time of the event.

“Not talking” about death is a fairly common social response in various societies and is not unique to South Africa or this particular group of poor people. What “not talking” means, however, is something that needs to be explored more deeply. Participants in this study did not often talk with the dying person about their death. It has been argued elsewhere that talking to the dying about death goes against Zulu culture. But this is only partially true, given that such discussions did occur where they were initiated by the dying themselves. It would seem that the dying told or made those caring for them aware that they knew that their death was impending.

“She once told us she was dying when she was in hospital, but because she used to joke a lot about it we did not take her seriously. She said she did not want to be buried in a cheap coffin and that if her husband could not afford an expensive one, we should help him out and a whole lot of stuff that people usually say that is not taken to heart. ... She gave away her wedding ring. She gave it to our mother. Because she could feel that she was dying she also requested that her mother-in-law not sit on the mattress as is traditional when somebody has been married. She requested that our mother be the one to sit on the mattress on the day of the funeral.” (CS3-W)

“I remember my daughter asked her older sister to look after her children. She said, ‘I can see that I am dying. Please look after them. Even if they bother you, be patient with
them.”
“My granddaughter also asked me to look after her children. I then realised that she was
dying and I asked her why she was saying this. She told me that ‘my time is up’.”(S1
Focus Group)

“One day my son said to me ‘Ma, don’t interfere with this car ...’ and he asked me if I
understood and I said yes. He asked me not to use his car to transport alcohol because
some of his brothers drink. He said I must keep it until it is so old that the children can
play in it. He told me not to even think about selling it. He just spoke about the car and
the children. He said when he dies, then I should take care of the children ... He did not
say ‘mother I am dying now’, but I could pick it up from what he was saying.”(CS5-H)

The dying who feel themselves very close to death also “tell”. It is said that a sign of
impending death is when the dying person avoids eye contact. They also “tell” by asking
to follow a ritualised ceremony which allows them to bid farewell to the living and to
prepare their ancestors for their impending arrival. Most people associate this ritual with
the aged.

“What I know is that when my mother was seriously ill, the men went to hunt for a wild
pig and gave her the pig’s liver to eat. After eating the liver she died.”
   “My grandmother ate the liver in the evening and died that night.”(C1 Focus
Group)

“When my father was dying, he called all his children – my brother and myself – and
then asked us to cook liver for him. My brother slaughtered a goat and I cooked the liver
for him and after eating it, he died.”
   “In most cases, the liver is given to the old people and not the younger ones.” (C2 Focus
Group)

In the focus groups, most participants said that if they were dying they would tell their
families, or particular family members or neighbours. In telling of their intentions, some
people also spoke of the experiences they had had with a dying person and how difficult
it was.

“Sometimes the person will tell the person who is helping them, like their eldest
daughter. My mother called me and told me, as the eldest daughter, that she was dying
and that my sisters and I should take care of the children.” (A1 Focus Group)

“It was difficult when my mother told me she was dying. She called me and said, ‘N, I
am now dying’. Thereafter she called my youngest child and asked her if she had been
fed. When the child came they looked at one another and my mother started crying and
she asked me to call the neighbour.” (C2 Focus Group)

Although people rarely seem to talk about death to the person who is dying, many talk or
say they will talk to other kin, friends or neighbours. More often than not, these are
adults.

“I don’t know if it has anything to do with the deaths of my husband, daughter and granddaughter, because we always comment on their deaths, especially my daughter’s death because she used to help around the house. Soon after, her daughter followed. We don’t discuss death with children. It is only us elderly who talk about it.” (CS8-S)

“Some tell the person who was taking care of them and was closest to them all the time, because sometimes non-family members take responsibility of taking care of the dying. There is no one in my family that I would tell. We are a small family and it’s clear to me that my family has no future.” (A1 Focus Group)

“I would talk to the neighbour closest to my heart. There are many neighbours to choose from but there is always that special neighbour that is dearest to your heart. If there are no children you can say which of your belongings you want them to keep.” (H1 Focus Group)

**Should the children be told?**
Views on whether it was appropriate or even possible to talk to children about death were mixed. Several participants in the study felt that it was only appropriate to tell children who were in their late teens and young adulthood.

“I would talk to a child who is 18 years and above.”
“I would only talk to the older children.”
“I would talk to the child I am living with (who is) 19.” (H1 Focus Group)

“I would talk to a child who is 21 or over. I wouldn’t talk to a younger child. They will just have to figure it out on their own when I don’t wake up next morning.”
“No, they shouldn’t know because they wouldn’t know how to handle it.”
“I think the older ones should be told, but not the younger ones.” (E1 Focus Group)

Mr S, talking of the death of his wife who died of “chest complications” in 1998, says that he never spoke to his children about their mother’s death.

“No, they could tell that their mother was ill ... Both of us told them that she was not well. When she died did you tell them that their mother was dead? No, they saw for themselves and they heard about it as well. From their mother’s family. So you did not say anything? No. I was brought up that way. Children were never told anything about death.” (CS4-M)

The reasons given for not wanting to tell younger children were that they would not be able to understand, that they would be hurt and upset, and that they could not benefit from knowing.
“A five year old child would not understand. She would cry and hold on to you and want to know where you are going.” (H1 Focus Group)

“The child might forget and be afraid and upset that I am dying.”
“The child may forget and I don’t think she would understand what I am talking about.” (W1 Focus Group)

Some felt that they would prefer their children to learn about their death from others, partly because they themselves would not have the courage to tell them.

“I will not talk to my children about death ... one is nine, the other is six and the youngest is three. I think that I might have the courage to tell the nine year old because he is older.” (X2 Focus Group)

“It is difficult to tell a child because the child will be hurt. The children do need to know, but they will be upset and I will be dead. The child would be disturbed at school thinking that I would die at any time. It is better the child finds out when I am dead. Although I know that the child will be told eventually, at least I will not be there to see the hurt in his face.” (X1 Focus Group)

Not telling young(er) children did not mean that people assumed they did not or should not know or would not find out. On the contrary, they assumed that children could see for themselves or would come to know about the death when they were older and more ready.

“Sometimes it is better for a child to see for itself when the coffin arrives what is going on, rather than to tell her that her mother is dying.”
“My grandchild could tell that her mother was about to die, even though she was not absolutely sure, but she could tell because everybody was in and out of her mother’s room. She would often go in to peep at what is going on and run out. After my daughter’s death she would often go and stare at the bed that her mother used to sleep in and cry. At other times she would just forget the whole thing. It also happens to us adults. We also feel that we are being mistreated because our parents are dead.” (S1 Focus Group)

Asked who told her daughter’s three pre-teen children about her death, Ma M responded:

“They could see for themselves, but they also heard about it, even though we had not told them. They heard it from us adults, when we were talking about it.” (CS2-A)

Ma N describes how her oldest granddaughter learnt of her sister’s and mother’s death. She says that they did not talk to the children about what was going on because they would have been very upset by the information. Her eldest granddaughter was away at the time of the illnesses and deaths.

“She came back after her mother’s death. She had come to inform her mother that she was being mistreated where she was staying. She asked her younger sister where her
mother was. I was in the bedroom at the time and told them to let her in. She asked, ‘Granny, where is Ntombkhona?’ (her youngest sister) and I told her that she was dead. This shocked her. She asked, ‘Where is my mother because I have come to tell her that I am not happy where I am staying?’ I said to her that these candles that you see signifies your mother’s death and she cried.” (CS10-S)

Some do tell the children

A sizeable number of study participants, by contrast, felt it appropriate and necessary to talk to younger children.

“I have a son who is six years old. I would tell him if I was dying because he understands what death means. We have taught him that the day will come for everyone to face our Creator and how you live your life on earth is what will determine that.”

“I have two children. One is ten and the other is two years old. I will tell them both. The two year old can’t speak yet but I think that it would be good for him to be there when I tell the older child.”

“I would talk to a five year old child because I think he will be able to understand. When I was five I could understand these things and I still remember what I was told about my history at that age.”

“My child is five years old and I would tell him if I was dying because they see this happening every day. One day my son came home to me and said, ‘Ma, Mrs M … has died, she is going to heaven.’ He told me this without me even asking him.” (X2 Focus Group)

“Take for instance, our orphaned grandchildren. They must grow up knowing that they do not have parents. They are usually able to understand what is going on by the time they are five or six years old. My granddaughter is three years old and she knows that her parents are dead and she is left with me.” (S1 Focus Group)

“My child is eight years old and I will talk to him when I am in pain. I will tell him. I would say now that I am dying, I will leave you with your granny, my mother.”

“I would tell the child so that he would know and stop asking about me. Although he might not understand now, but when he is grown he will know what I meant.” (C2 Focus Group)

Not only do some people feel children understand or will come to understand, but they also believe that talking to young children about dying and death will help them manage their lives better when they don’t have their parent to help them.

“As we are speaking about these orphaned children, it is wise for them to know who their mothers are because somebody out there is going to tell them that so and so is not your mother. So the child must be able to say, ‘I know that this is my granny or aunt and that my mother has passed away.’

“Nothing is more painful than hearing someone say to your child ‘you were brought from the orphanage’.” (S1 Focus Group)
“You need to tell the children.”
“I think that it helps when a child knows, because when she needs something and can’t get it, then she knows she can’t get it because her father is dead.”
“It will help the child because she will realise that the one who used to help her is no longer there.” (A2 Focus Group)

“It is important for the child to know because should he encounter problems, he must be aware it is because he is an orphan and he can’t compare himself with children who have parents. He must (not) expect anything because he has no parents to defend him.”
“It is important for the child to know so that he can respect the people that he lives with. That will prevent him from doing things that are wrong and expect to be rescued by me. He must know that he must respect his granny because she is looking after him. And he must complete his studies because his granny will die some day and he would not have anything to fall back on.” (X2 Focus Group)

Children and their circumstances differ, and telling them is not always easy. For some caregivers the process is painful but fairly smooth. For others it is traumatic and far from straightforward as the following two responses reflect.

“I whispered in my grandchild’s ear at the graveyard and told her that her mother was dead and that she would be with me, because she would not be seeing her mother again. My grandchild has not forgotten her mother’s name and she would say to me that Ma is coming.”
“I did not tell the child outright. I took the Bible and opened it where it speaks about death. I called the child and said, ‘listen, seeing that your mother is very ill, what am I going to do’ and she said, ‘I want to go with her’. After that I never spoke to her about death. One day when she came back from school and she asked me where her mother was, we said she had gone to hospital. She cried for a very long time and I told my oldest daughter that she needed to sit with my grandchild and talk to her about this. I told my daughter to go and buy some sweets and chips for my grandchild and tell her that her mother had died. That is how it was done. I do not remember where my daughter’s grave is at Mountain rise, but when I go there I go with my grandchild who always manages to find it for me.” (S1 Focus Group)

Talking about death is seen as creating an opportunity for children to come to terms with their experiences.

“Even if you tell them there are many questions. Like my child, his father died and he asks a lot of questions, like when will his father come back, who will go to him – is it me or him? He also goes to A ... to look at his father’s grave. He knows that he is buried.” (A2 Focus Group)

“I talk to them and tell them that death is something very sudden. I have two children now, and two grandchildren. One is three and the other six. I talk to them and they ask me lots of questions. They ask me, when a person dies, where do they go. Everybody that has been close to them has died and the granddaughter is always asking about them. She
asked me ‘when is God going to return them’ and I say they will come back and we will be able to go to them. She even asks her friend and another boy from the neighbourhood where they think that her uncle went to.” (CS1-H)

Generally speaking it would seem that death is recognised or acknowledged very late in the process of dying or only with the fact of death itself. In this context, facing death as a practical set of activities seems more often than not to be concentrated in time and scope. Preparation for death is predictably something that is very limited and specific.

4.2 Preparing for death
Most respondents talk about preparing for death in an abstract way. When they say they will tell others about their own impending death, they mean that they will leave their last wishes and requests. These wishes invariably relate to their worries, their possessions and especially the future care and well being of their children.

“I would tell my children to behave well when I am dead, so that people will also be sympathetic to them.”
“I would talk to my mother. I would tell her that I am now dying and request her to look after my children.” (M2 Focus Group)

“I would tell them about the disease and ask them to look after my child.”
“I would talk to my mother and tell her not to have a big funeral for me.”
“I would talk to my younger brother and tell him to behave and respect other people.”
“I would say goodbye and then ask her (mother) not to worry about a lot of things as long as I am buried.” (C2 Focus Group)

“If you are about to die and if you have quarrelled with people, then you should make your peace with them, when you are still able to talk. And if you can no longer talk then you should ask for God’s forgiveness.” (A2 Focus Group)

“I would talk to the father of my children and if he won’t be around during that time, I would talk to my child and tell her where to find my things. If I am fortunate enough I would write a letter just before I die, which I would place where the child would be able to find it. She would read to the others and tell them what is written.” (H1 Focus Group)

“I would talk to my granny. I would say, ‘Granny you know all my secrets, because I confide in you.’ I would ask her to look after my children if she is still alive. They should go to school and be what I would have loved them to be. I have two children.” (X1 Focus Group)

Their vision of what they will do is informed by their own experiences of death or by common practices around them.

“My father did not like us, but when he was about to die he called all of us and asked us for forgiveness and told us that he was dying.”(A2 Focus Group)
“Some people share out their belongings among their children.”
“Sometimes a person doesn’t have any belongings to distribute so they don’t write up a will.”
“Some people make arrangements for their children, like who they will live with when they die.”
“Some tell you to come and collect their belongings when they are dying.”
“Others tell their children where they have been keeping their money and they share it among the children.” (E1 Focus Group)

“In our case she called everybody in the family and told us who had poisoned her, but it is something that you cannot talk about because there are people who do not believe in bewitchment. She told us not to do anything about it.” (C2 Focus Group)

“She spoke with her family and she asked them not to send her children away, but to look after them because they had nowhere else to go. She said she wanted them to stay in their home.”
“She spoke to my mother. She said that if her children were ill-treated by her in-laws, she should take them away and look after them herself.”
“She spoke with me and asked me to look after her child.” (S2 Focus Group)

**Disempowered even in death**

Study participants generally hope to be able to express their last wishes. Although several among them had experience of a dying person being unable to say anything on their death bed, most foresee or hope that they will express these verbally and when they are close to death. In other words, by the manner and timing of delivering their last wishes they are left or leave no opportunity to see people’s disappointment or to be contested and drawn into controversy.

While some people feel there is no need for them to make preparations as they have nothing, part of their unwillingness to be prepared derives from a fear that talking and thinking about death somehow precipitates the event. Talking of her own death, Ma M whose daughter died of AIDS, says:

“I have not made any arrangements. It’s because of this fear I have of death. If I draw up a will it might scare my grandchildren and children. Do you think it’s important to draw up a will? Yes, especially concerning the house. I do not have any money or decent furniture. Who would look after the children when you die? Only God knows because even my youngest daughter that I was relying on to take care of the children does not work. I always pray that by the time I die, she will be employed.” (CS8-S)

Partly, their inaction is driven by fear of controversy and a sense of powerless to act to help those who will need them when they are not around. Partly, they are made inert by a sense of fatalism about death as something that is out of their control.
There are two other important factors that contribute to people’s general lack or low level of preparedness for death. One is economic. Even if people feel they would like to do something, like stipulate the kind of funeral they would like, their own lack of money and their awareness of their family’s limited resources prohibits them from acting on their wishes.

“You might have AIDS and hope for certain things, but because of unemployment you may not be able to carry out these wishes. You can’t write up a will when you have nothing.” (S2 Focus Group)

The other factor is the general absence of systematic advice and support on these kinds of issues in the communities of the poor.

“As people who know we are dying, I wish something could be organised … I have children and when I die I don’t know who is going to take care of them. Most of us do not work and I would like the government to do something to assist us to prepare for our death and the welfare of the children we leave behind with no one to look after them. We don’t know who to talk to about these problems that we are facing … Lifeline is mainly concerned with solving psychological problems. We need somebody to help us handle urgent matters.” (X2 focus Group)

Generally, only a few study participants indicated that there was a need to be more proactive in their preparations for death. This usually was expressed as an intention to make a will, join a burial society, find somebody to take care of children, pay off debts or make peace with those with whom you have quarreled.

“I would write a will.”
“I would join a burial society.”
“I would look for somebody to look after my children.”
“I would talk to relatives who would stay with my children.” (C1 Focus Group)

“People must join burial societies within the community and their payments must be up to date.”
People must pay all their debts so that their children are not left with these.”
“A person should sort out their life and resolve any problems they have.” (H2 Focus Group)

“In my opinion all that has been said should be done long before the person falls ill because we all know we are going to die some day. But when you are dying it is important to attend to these things immediately, like telling your children where they will stay once you are dead. You must at least settle this before you die.” (X2 Focus Group)

While several people realise the importance of making advance preparations for death, they do not necessarily act on their intentions.
“I often tell myself that before I become ill, I should tell my children where my things are kept. To say this as a joke, so that I do not upset them. I would like to tell them about this now, instead of when I am dying, because it would disturb them (then). It would also be disturbing for me to have to worry about all this when I am about to die. I really think it is something that I need to take care of soon.” (H1 Focus Group)

Some people do prepare
On its own, exposure to death seems to be insufficient motivation to get people to be better prepared for the event and its outcome. Rather, a range of circumstances seem to have to converge before they become proactive. Sometimes it is their own illness in the context of the death of another adult that pushes people into action. Thus, for example, since his wife’s death Mr. M has decided that he would prefer to die at home so that he does not leave any hospital debts or expenses. However, he feels that he is unable to make plans for his funeral because he can’t afford the event he would like to have. In fact, he regards himself as being unprepared for death, not in the psychological sense, and he would like advice. He nevertheless has taken several practical steps to secure his children in the event of his death.

“I have signed forms for a title dead for this property. My sister will look after them (the children). She agreed to take care of everything. Will they stay in this house? There is nowhere else for them to stay. What guarantee is there that this house belongs to them? I have signed this in the deed.” (CS4-M)

Similarly, the death of his partner and child, combined with his own illness, prompted Mr. Z to make preparations for his own funeral.

“I do not want people to worry about how they are going to prepare for my funeral. I have some money saved and I am also a member of a burial society. I know for sure that they will bury me. I only became aware of the burial society when I lost my child, as I was not prepared for this death.” (CS6-M)

At times, people are driven to prepare by the fact that they are responsible for everybody and everything around them, as the above and following examples underscore.

“My sister’s death did not affect me that much, but my mother’s death affected me greatly. … because it is I who is now mother and grandmother of this household. When my mother died I started talking to my children about AIDS. I tell them that nobody is here forever. All those who are at school must study hard. I warn my sister’s twelve-year-old daughter against good-for-nothings like taxi drivers’ assistants.” (CS3-W)

Also, when death moves from an abstract and unspecific event to a known, impending reality, then people feel more inclined to prepare for it. Some of the study participants who know and acknowledge their HIV status describe the ways that they are preparing for their death.

“Let me make an example about myself. I have my will and the program of my funeral so
Aside from preparing for the event and issues of inheritance and care giving, people generally regard preparing as important. Some are practically trying to leave their children with skills to survive “on their own”, when they are not around to care for them. These largely relate to domestic and social skills, although some people also try to transfer skills that might generate income. There is a fairly strong sense of needing to impart both family history and culture to children as well.

“My child is 14 years old and I think that it is the right age to explain what to expect in life. I don’t have to wait until I am dying to do so. I think that it now is the opportunity to do so … (even) that it is a bit late. I’d tell them about their family history. I am teaching my son how to cook at the moment. I will also tell him that I don’t know where he would end up in the future so he should be able to do things for himself.”

“I’d teach my children the skills of informal trading so that they can survive when I am dead. At the moment I am teaching my children to knit jerseys. What about their family history? They know all about it, because I talk to them about it a lot.”

“I have taught my child to put her dirty clothes together with the other laundry when she comes back from school. I have also taught her to wash her dishes after she has finished eating … to polish her shoes and to go to her granny, greet her and ask if there is anything she wants. I also tell her I never had the opportunity to learn these things when I was her age. I had to learn myself when my father was ill. I want my children to know this as part of my family’s history and I also tell them about their father’s family history.”

“I teach my daughter manners and respect. She also knows how to prepare herself for going to school, because there will come a time when she would have to do it without help.” (X2 Focus Group)

“I have taught them what is expected of them traditionally, as boys and girls and how they should behave.”

“Yes my children know what traditions and rituals are followed in this house.”

“We talk a lot about family rituals and about their family history.”

“I talk to them about our culture and how they should go about thanking God, because I am someone who worships God.” (A1 Focus Group)

Generally, however, the absence of systematic support and advice on the practical actions that can be undertaken by people who are terminally ill or are caring for the terminally ill also affects those few who initiate preparations for their own death.

“I know of somebody who has just experienced a death in the family. The deceased was the only breadwinner and had children. This person is having problems of getting food for the children. The situation is tough because we do not know what to do. When (the deceased) started getting critically sick I asked her who her beneficiary would be. She told me that her mother’s brother’s wife was the beneficiary. This person did not even care or look after her when she was sick. I asked her how she could put down this person as a beneficiary when she did not care about her and whether she thought she was capable
of looking after her children when she was dead. I told the deceased to think about it very carefully and at least write down one of her children as a beneficiary. She told me that the children were still very young and they would not be able to get the money, that they would need somebody older to get the money for them and to raise them with it. The problem still exists, because she did not sort it out before she died.” (X2 Focus Group)

4.3 The event of death

The event of death itself sets in motion a flurry of activities that are circumscribed by economic circumstances and social practices.

With death, kin are informed and arrangements are made for the funeral. This is an activity that involves adult family members, first and foremost.

“We sat down as a family and made arrangements about her funeral.” (CS2-A)

“When we came back from the hospital after he died, we informed his brother and relatives. We also called other relatives in Durban at his brother’s place and they all came to prepare for the funeral. I sat on the mattress and I sent the children to the hospital to take their father to the mortuary. We waited a few days and then we had the funeral.” (CS1-H)

Burial societies

Making funeral arrangements is something that is done by burial societies as well.

“In our community, it is burial societies that do most of the work for the funeral and only if you are a member. They take responsibility for the whole funeral ceremony. This community is not as well established as the one I come from, and maybe it too has changed.” (CS3-W)

Not all communities have burial societies and even where they exist, many people aren’t members for a range of reasons, key among which are the cost and the general lack of practical preparation that is made for death.

“The community where I come from are ignorant, because we don’t have things like burial societies. But these women that help out in the community share responsibility of buying food for the funeral.”
“I have seen women taking potatoes and other small things to the bereaved family.” (X2 Focus Group)

“To be quite honest with you, we have never prepared for death in the family. Most of my family members do not have money and none of them have joined a burial society. If somebody were to die now we wouldn’t know where to go or what to do. It is only recently that we have discussed becoming members of burial societies. If I were to die now I don’t know where I would be buried. The money that we get we spend on food.” (CS3-W)
“What we do in our street is that if somebody dies, each household contributes R5.00 and that money is taken to the family that has had a death. Well, in my case, where I experienced a death one month after another, Mrs. S and some other women had to come to my assistance and they bought the food and hired the cars for the funeral.” (CS10-S)

But even where there are burial societies, they are having problems coping both because of the number of deaths they have to support and because people are having difficulty keeping up with payments.

“My community is willing to share and help, like the burial society. The community had a discussion about helping the burial society by making contributions when there is a death. There has been an increase in deaths and the burial society is feeling the pinch.” (X1 Focus Group)

“We used to belong to a burial society, but because we no longer have money to pay for it each month, we no longer belong to one.” (S2 Focus Group)

**Limited community and church support**

Some neighbours, as individuals, play an active role in supporting the family of a dying or deceased person. However, the community response to death largely seems to be confined to one of offering moral and spiritual comfort as well as some financial relief during the initial period of mourning and until after the person is buried.

“At Sweetwaters, where I was born it is very different from here. Elderly women would come to your home and bring you some food. Nobody came empty handed. Ever since I have lived in this community I have never seen something like that being done. Instead you have to provide the community with food, because you know death is something that is always there, so you should be prepared. Nobody helps you out, that is how it is different.” (CS3-W)

“There is not much that I can say about the community. If you have somebody ill in your house then it is your sole burden. They only help you out when they hear that the person has died and they leave once the funeral is over. They comfort you while the body is still in the mortuary and they give you some donations. But after that there is nothing they can do for you. That is how things are done in this area.” (CS5-H)

“The community made a donation.”
“The community gave some money.”
“The community brought some groceries.”
“The schools offer us benches when there is a funeral.” (C1 Focus Group)

Divisions within communities, the general high rate of unemployment and lack of resources as well as established social parameters make people doubtful about the scope of community involvement in the process of dying and death.
Like the community, the church as an institution occupies a specific place in these processes and events that is demarcated in time and function. For the most part, the church prays and helps bury the deceased.

“The congregation members come and pray with you and do not give any help after the funeral.” (CS1-W)

“The church buries our relatives.”
“The minister conducts the funeral service.”
“The church conducts prayers for us.”
“The church encourages us to support each other by paying R10.” (C1 Focus Group)

There are exceptions. In one area in this study, the combined efforts of the church and hospice have generated an initiative of solidarity and material support across communities.

“Our minister said that he was going to ask a white family to look after me because I was the only breadwinner – my mother is a pensioner. This lady came to see us and she brings us basic groceries at the end of the month. She also brings us clothes. She started two months ago.”

“There is the social worker from Hospice. They come and check up on us on Mondays and ask us our needs. Like if we are in pain they give us pills with the groceries that they bring on Wednesday. The minister asked a white lady to look after my family and she brought us food for one month and then never came back. The minister then asked another lady to look after us. She came with some groceries and then gave my mother material to make cushions.” (M2 Focus Group)

**Burial rituals**

The rituals around burial and mourning are general to all the communities and seem to be widely known, albeit with variance in detail.

“Before the deceased’s funeral there is a waiting period and candles have to be lit. Then there is the period of ukuhlambuluka, the washing of the hands … (when) the deceased is said to be freed to join his ancestors.” (H2 Focus Group)

“A cow and a goat have to be slaughtered. The dung has to be taken to the graveyard and placed on top of the grave. Then you must speak to the deceased and tell him that you are now taking him home, where he has to keep watch. When you come back, the goat has to be slaughtered and mpepho (incense) has to be burnt in the house where the traditional beer has been placed and all the … ancestors are called upon.” (CS7-W)

“If the head of the home dies, an ox is slaughtered. If it is an old woman that dies, then a cow is slaughtered.”
“If it is an old person, then a cow or a goat is slaughtered.” (W1 Focus Group)
“If the deceased is a child, a goat is slaughtered and if the deceased is an older person then a cow is slaughtered.” (A1 Focus Group)

“If you don’t slaughter anything for the deceased she will come back and demand that you bid her farewell in the proper way.” (E1 Focus Group)

“The skin of the animal is folded and placed near your feet in the coffin.”
“The family throws some sand into the grave.”
“Water is mixed with umswani (grass from the cow’s stomach) and intelezi (traditional medicine to chase away evil spirits) is placed by the gate for mourners to wash their hands in.” (H1 Focus Group)

“After the cleansing ritual, there is a bath ritual … A goat has to be slaughtered and the goat’s dung and bile is poured into the water. Then you have to go by the river to wash yourself in that water. There is no time frame set aside for the bath ritual … However, you cannot go to the next ritual known as ‘the big ceremony’ (idilelikhulu) if you have not completed the bath ritual.” (CS3-W)

“A year later a cow has to be slaughtered for idilelikhulu.”
“Usually when this is done the family would’ve gone beyond the mourning period and it is meant to bring joy to the family of the deceased.” (E1 Focus Group)

4.34 Mourning periods and etiquette
There are also expectations about etiquette and the behavior of surviving kin that are common across the communities.

“If the person died from a long illness, the mourning period is usually a year. But, if the cause of death was not related to an illness, then the mourning period is a month.” (H1 Focus Group)

“If a man has a natural death, then his wife mourns for one year. If he died an unnatural death she mourns for six months.” (W1 Focus Group)

“For a young person you mourn for one month and for the older person you mourn for one year.” (A1 Focus Group)

“The bereaved family may not have the radio or television on. The children are told not to make any noise and that they should not go out with their friends. The girls are told not to be intimate with their boyfriends.”
“We men are also told not to be intimate with our girlfriends until after the mourning period.”
“One is not allowed to eat while standing up or talking.”
“The hair of the head has to be shaved off.”
“The family is told to behave accordingly and to be humble.”
“In the past when someone has died in the rural areas, I have observed the huts being

“Water is mixed with umswani (grass from the cow’s stomach) and intelezi (traditional medicine to chase away evil spirits) is placed by the gate for mourners to wash their hands in.” (H1 Focus Group)
smeared with a black substance as a sign to others that the family is in darkness.”
“The family has to wear a piece of rag on the shoulder of their clothing as a sign of mourning.”
“After the mourning period, the family removes these rags of mourning.” (X2 Focus group)

**Changing norms and values**
While norms may persist, the values attributed to them as well as the actual practices are continuously interpreted and often modified in response to changing social and economic circumstances as well as belief systems. Thus, although many participants in the study follow customary slaughtering practices, there seems to be a reduction in the number of animals used as well as a tendency to use those that are less costly. Some families no longer slaughter, preferring to buy the required organ (liver) or meat from the butchery. Some don’t follow any of the customary rituals.

“Sometimes it is because people have become Christians and other times, it is because you don’t have the means. Things are not as they used to be in our days. Before people used to have cattle, which is expensive to buy now. I have seen people bid farewell to the dead by slaughtering a cow and those that cannot afford a cow, slaughter a goat.” (CS5-H)

“We just got together as family and relatives and we all contributed towards buying beef.”
“No we don’t slaughter animals in our family. We buy the meat from the butchery.”
“We made preparations for the funeral by buying food, a blanket to put on top of the coffin and some candles. After the funeral the mourners had something to eat.” (S2 Focus Group)

“The ritual is slowly fading because cows are scarce and they are expensive to buy.”
“We ... sing hymns.”
“Candles are lit and chickens are sacrificed and you speak to the deceased through the chickens.” (E1 Focus Group)

“When my husband died I slaughtered a cow for him, but when my children died I did not slaughter any beast.” (A1 Focus Group)
“We wore mourning clothes, but we did not slaughter a cow. We only slaughtered two goats when we took off the mourning clothes.” (CS2-A)

An insightful discussion around values reflecting changed perceptions developed in one focus group.

“I don’t see how slaughtering helps the deceased, but it helps the family have enough meat to feed the people that come to the funeral.”
“I think that slaughtering is a waste. A beast is slaughtered for the funeral and after three
weeks another beast is slaughtered to celebrate the finishing of the first period of mourning. After one year you slaughter another beast to end the mourning period.”

“You say that you slaughter for the dead, who does not eat the meat.”
“I think that it is good because it is a way of feeding the people who were helping you, keeping you company, assisting and helping with the funeral. The deceased does benefit from the beast.” (X1 Focus group)

Lack of resources to live and to die in a proper way, adds to the burden of death for those that survive. They have no means of responding and can envisage no way out of their circumstances.

“B’s (my son’s) death has left me with shattered dreams because even the house he was trying to build for me is not complete. I do not have enough money to complete (it), it is just enough for food. I have left the house as it is ... A year has passed by and we have not been able to have a memorial for him. Even if you don’t have a tombstone to unveil, there must be something that is done in memory of him. That is very painful for me because the time for his memorial has passed and I have not been able to do anything for him. This is the second year and I am still unable to do it and I don’t know how to do it in future. I no longer have the strength to go and work. I have osteoporosis.” (CS5-H)

After I die...
The experience of death of others also makes people very aware of the transience of their own lives and the extent of both individual isolation and interdependence. In anticipating their own deaths, study respondents express a mixture of feelings. Many are anxious as they already bear all responsibility for caring and keeping their families together. They fear their deaths will lead to destitution and family dissolution.

“I know that I am alone and no one can take over this burden that I find myself carrying.” (CS2-A)

“It would mean the end of everything, because I am responsible for everything at home.”
“The children would become very poor because I am the one who sees to their needs for school, clothing and food.”
“They would all probably follow me to my grave, because none of them work and they are all living off my pensions.” (E1 Focus Group)

“There is nobody who would do my work and I am the only breadwinner.”
“There would be nobody to look after my children and they would suffer.”
“My children would suffer. There would be suffering.” (C1 Focus Group)

“My sisters live far away from here and they would have to come and help my children. My eldest daughter always tells me that when I die she will leave home, because her brother is not someone she can live with. He is very rude and hard-headed. So I don’t think that there is anything that will continue when I die if the situation is like this even before I die.” (H1 Focus Group)
Others have a sense that although some everyday things would continue, life would be disrupted and some things they do would stop.

“I live with my child and my child’s education would not continue because we are the only two members of my family that live here. My mother lives in the rural areas and the reason that my child is at school is because she is living with me, although I do not work.”
“I make a living by sewing clothes and that wouldn’t continue because my children are boys. But they know how to cook and do household chores.” (A2 Focus Group)

“What would stop is the money that I was giving my mother when I was working. They would stop buying the food that they used to buy and would eat anything.”
“My contribution of money would stop because I used to work and feed my children. What would continue is eating, washing and cleaning once I am gone.” (M2 Focus Group)

“I don’t know if my children would be able to live together peacefully. Farming and cooking can continue. My pension would stop.” (W1 Focus Group)

“It is a difficult question to answer, because you never know for sure what your children will do when you are dead. Sometimes they become mischievous. At times they fight over my things and claim them as their own.” (H1 Focus Group)

“Other things would continue, but gardening would stop, because my family does not like it ... Cleaning and cooking would go on, but looking after my mother by collecting her tablets for diabetes and high blood pressure will not continue the way I have been doing it.” (S1 Focus Group)

Some feel that life will go on as usual, although their presence will be missed.

“Many things would continue because my child lives with the father. She will miss me … I think that life will go on, but my children will miss me and my assistance, like the cooking and cleaning.” (A2 Focus Group)

“There would be a lot of crying.” (E2 Focus Group)

“I do not do much, except for cooking for my children and bathing granny. These will continue because there are others.” (H2 Focus Group)

“All things will go on well, but they would miss my jokes.” (S1 Focus Group)

And there are also some respondents who feel their presence makes no difference and that their absence would go on unnoticed.

“There is nothing useful going on because I am not doing anything. I am unemployed and
if I die and can have a decent funeral, that will be alright.” (C2 Focus Group)

“I would leave nothing because I do not have a child.” (A2 Focus Group)

Drawing from their own experiences of the impact of death as well as their understanding of the roles they play in their families, respondents generally paint a bleak future. They mostly foresee their children’s lives as being filled with greater hardship and deeper poverty. Only a few suggest that life will go on much as before. This either suggests that they feel sufficiently confident about their home circumstances or that nothing will change because these are operating at a minimal level already or that, in fact, they are articulating a false optimism about circumstances that they feel they cannot control.

**Analysing the Data through the Literature**

These experiences and perceptions of death need to be put in context. Without making claim to represent anything like an exhaustive search across vast fields of study and practice around the globe, it is possible to highlight some critical issues that underlie contemporary experiences in South Africa.

**5.1 Death in a contemporary context**

The first set of issues relates to locating HIV and AIDS in the context of contemporary experiences of terminal illness and death. We all live in the presence of death. It is the only certainty that applies universally across all societies, to all individuals through time. For all its universality, when and how we die is everywhere specifically located in time and place and is intrinsically a social process. This said, dying is also a biophysical process of progressive decline and irreversible degeneration, which culminates in the end of material existence (Mtalane 1986). What this study suggests is that while biophysical changes invariably inform people’s interpretation of death, they are not necessarily used to explain the process, the event or the outcome.

Generally, with the exception of war and accidents, death in many parts of the globe has become the prerogative of the old. In this, South Africa and other societies that are variously described as underdeveloped or developing are similar, even though death comes more frequently and earlier (Frankenberg 1989, Thompson 1979). Now, AIDS is radically reorganising the demography of death, because as Frankenberg (1989:31) pointed out a decade ago, AIDS strikes at people who are in their procreative and productive prime. It interrupts the way contemporary societies have come to organise around the life cycle, as this study clearly shows.

Significant economic developments as well as advances in bio-medicine and technology, especially in the second half of the 20th Century, have influenced social and cultural responses to death. One outcome has been to place oversight and management of dying and death in the hands of hospitals and the medical profession (Thompson 1979). This has several consequences. In medicalising terminal illness and death, dying patients and their families find themselves in a complex medical system that is oriented to the cure of
disease (Buckingham 1992:33), that attaches a high priority to life saving procedures and technical activities and is poorly organised to offer personalised, palliative care (Feifel 1977 cited in Mtalane 1989:29). The practice of medicine establishes an inherent inequality in doctor-patient relationships. The findings of this study suggest that irrespective of the diagnosis, people often have a great deal of difficulty in establishing their own health status or that of the person they are caring for. The uncertainty about prognosis that this lack of information generates is widely recognised as one of the major pains associated with many kinds of chronic disease and disability (Locker 1983 in Frankenberg 1989:31)

Also, clinicians find ways to routinise activities, encounters and issues in managing disease. They manage terminal illness and death in much the same way, relying on medical dogma rather than on patient preferences and values (Kutner et al 1988:1342, Mtalane 1989). In South Africa (Mtalane 1989) as in developed countries (Thomson 1979) the preparation of health care professionals is inadequate to deal with death. It can be expected that the inappropriateness of existing approaches will be magnified by HIV/AIDS, not least of all because of the complexity of managing curable illnesses that are made fatal by the syndrome.

The bio-medical profession is placed at the forefront of explaining and managing social processes and conditions that they don’t necessarily understand and are often poorly equipped to handle. Writing about modern Britain, Thomson (1979:2) argues that the public has abrogated terminal care to medical professionals. In South Africa, while there is such a trend, it is much less generalised. The preeminence of the bio-medical model in shaping people’s responses to managing (terminal) illness is tempered by people’s parallel pursuit of traditional medicine, which includes spiritual healing and which systemically assumes home-based self-care. Given this dual system of explanation and treatment, the debate around the scope and limits of professional care needs to be broadened to encompass people working in traditional medicine as well as other professionals.

The biomedical model of death as pathology has appropriated grief, constructing it as if it were a non-fatal disease “that it has a normal course or expected set of symptoms which progress in a generally predictable manner” (Fulton et al 1996:1352). As an “intrapsychic attribute” grief can be staged (Kubler-Ross 1991), generating notions of “anticipatory” or post-mortem grief, and pathologised, requiring specialist professional intervention. With death there is grief, which is a generalised sense of loss and sadness that is expressed through a set of socially accepted customs and practices. This study suggests that people’s responses to dying and death are generated and informed by socially derived circumstances, the progression of the illness and changes in health status as well as their understanding of life and death itself. There is also no evidence to suggest that grieving takes place in advance of death or that the absence of “anticipatory grief” is in some ways pathological, a denial of impending death.

Like Kutner et al (1988:1348) this study shows that the dying, and those who care for them, are preoccupied by personal and social issues. Disease related issues are also
important, especially in the context of home based care where the physical and economic resources to manage pain, discomfort and personal hygiene are scarce.

In this study, preparation for death seems to be something that people generally undertake close to the time of death. Resolving unfinished personal business, bidding farewell to family and friends, advising ancestors that one of their kin will join them, bequeathering possessions and giving advice or instructions for care are all activities which are undertaken when death seems inevitable. Unlike elsewhere (Fulton 1996), most people do not have written wills and with few exceptions, funeral preparations are generally only made after the death, although money is set aside for burial by some.

It is useful to separate out the kinds of support that people need in the face of terminal illness and bereavement. On the one hand, people need spiritual, emotional and psychological support. From this study, such support is invariably forthcoming and is provided mostly by family, friends, neighbours and the church. There is only limited evidence of self-help initiatives (support groups) and these seem to be confined to those who are living with AIDS and who are prepared to make their status known to a restricted public. Several of the bereaved felt that they would like to have more opportunities to share their experiences and personal worries.

On the other hand, people need support in managing the practical issues that engulf them in the face of death. Such support is notably weak. While funeral services or burial societies may practically help manage the burial, little systematic support is available to help people take care of the practical matters both up and downstream of the event of death itself. In other contexts where either wealth is greater or the approach to social service provision differs (Thompson 1988, Fulton 1996), the response to this need has largely been to turn to public and private professionals – in welfare and the police services as well as in the funeral and insurance industry.

As elsewhere (Thompson 1979:184, Garrity et al 1980:113), this study shows that views on preparing children for death as well as acknowledging and helping them manage their grief are mixed. While some see the inclusion of children as necessary and appropriate, others do not. Both responses warrant comment. Recognition of the need to communicate with children about death and grief reflects a break with historical practices and suggests changes in traditional assumptions about children and their place in the organisation of the family and home. This trend may also be true even for some among those who express an unwillingness to talk to children about death, as their concerns seem to center on their own inability to articulate their fears and expectations or to face the hurt that death will bring their children. There are also those who think it inappropriate because of their assumptions about what children can understand or need to know. As Kubler-Ross (1991:157) points out, “few people feel comfortable talking to a child about death”. While the desire to protect children from harsh realities is understandable and common to many less finite aspects of social life, shielding children from death may equally be read as leaving them stranded without any support in grief and without any preparation for their future. Although silence and exclusion goes against current thinking on children and their rights (Barrett 1998, Skelton 1998), as a practice it is probably the rule, rather than
5.2 The social and economic impact of HIV/AIDS

The second set of issues revolves around the social and economic effects of HIV/AIDS on households. Research into developing countries is recent, dating back to the early and mid-nineties (Aggleton et al 1997). Yet, as this and other studies (Over, Chevalier et al, Bharat, Leshabani and Singhanetra-Renard reported in Aggelton et al 1997) unequivocally show, adult deaths have profound social and economic consequences for households. Where people die from terminal illnesses, especially HIV/AIDS, these shocks are felt in various ways and long before and long after the event of death itself. They are also impact differentially by gender and age.

This study’s finding that families are under pressure to reorganise either by reducing their numbers or by absorbing more, invariably dependent members is similar to changes that have been noted in the composition of households in Tanzania. Movements in and out of households there have been linked in time, and are shown to occur six months prior to and immediately following the death of an adult household member (Over in Aggleton et al 1997:3 of 22). Notwithstanding the fluidity of household composition in the extended family system in various parts of Africa, with AIDS related deaths, this movement seems to increase substantially (Ainsworth in Webb 1996:10). A study of orphans in Kenya found that only 27% remained in their original parental home. Ayieko (1997:11 of 29) attributes this dispersion to Luo tradition, which does not permit houses to be maintained by non-clan members.

Leshabari’s study of household responses to HIV/AIDS in four villages in Kyela district of Mbeya, Tanzania (ibid. 7 of 22), shows that, as in the South African case, long established ways of coping with critical illness and death are under strain and becoming less effective. There, increasingly, responsibilities formerly shared across the extended family are being shifted onto the immediate family, even though widow inheritance and clan solidarity in relation to the care of orphaned children still continues.

This study highlights the complexity of the family as an institution in contemporary South Africa. The family covers a spectrum of organisational forms. These range from ties of blood, marriage or other arrangements that extend over generations, to more nuclear-type families of which many are anchored around a single, invariably female, caregiver.

A popular currency in the literature is the assumption that AIDS deaths generate child-headed households. While in this study a few people observed that there were one or two such families in their communities, generally these were the exception. This is true elsewhere where the effect of AIDS on household structure has been felt for longer. Thus, Ayieko (1997:11 of 29) found that only a small fraction (57 (5%) of 1100) of the households he studied had no adult care giver and were run by children alone. Generally, the family – recomposed and often under enormous social and economic strain – remains the primary institution of care and organisation for children.
This said, much of the burden of caring is being shouldered by the aged, particularly grandmothers. In other contexts this trend is new and is particular to AIDS. Ayieko (1997:18 of 29) writes:

“It is ironic that the caregivers who are also elderly grandparents have to provide economic support for the orphans. This is unexpected because the grandparents in the past depended on the children’s parents for assistance in their old age.”

In South Africa, the practice of leaving children born out of wedlock with grandmothers seems to be widespread. What terminal illness and death of younger adults changes is the breadth and depth of this burden. The aged are forced to take on parental responsibilities that they have long ago seen through and, at the same time, manage the care needs of terminally ill adults. This they have to do in a context where both age and the absence of support (from their adult children) compromise their physical as well as social capacity to act.

This study has found that there are also adults and children who are “out of family”, either because their families of origin have dissolved or ties have been broken. While presently such individuals are still in the minority in South Africa, it can be expected that the number of children in these circumstances will increase in the wake of AIDS.

Other effects of death and dying described in this cross-sectional study include deteriorating economic circumstances, inability to purchase the same amount or quality of food, withdrawal of children from school, and pressure on aged care givers to re-enter a depressed labour market. Bharat’s study (in Aggleton 1997:6 of 22) of predominantly marginal households in Bombay reported similar effects of AIDS related death, namely a noticeable drop in income and the withdrawal of children from school. He also found an increase in debt mortgaging, as well as early entry of children into and the extended presence of aged family members in the labour market. In Tanzania, where economic effects were observed over time, Over (ibid.) found that the effects of an (adult) AIDS related death was visible in a variety of economic indicators for up to 18 months before and 30 months after the event. There, the death of a female adult member in a household correlated (statistically) significantly with a reduction in the number of hours children spent at school.

The South African study also shows a decline in sources of household income. Similarly, Chevalier et al (in Aggleton et al 1997:4 of 27) found in Cote d’Ivoire and Haiti that there was a steady decline in the number of economically active members in the household and that ill household members were not replaced in their occupational activity.

The study conducted around Pietermaritzburg did not seek to distinguish between AIDS and non-AIDS derived deaths. However, it is possible to discern that young adult deaths (which are likely to be AIDS related) have a greater negative impact on households both because they remove income earners and because they increase pressures on already
overburdened caregivers, many of whom are grandmothers. A study of the relative socio-economic costs for households of AIDS and non-AIDS related deaths in Changmai province, Thailand, conducted by the UNDP concluded similarly. It found that the impact of an (adult) AIDS death on the household is substantial and generally greater than one that is not AIDS related (Pitayanon in Aggleton 1997:8 of 22).

This study shows that the quest for bio-medical and traditional treatment absorbs considerable energy and resources, and that a substantial proportion of this cost seems to be borne by individuals, their families or caregivers. A study comparing the public and private health costs of treating AIDS related infections and illness in Sri Lanka has quantified this differential. Jayasinghe (in Aggleton 1997:9 of 22) found that the direct cost to the public health sector was 18 to 21 less than the amount spent privately, depending on the treatment regime followed. Also meeting the medical costs of managing AIDS depletes household resources and has been shown to lead to indebtedness and loss of property in other developing countries. For example, in Kenya some hospitals encourage the terminally ill to surrender title deeds as security against medical costs (Ayieko 1997:16 of 29).

As this study shows, funerals too are costly. They dip into already depleted resources, diminish existing money and other assets that surviving family members will need to go on living, and increase household indebtedness, especially where families have not made allowance for or cannot meet the costs of burial. In a journalistic report of the impact of AIDS on the culture of mourning in Zimbabwe, McNeil jr. (1998) points to a thriving funeral industry and a re-organisation of burial societies. In the latter, costs of joining have increased, membership is restricted and there is a probationary period to prevent people joining when they are close to death.

Traditional practices around death also are being modified, both because of the added costs these bring and because people are emotionally exhausted. Singhanetra-Renaud (in Aggleton at al 1997:8) in her study of two villages in Changmai, Thailand, found that payments made by funeral associations were only rarely used to support remaining family members. As elsewhere, these were absorbed in the main by the actual costs of burial and the subsequent village feasts that accompany funerals.

Dying intestate, leaving surviving children disinherited and with uncertain guidance or support for their future placement or care taking found in this study, is a problem that is typical not only the poor communities living in and around Pietermaritzburg. As in South Africa, Ayieko (1997:21 of 29) found that 82% of orphaned households he studied were left without property, and even where people had title deeds, there are many instances where the male household head had sold the land without the knowledge or consent of widows and sons. In only 4% of households had parents appointed a person to care for their children before their death (ibid. 11 of 29)
5.3 The role of women and family

The findings of the study highlight the disproportionately negative consequences of HIV/AIDS and other chronic illnesses for women in poor communities around Pietermaritzburg. For the most part it is the women who nurse the chronically ill and dying and who struggle to meet the costs of treatment. Invariably it is they who are left with the children of the deceased, adding to domestic and economic responsibilities that for many are already onerous.

As Budlender (1997:282) points out, it is women in the family context who provide the bulk of services to the majority of children. And it is women who are left without shelter or property or even means of support when their partners die or when they themselves become ill.

Gender asymmetry in the impact of HIV/AIDS has been found by other studies in South Africa and elsewhere. In Bombay, Bharat (in Aggleton 1997:6 of 22) found that not only was the burden of care giving largely borne by women, but that HIV/AIDS in women was treated far more negatively by household members. Sewpaul et al (1998:38) record that following disclosure of their status, two of the HIV+ mothers in their study were beaten by partners or brothers. In contexts where women are encouraged to remarry within the extended family, as in Kenya, they are often accused of killing their new partners, when they die and are forced out of their nuptial homes (Ayieko 1997:10 of 29).

Studies in East and West Africa (Du Guerny 1998:6 of 11) show that widows are frequently subject to land grabs. They also take on the care of children born to other wives of their husbands and sometimes they are put in the care of an economic tutor or male child of a relative to prevent them from becoming destitute. Notably, they also find that women tend to receive less medical treatment than men, partly because resources are often depleted in caring for and burying the men, who frequently become ill before their wives. It is hypothesized that this reduction in spending partly also reflects disillusionment with the pursuit of treatment, where it is shown to be of little or no effect. Sewpaul et al (1998:35) found that HIV+ women who had HIV+ babies were unable to manage the costs of treatment for themselves. While the South African public health system gives free care to children under six it does not give free symptomatic treatment or palliative care to their sick mothers. They note, as a result, that in emphasising women in their role as caregivers of infected babies, the system overlooks these women as people and patients.

The symbiotic relationship between women and children that is structured into family life, means that like women, children generally are often both subordinated and placed at greater disadvantage in life in general and especially in the wake of death. A tendency not to inform children of the gravity of parental illness or sometimes even of the event of their death and not to include them actively in mourning practices has already been discussed above. Also the socio-economic impacts of chronic and terminal illness on families as already described, by definition impact on children.

Being orphaned, then, is likely to reflect a range of circumstances with differing
consequences, depending especially on the family context in which parental death occurs, on gender and on age. In rural polygamous communities in East and West Africa, the extent of orphanhood as well as the impact of parental loss on children was significantly influenced by which parent died (Du Guerny 1998:6 of 11). Ayieko’s study of children orphaned by AIDS in Kisumu and Siaya Districts, Kenya, (1997:8 of 29) found that with orphanhood, more households were found to have no girl children than those with no boy children. He explains this change in the gender distribution of children across households by the fact that girls are more likely than boys to be separated from and taken in by other family members, partly because of inheritance rules and partly because of domestic labour issues.

In studying the impact of adult death on the nutritional status of children in Northern Tanzania, Ainsworth (in Webb 1996:9) finds greater stunting among orphans but not greater wasting when compared with non-orphaned children. However, the condition of orphanhood does not have a uniform impact on children’s nutrition. The age of children at the time of parental death made them more or less vulnerable, with the greatest malnutrition found among children born three to four months prior to parental death. Also, children’s nutritional status is affected by the sex of the deceased and the children that survive them. In northern Tanzania, girls are found to be more nutritionally vulnerable in households with an adult male death while boys are more vulnerable where adult women have died. While gender asymmetry seems to be extensive, how it manifests in particular contexts is likely to vary considerably. A qualitative investigation of stunting in KwaZulu-Natal, for example, found that where food was preferentially allocated it tended to be to adult men and it also tended to be food-type specific – namely, proteins (Marcus et al 1999).

As an investigation of experiences and perceptions of terminal illness and death, this study has been conducted with and through the eyes of adults. While experiences of orphaned children in South Africa have yet to be explored, studies in other parts of the developing world show children to be both proactive and vulnerable. One of the observations about the effects of death and dying on children made here is that siblings sometimes are separated, either by force of circumstances, or because of kin-assumed ties or out of choice. Ayieko (1997:12 of 29) finds a similar mix of responses in Kenya. Generally, orphaned siblings try to stay together as much as is possible. They often start to worry about separation from kin when their parents become ill, having witnessed their friends being separated from siblings on parental death. The rate of dispersion is higher among older children where adolescents leave in search of a better life. And others are taken away from home to live with sympathetic and supportive relatives.

5.4 What about the community?

So what about “the community”? The findings of this study show that what is often referred to as “the community” is in fact a response of individuals acting as friends or good neighbours to help out. Invariably the people in the community who respond in such a manner are adult women. Sometimes and around some issues – like a medical emergency, rape or other forms of abuse of children – these individuals are able to
mobilise others into action (Marcus 1999:7). Otherwise, when it comes to terminal illness and death the community response, understood as organised collective action, is limited in both time and content. In other societies, these established community practices and responses have diminished in the face of pervasive illness, an endless round of funerals and the economic and social strains that individuals and households face personally, in their own families (Aggleton et al 1997, Ayieko 1997).

The evidence here and elsewhere, as Budlender (1997:284) argues, shows that a call on community, like a call on family, is a call on women. It is women who invariably maintain the social fabric beyond the individual household or family, with little public acknowledgement and often only a limited role in decision making.

Non-governmental initiatives to stimulate community action to assist children in distress in South Africa have drawn positive but limited responses. Mostly they are constrained by the assumption that it is sufficient to catalyze action without bringing in or facilitating access to material resources. On their own, poor communities do not have the material and frequently lack the skill resources to initiate meaningful and enduring collective action (Marcus 1999).

The pressure for “resourceless” community based development arises from New Right thinking that dominates the development field in general and which characterises mainstream thinking in the South African state. In this model, state welfare responses are dictated by logic of economic rationality and cost efficiency rather than social obligation, while the community is exhorted to self-reliance, community care and (self) development (Harber 1998:2,18).

Stimulating community level responses also takes time (Marcus 1999, Parry 1998). The needs of children who are orphaned or their caregivers are often immediate. This gives rise to a tension that is both practical and theoretical and is embodied in the differences between developmental and remedial approaches to welfare. Reformulated welfare policy in South Africa is based on the principles of “developmental social welfare” (Harber 1998:2). At the same time, there are many non-governmental welfare service providers, some of which offer remedial welfare, some of which strive for developmental welfare objectives, and some of which combine the two (Budlender 1997:242). As Budlender notes (ibid.250), there is a need for both approaches to welfare service provision service and that they should not be juxtaposed as alternatives.

5.5 The need for welfare, support and intervention
The findings of this study and the experience of non-governmental welfare organisations (Budlender 1997:250) clearly show the need for welfare assistance and support, and that the demand is growing and will increase. In the face of this reality, welfare is likely to flounder, however it is approached, in the absence of sustained and increased resource inputs, especially from the state.
Currently, as they struggle to get services to manage terminal illness and death, people seem to be mainly exposed to the medical profession. Contact with the welfare service seems to be limited. Social workers seem to be few and far between and they only appear to be proactive on the issues that the crisis of younger adult death raises where they are working with the hospice movement or welfare arm of the church. In other societies where there are state welfare systems, there are social workers who help people cope with the distress and multiple social and economic difficulties that follow terminal illness and death (Thompson 1979:28). In South Africa, much of the existing contact with the department of welfare centers on procuring grants either for pensioners or for children. Pensions, which largely go to women, have been shown especially to be an efficient source of regular income with redistributive effects that directly benefit children (Ardington and Lund cited in Streek 1999). There is a recognised need for improvement in access to pension and other grant delivery (De Beer 1998). Additionally, the AIDS context requires that welfare services designed effectively to reach children need to reconsider the age of pension, the variegated structure of the family as an institution and the growing number of children who are “out of family” who will need state support.

Aside from medical and welfare services, death brings people into contact with other professional services, particularly the police and the funeral industry. The role of the latter in contemporary South Africa is poorly understood and will be investigated in further studies. However, it seems probable that they, like medicine and welfare, will need to be restructured to manage what is for everybody a new and unprecedented crisis of enormous social fallout.

The possibilities to develop appropriate interventions to respond to the crises generated by AIDS related deaths are many. Aggelton et al (1997:14 of 22) have suggested a range of responses which need to happen at all levels of society, from the individual to the system. These include the need to target credit, develop social benefits, develop legal aid, provide psychological and social support in communities and workplaces, raise awareness and help people anticipate and better prepare for death, stimulate home based care at the lowest cost to individual households, and encourage self-help and community based support groups. While important initiatives have been taken in different countries, it is fair to say that for the most part, these have all been partial, reflecting, amongst other things, the limits and constraints of national resources, the balance of political and social forces and the stage of the epidemic itself.

With regard to orphans the experience generally (Krift et al 1998, Parry 1998, Marcus 1998) is that the needs of orphans cannot be abstracted from the general care needs of children and that, therefore, responses need to be developed as part of broader based community care initiatives. In Malawi, the COPE program was initially set up around service provision and volunteer recruitment. Within a short space of time the approach shifted to that of community mobilization, emphasising linkages between economic opportunities, school support initiatives and HIV/AIDS prevention, through the involvement of government, non-government and civil society organisations (Krift et al 1998). In South Africa, Zimbabwe (Parry 1998:8) and other developing countries high
rates of under and unemployment negatively impact on the effectiveness of programmes that are based on voluntarism. The FOST (Farm Orphan Support Trust) initiative, for example, which works among people employed in large scale commercial agriculture in Zimbabwe, has moved from voluntary to paid employment in order to make their model of care and service provision to be effective.

A widely held assumption here and abroad is that policy should aim to keep children in families and in communities rather than in institutions, an approach held to serve the interests of children and society best. In reality, this may neither be possible nor preferred, given that the welfare of children raised in a community greatly depends on the socio-economic welfare of the whole community. The more general well-being is compromised by AIDS, the less well are children likely to fair. Ayieko suggests that even among the Luo in Kenya, thinking has changed. Whereas historically the notion of institutional care for children was foreign, now orphans have come to be seen as a liability and an obligation to be avoided and many would opt for orphanages, albeit continuing to maintain contact with their surviving kin (1997:26 of 29). Arguably, institutional and family or community based care need not be juxtaposed as alternatives to one another. Rather, they should be developed as potential routes of choice or necessity in a range of care options. The FOST initiative has identified five levels of priority care that they have ranked in order of preference. These are the extended family, substitute or foster care families, family type groups, child headed households and orphanages (Ibid. 8).

For family and community based care to work as an option there is a need to inject resources into communities. In Thailand, for example, such initiatives are made possible through state sponsored financial subsidies and family as well as community counseling (UNAIDS Undated). In Zimbabwe, the FOST initiative looks for direct funding from industry and commerce and indirect funding from the state, for example, by organising support for free education and health care as well as tax credits to large scale commercial farmers who come into the initiative (op.cit.9).

The effectiveness of interventions varies considerably and depends, amongst other things, on the assumptions that underlie them and the context in which interventions are applied. Bajenja (in Webb 1996:9) reported that income-generating projects designed to improve socio-economic conditions for orphaned children were mixed and were invariably hampered by the myriad problems that are typical of such development projects initiated for decades in a pre-AIDS context. Senkuntu (ibid.) argues that support to care givers or guardians is often more successful as is accessing non-material assistance, for example, free schooling, in exchange for labour and materials. Such exchanges increase school enrolment of orphans, improve the condition of schools and reflect the educational priorities of individuals as well as the broader community. By contrast, financial support in the form of school fees only forces these to go up. Generally, income generation projects are risky and difficult to sustain. In the context of low levels of waged employment, typical of a large segment of South Africa’s and other developing countries’ populations, the route of barter and labour exchange for services may become the more practical and sustainable option.
6. Conclusions and Recommendations

Several conclusions can be drawn from this study and review of other research on the socio-economic impact of terminal illness and death on poor people. These are:

that the family is the main site of care giving of the terminally ill and of those who survive their demise;
that the social and economic consequences of these deaths is profound and essentially negative, for the individuals concerned and the institutions they are or have been part of;
that much of the burden that these deaths generate is borne by women, especially the elderly;
that the social and economic consequences of adult death for the children they leave behind compound the severity of the personal loss and psychological pain they experience;
that the absence or low levels of social preparation for death, especially, leaves many survivors stranded or in dire straits;
that these circumstances are made worse by the fact that both sex (being often women) and age (being children or aged) act as a double constraint on the future of those who survive;
that historical community practices are altered and undermined by the impact of terminal illness and death of younger adults;
that there is a displacement of children who find themselves out of family and/or out of community;
that existing service provision has to be spread more effectively across a broader range of professions;
that the professions that deal with dying and death need to be better and more appropriately organised to account for the complex medical, social and economic consequences of HIV and AIDS;
that stratified, variegated responses are needed to deal with a social reality that will become increasingly complex and disaggregated;
that there are major nodes for meaningful social intervention;
that intervention needs to be multi-faceted, proactive and purposive;
and that the state needs to drive a process that involves non-governmental and private sector role players.

Dying is a very emotional and personal experience. It is also a very social process. There are social expectations about how the dying and those around them should respond to death, and these are articulated and acted out through social institutions developed to respond to death. By force or choice, these are being made to adjust to the modern day context of death – namely AIDS. The impact on individuals and institutions will vary, but none will remain unaffected.
Endnotes
Lifeline is a voluntary service which offers 24 hour telephonic counseling in isiZulu and English as well as face to face individual and group counseling, where requested. The potential of the notion of “developmental welfare” is paradoxically straitjacketed by interpretation it is given in the present international and national context. Of the 4,800 organisations registered in terms of the Fund Raising Act (No 107 of 1978), about half are registered as welfare organisations under the National Welfare Act (No 100 of 1978) and most are affiliated to one of the 25 umbrella organisations that come together in the National Coalition for Social Services. (Budlender 1997:242)

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UNHCR Committee on the rights of the Child Geneva 5 Oct 98


Appendix

Interviews and Focus Groups

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